The Reforms to Mental Health and their impact on the empowerment of consumers and carers.

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Abstract.

The intention of this thesis is to explore and discuss the experiences of consumers and carers with psychiatric disability support services. In particular their participation in service development and delivery and the degree to which their relationship with services and providers has influenced this participation, is explored and discussed. These relationships are particularly relevant in the context of the dynamics that determine power and the strategies that consumers have adopted so that they become more empowered and have control over their own lives.

Consumers and their carers are placing greater demands on the mental health service system within Victoria. Reforms to mental health and psychiatric disability support service delivery and practice have resulted in deinstitutionalisation, recognition of fundamental human rights and changes to mental health legislation. Participation by consumers and carers in service development and delivery has been viewed by governments as necessary and important in contributing to care, treatment and support systems.

The National Mental Health Policy developed by the Australian Health Ministers paid substantial attention to the need to include consumers and carers in decisions that shape mental health services. These are underpinned by the World Health Organisation’s doctrine that people have the right and duty to participate individually and collectively in the planning and implementation of their health care. (WHO 1990, p. 14). In Victoria, the National Mental Health Policy lead to the development of a framework for mental health services that reinforced consumer and carer participation in service development and delivery.

A qualitative methodology was used for this investigation. In-depth interviews were conducted with consumers and carers to gain a thorough understanding of their experiences and perceptions of the current mental health system. A review of available
literature on the developing mental health consumer movement and on the concepts and practices of empowering strategies was undertaken. The opportunities for participation in the design, development and delivery of services in the context of actual experiences, are discussed with consumers and carers with particular emphasis on consumers’ perceptions of power and empowerment.

The transition from institution to community, known as deinstitutionalisation, has not been an easy one to accept by consumers and carers alike. The changes to service design and delivery with a greater focus on community and outreach services, and the necessary changes in attitudes by providers toward consumers as a result of these changes, have established major challenges for the mental health and psychiatric disability support services sector. Consumers and carers argue that the rhetoric inherent in the decision to implement deinstitutionalisation policies and practices that have lead to a shift to services primarily delivered outside of institutions, needs to be taken to another level. They want to ensure that they are recognised and accepted as bringing essential knowledge and experience to a service system that should be designed to support consumers and carers who face life altering circumstances as a result of a mental illness.

The information provided by consumer participants suggests that the reforms to some degree have provided them with more opportunities to take control over their own lives particularly in relation to their involvement in community based psychiatric disability support services. However, they describe the attitudes of providers as remaining the greatest barrier to advancing consumer participation. Carers on the other hand describe their experiences with psychiatric disability support services as disempowering. Their disillusionment with the mental health system is attributed to the lack of support and their perceived lack of recognition in their role as carers.
Statement of Authorship.

This is to certify that:

(i) the thesis comprises only my original work towards the Ph.D. except where indicated in the Preface,

(ii) due acknowledgment has been made in the text to all other material used,

(iii) the thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

Arthur John Lammers
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Chapter 1: Background to the Study.

Introduction.

The care of people who have a severe mental illness has evolved significantly since the early sea voyages which brought to Australia from England boat loads of criminals and lunatics (Dax 1989). In his article, the first 200 years of Australian Psychiatry, Dax (1989) describes the extent and conditions of the first asylums and the way in which people with a mental illness (mental patients) received care and treatment. In subsequent writings he discussed the history, evolution and development of community psychiatric services including the changes to treatment modalities and management of the mentally ill (Dax 1992). As an eminent psychiatrist practicing in Victoria, Australia, Dax contributed further to understanding the development of community psychiatry more than any other psychiatrist of his era. It is in his discussion about this period of development, which impacts significantly upon the role of the community and its responsibility to people with a mental illness, and this is so even today.

Dax described the development of community psychiatry in Australia as occurring in four phases. Phase one saw the demand for asylums to remove lunatics and more dangerous inmates from gaols. This situation was largely a consequence of the rapid expansion of the population due to the gold rush. There was an over-crowding of the gaols and not enough staff (who in any case were not skilled enough to manage people with a mental illness). Phase two resulted from the criticisms of care for the mentally ill which had to lead to changes. During this phase there was an establishment of early treatment centres and people with less severe mental illness were admitted. In the third phase, the type of patient under care began to change. At the end of the 19th century, neurotic disorders were recognised, psychotherapy initiated and psychiatric treatment was commenced in out-patient clinics. Private practices specialising in psychiatric treatment started to expand. Phase four saw the introduction of a range of physical and biological treatment methods which brought new and 'fresh hope' for people with chronic intractable mental
illness, (described as backward patients). These four phases have since been further progressed to extend to the current and prevailing deinstitutionalisation and other social policies that are in place today.

The evolution has not stopped there. Changes to the way in which mental health services are delivered continue to be implemented and Governments and communities continue to aspire to changing the culture in which mental health services have existed for so long.

On many occasions, the changes have occurred largely in response to the concerns and criticisms raised about the quality of care that people with a mental illness have received, both in institutions and in the community. Over the past three decades, Governments at state and federal levels in Australia have responded to these concerns by commissioning a number of inquiries. These inquiries investigated the clinical and management practices undertaken within psychiatric institutions in particular, and with some individuals involved in unscrupulous practices specifically. These investigations and the subsequent policies were initially focused on correcting the appalling conditions that ‘institutionalised mental patients’ were forced to endure (Human Rights and Equal Opportunity Commission 1993). The rapid and relentless process of deinstitutionalisation provided a decisive strategy for the government, particularly within, but not restricted to, Victoria. The process of deinstitutionalisation attempted to assist in restoring the declining reputation of the mental health system, and at the same time, recognise the importance of the rights of people with a mental illness to a better quality of life that could be achieved outside of long term institutional care.

There can be no question that we have come a long way. Not only in recognising that the mental health system in Australia deserves a sound history from which we can continue to learn, but also in the recognition that problems and challenges continue to exist and need to be addressed. It is with the knowledge of this need to respond to problems with which people with a mental illness are faced that will provide opportunities to develop
more creative, successful and flexible ways of providing treatment, support and care. At the same time we must afford those people with a mental illness the same rights as others within our communities without them experiencing the fear of discrimination, stigma, and unfair and unnecessary treatment.

In Victoria, the ways in which mental health services are provided, has to a large extent, already been pre-determined by the policies of deinstitutionalisation and the development of community mental health services. The focus of care has shifted from being provided almost exclusively by institutions, established as bureaucracies, to a range of services and providers within the community. (Victorian Government Department of Health and Community Services 1996).

The literature which discusses issues related to psychiatric illness suggests, that over recent years there has been growing recognition for the need to involve consumers and their carers in managing virtually all aspects of their own mental health. (World Health Organisation 1988). There has been a gradual but constant shift in the perception of mental health consumer and carer groups that they should be included in the planning, development and delivery of programs at almost every level. In Victoria, it is the contention of the State Government that people who have a mental illness have not been treated with equal concern in comparison to those who require treatment, care and support for physical conditions and attempts are being made to correct these anomalies. (Victorian Government Department of Health and Community Services 1996). Mental health services and the people who provide them have struggled with issues ranging from treatment under various acts of Parliament, institutional versus community care, drug treatments and the various levels of community acceptance and/or stigma. The way in which services have been developed, implemented and managed have changed to reflect greater community participation at several levels as the struggle continues to ensure better outcomes for people with a mental illness. (Victorian Government Department of Health and Community Services 1996).
The challenge remains significant though, particularly as the struggle between consumer and provider continues. This struggle has taken many shapes and forms and has been manifest both overtly and covertly. Clinical providers of services within institutional mental health care settings have traditionally assumed almost total responsibility for the clients under their care and this right of treatment imposed on patients has been an expected outcome by their respective employers. Whilst some clinical providers have not been comfortable about this position, little was done, until recently to change this perspective. Whilst not comprehensively addressed in the Commonwealth’s Human Rights report (Human Rights and Equal Opportunity Commission 1993), references were made to the need for almost all disciplines to undergo additional education and training that would contribute to a better understanding of the needs of the mentally ill. Psychiatric nursing training for instance has now become a postgraduate specialty nursing and is conducted within academic institutions. Training for both general and psychiatric nursing was formally conducted by teaching hospitals where the emphasis was on clinical practice with a component of ‘school’ added. It can be argued that the training now, as a post graduate component of the generalist nursing course, has achieved a more professional status, something that the numerous reports and inquiries have stated was a prerequisite to improving standards that existed within psychiatric institutions of the past.

Education and training alone is not enough as the providers with a new vision and mission of mental health services grapple with the existing and resistant culture of staff formerly associated with the institutional care. Attitudes of providers are changing to reflect adaptation to a community focused service system, however, there is a long way to go. Consumers of mental health services have questioned the assumed right of providers and the system within which they operate, and have, over the past three decades increasingly challenged the very nature of their relationship with the mental health system.
They have done this through rallying together to form what has been described as the 'consumer movement'. The movement has focused on accepting consumers as potentially valuable members of treatment and disability support teams, and therefore redefining the rules of engagement in negotiating a better deal for people with a mental illness. (McLean 1995).

The literature on the origins and principles of consumer movements, indicates that to a great degree these movements commenced with the vision of often a single activist who had the energy to attempt to right a wrong (Pagan Jr. 1989). In Victoria, there have probably been a number of such individuals from both the government and community who can be singled out for their role in attempting to advance mental health services to include consumers and carers. In the most recent past, other attentions have been paid and efforts made to achieve a better understanding of what consumers want from their relationship with the service system and service providers. These include various reforms to legislation in particular the mental health Act 1986. There have also been stricter guidelines introduced on standards within mental health institutions in response to the various investigations, reports and royal commissions.

The contents of professional education and training curriculums, although not the focus of this research is discussed briefly with participants and is presented in later chapters. However in the context of evolutionary processes that have included some changes to the way in which education and training has been delivered in recent years, it is worthwhile to provide an example of one such change. There has been a change in the way psychiatric nursing courses are delivered, from hospital based psychiatric nursing education to the higher education sector where this form of education results in a degree qualified registered General Nurse and psychiatric nursing becomes a post graduate enterprise. A study conducted by Happell (1994) investigates in detail such a transition. Happell compares the opinions of the new tertiary based psychiatric nursing course
students with those of the hospital based course in Victoria at a time when the transfer to tertiary based education was almost complete. The purpose of the study was to broadly establish whether there were any significant differences between hospital and tertiary qualified psychiatric nursing graduates in particular whether there was any merit in changing wholly to tertiary education. As stated by Happell:

One prominent expectation of any professionally oriented course is that it will produce a high calibre of graduates. Graduates who as professionals can both meet the needs of, and contribute to the development and advancement of the profession of which they have become a part (Happell 1994, p. 8)

The recognition of the need to continually improve training and education for those providing care support and treatment of people with a mental illness or psychiatric disability, can be assumed to be a necessary part of the overall evolution of the mental health service system. This contention has been supported through the underlying principles that guides Australia’s National Mental Health Policy that states:

... positive consumer outcomes depend on informed and well trained mental health staff and strong support from carers and advocates. Mental health services should seek to ensure that all provider groups receive appropriate support and training (National Mental Health Plan 1992, p. 7)

Whilst these events are both significant and important they indicate the importance of continually improving services for people with a mental illness and disability. There exists in Victoria a clear example of rhetoric that had become practice. It perhaps did
involve initially just a few people, researchers, educators and consumers who were determined to involve both providers and consumers in a collaborative process designed to achieve a better understanding and real results by bringing the two ‘groups’ together through active research. A ward in a large psychiatric hospital in Victoria experienced a series of action research projects commencing with the Understanding and Involvement projects (Epstein and Wadsworth, 1994). These projects were aimed at establishing a collaborative approach to research and evaluation of in-patient services. They included feedback from consumers in relation to their inclusion about decisions in their own treatment. They attempted to bring about positive changes to the way in which mental health providers recognise the important contribution that consumers can make therefore assisting providers to rethink their attitude to practice. The goal of this project was clear:

*Establish and refine processes by which staff and consumers in psychiatric hospital wards can routinely collaborate to research and evaluate the experiences of consumers and make the consequent relevant and appropriate changes to hospital practice* (Epstein and Wadsworth 1994 p. 7)

The scene was set in Victoria to explore and improve not only the communication between consumers and providers but also to recognise an equal partnership between them.

Community participation in the management of people with mental illness is widely encouraged and supported in Australia and in other countries with the core of this doctrine being unequivocally supported by the World Health Organisation (WHO), (WHO 1988, p. 13). In 1988 the WHO convened a meeting to specifically discuss the involvement of consumers in the design implementation and evaluation of mental health services, a topic that had been identified at previous meetings.
The WHO/UNICEF Declaration of Alma-Ata (1978) affirms in Article 4 that

*people have the right and duty to participate individually and collectively in the planning and implementation of their health care* (WHO 1990, p. 14)

Amongst the four specific objectives identified by the meeting was:

*Presentation of development in each participant’s local area on the topic of consumer and family involvement in community mental health services.*

*Determination of steps necessary for the development of greater input from consumers and families in community mental health services* (WHO 1990, p. 14)

It is clear that consumers of mental health services themselves and their carers, play a large part in moving this phenomenon forward particularly because of the unique contribution they have to make. In the United States, the consumer movement has emerged as a strong political group who have challenged traditional mental health practice and the power and control exerted by professionals in that field. (McLean 1995). A more in-depth investigation on the status of the consumer movement generally and those activists who support consumers of mental health services appears in chapter three.

A position paper released by the National Association of State Mental Health Program Directors (NASMHPD) in the United States, has clearly established a recognition that
consumers of mental health services can make a significant contribution to the quality and improvement of services. (NASMHPD 1989). Primarily, their contention is that:

*The National Association of State Mental Health Program Directors (NASMHPD) recognises that the former mental patients/mental health consumers have a unique contribution to make to the improvement of the quality of mental health services in many arenas of the service delivery system. The significance of their unique contributions stems from expertise they have gained as recipients of mental health services, in addition to whatever formal education and credentials they may have. Their contribution should be valued and sought in areas of program development, policy formation, program evaluation, quality assurance, system designs, education of mental health service providers, and the provision of direct services (as employees of the provider system). Therefore, ex-patients/consumers should be included in meaningful numbers in all of these activities. In order to maximise their potential contributions, their involvement should be supported in ways that promote dignity, respect, acceptance, integration, and choice. Support provided should include whatever financial, educational, or social assistance is required to enable their participation* (NASMHPD 1989)

The position taken by the NASMHPD has been supported through the initiatives of Government and Not for Profit (NFP) organisations who have been instrumental in establishing community support, self help and advocacy services for consumers and
carers in the U.S. Likewise, in Australia, organisations are rallying to form consumer support and advocacy services for consumers and carers who use mental health and psychiatric disability support services. Two such organisations within Victoria are The Association of Relatives and Friends of the Emotionally and Mentally Ill (ARAFEMI) and the Victorian Mental Illness Awareness Council (VMIAC) both of whom invite consumers and carers to become actively involved in their organisation’s activities. Both organisations have consumer representatives included on their Boards.

Whilst the not for profit sector has been coming to terms with the need to involve consumers and carers in their decision making processes at every level, this is not a new phenomenon for the commercial sector who have seen it as imperative in order for them to gain and maintain market share. In our society today ‘consumer choice’ is often the corporate entity's most important marketing strategy, which underpins the organisation’s mission in achieving successful outcomes whether in industry, manufacturing or delivering services or just improving the ‘bottom line’. (Berry 1992, Porter 1990)

“The voice of the customer must guide service development
(Berry 1992, p. 59)

The imperative for both the profit and not for profit sectors is to ensure that consumers are involved at various levels in decision-making processes. This concept of understanding what customers need and want in order to succeed in business is shared by business leaders and organisational strategists around the world. The experiences that consumers of mental health services have had as patients or survivors, has lead to the position taken by the NASMHPD where those consumers are valued and their contribution to the delivery and enhancement of services keenly sought. The business sector has a clear purpose in mind when involving consumers. As mentioned earlier, the concept can and must be transferred to the service industry and it is the industry
providing mental health and psychiatric disability support services with which this thesis is concerned.

Psychiatric disability support is a necessary part of a mental health system for people with enduring, intractable mental illness. The period following acute or recurring episode of psychiatric illness entails stages of recovery where consumers often require additional support within the community. Within Victoria these services are available to consumers and to some degree there is evidence that consumers can become involved in decision making processes and assist in determining what is needed to achieve improved quality of life options outside of the pre-existing institutional care. (Vicserv 1998).

For some services there is a necessary distinction drawn between mental illness and psychiatric disability and consequently between acute services and services established to provide rehabilitation and support. According to Vicserv, Victoria’s peak body advising on and participating in the continual development and improvement of psychiatric disability support services:

\[ \text{there has been a great deal of confusion regarding the use of the terms mental health and psychiatric disability} \]
\[(\text{Vicserv 1998, p. 18})\]

This is particularly apparent in relation to the debate about what constitutes clinical treatment services and where these services ostensibly end and where psychiatric disability support services commence.

One consumer consultant has articulated the importance of making a distinction between mental illness and psychiatric disability:
Mental illness involves clinical symptoms and medical treatment, whereas, psychiatric disability refers to the consequences following illness or disorder – which can linger quite some time even after an illness has subsequently abated – such as a person’s ability to carry out activities or tasks of everyday living and to develop and maintain effective personal and social relationships (Pinches 1996 p. 3).

This distinction will become clearer in future chapters, however it is worth making some mention of what is currently occurring in terms of the differences between the delivery of general disability services and those which are provided for people with a psychiatric disability. One such difference is the right to services in the community for people with disabilities such as the right to dignity, integrity and the right to control every aspect of their own lives. This situation is juxtaposed, as outlined by Vicserv, by the conflicting messages about the so called right to treatment for a person with a psychiatric disability which can be transformed into treatment imposed through legislation under statutory powers conferred upon certain mental health authorities (Vicserv 1998). The mental Health Act (1986) through its explanation of the objects of the act does state that:

*Persons who are mentally ill receive the best possible care and treatment in the ‘least restrictive environment’ enabling the care and treatment to be effectively given* (MHA 1986, p. 3)

In addition and as part of the objectives of the Mental Health Act, there is a clear statement that allows those empowered to provide care and treatment to people with a mental illness to reasonably restrict the liberty of those ‘patients’.
In providing for the care and treatment of persons who are mentally ill and the protection of the public any restriction upon the liberty of patients and other persons who are mentally ill and any interference with their rights, dignity and self respect is kept to the minimum necessary in the circumstances (MHA 1986, p. 3)

The differences pointed out by Vicserv suggest that there is not equal consideration given to those persons who have a psychiatric illness and those who have a physical illness. People with a mental illness apparently have less rights to maintain their freedom and independence when they are unwell as opposed to those who have a physical disability and who are encouraged to retain their independence. Certainly, the needs and rights of people who have a psychiatric disability is not yet clearly understood in this context.

Aims of the study.

The aim of this study was to explore and discuss the experiences of consumers and carers involved with psychiatric disability support services particularly as they relate to consumer and carer choice and participation in service development and delivery. The relationships that consumers and carers have with professionals and the mental health service system, in particular psychiatric disability support services, will be examined. The degree to which consumers participate at various levels within the service system will be explored and discussed.

Summary of the research focus.

This study will explore consumer and carer involvement in, and experience with psychiatric disability support services in Victoria. The focus of this research is therefore
on consumer and carer experiences and understanding and particularly their ability or otherwise to participate in psychiatric disability support services.

The study will:

1. Discuss the development of current mental health and psychiatric disability support services.
2. Explore the evolution of deinstitutionalisation policies by the Victorian Government and the effect those policies have had on the delivery of psychiatric disability support services within the community.
3. Explore the current trends within the mental health consumer movement and what effect and influence the movement has had on further developing the mental health service system.
4. Examine the concepts of power and empowerment and discuss the impact of these concepts on consumers and carers.
5. Explore the transition of empowerment concepts into practice and seek to understand the experiences of consumers and carers with respect to this transition.
6. Explore consumer and carer understanding, knowledge and experience of psychiatric disability support services and their level of participation in the development and delivery of these services.

A brief definition of the terms consumer and carer.

The terms consumer and carer appear throughout this thesis. Whilst specific definitions of these terms in their literal sense have been provided in chapters three and nine respectively, it is necessary to explain these terms in the context of their meaning for this research. In doing so however, it is recognised that there may be differences of opinion with respect to interpretations about what constitutes people with a mental illness or psychiatric disability and those people classified as carers.
For the purposes of this thesis:

The term consumer is used here to describe people who have a mental illness or psychiatric disability and includes those people who use or have used mental health or psychiatric disability support services.

The term carer is used to describe those people who provide care and or support for people who have a mental illness or psychiatric disability.

**Organisation of the thesis.**

This research has been organised into chapters that outline progressively the process of the investigation undertaken. This allows the reader to follow the course of the study as it unfolds. Each chapter contains an introduction or provides a background to the discussions. The narrative that follows generally includes evidence of practice or application supported by citations where necessary, a body or discussion and conclusions or summary where appropriate. Chapter ten presents the findings and conclusions and elaborates further on the research question and implications for further study.

It was not always possible to present information in chronological order. Extensive references to policy formation within Victoria, nationally and internationally created an opportunity to cross reference and validate information which ensures that the themes which emerged throughout the course of the study were consistently presented and discussed. A second purpose for this approach can also be explained. Much of the policy developed, particularly in Victoria, had its origins in the various reports and Royal Commissions which lead to or had a significant impact upon the reforms within the psychiatric disability support sector and more broadly, within the mental health field. It was necessary to refer to and debate these policies so that their effects could be taken in
context with the themes that have emerged and been developed for discussion in each chapter.

Broadly, the thesis will be presented in the following chapters:

Chapter 1: A discussion of the history and evolution of mental health and psychiatric disability support services within Victoria provides a background for introducing the discussion of recent reforms. Secondly, the transition from traditional institutional care to community care is discussed in relation to the developing mental health and psychiatric disability support services system and the changing attitudes of consumers and providers. Finally an overview is provided of the relevance of the consumer movement and the emergence of consumer participation.

Chapter 2: This chapter explores recent changes to the structure of the mental health system and psychiatric disability support services in Victoria. The development and progression of reforms including Australian National and State policy development is reviewed. A discussion of the implications of deinstitutionalisation is presented.

Chapter 3: Introduces and discusses the consumer movement as presented in the literature. This chapter commences with definitions of consumers and consumerism. The origins of the broader generalist movements and their purpose is discussed with a review of the consumer health movement and finally focuses on the mental health consumer movement. Movements that are active outside of Australia are briefly discussed prefacing what is occurring within Victoria.

Chapter 4: Explores the concepts and practices of power and empowerment as presented in the literature. The concepts of power and empowerment are explored in relation to the attitudes of providers towards mental health consumers. The application of strategies that
seek to empower consumers is illustrated through the presentation and discussion of models of self help and determination.

Chapter 5: A detailed account of the methodology used for this research is presented in this chapter. Specifically the chapter presents a discussion and justification for the use of a qualitative method; sources of data; an explanation of the respondents sought for interview; the process and use of interview techniques; methods of data analysis and representation and measures employed to establish trustworthiness. A detailed analysis and discussion of the use of in-depth interviews used for this thesis and the preference for thematic analysis is presented.

Chapter 6: Provides a background and introduction to the formation of a reference group comprising consumer consultants and a carer who helped to guide the conduct of the study. This group was formed to provide a consumer and carer perspective from individuals who have considerable knowledge and experience of the mental health and psychiatric disability support services systems. The chapter discusses the contribution the group made to this research and their desire to contribute more than guidance.

Chapter 7: In this chapter the reference group participants discussed in chapter 6 provide their experiences and opinions of mental health and psychiatric disability support services within Victoria in addition to their role in guiding the research. Their views on the range of issues that affect consumers and carers is presented and discussed. The developing role of consumer consultants and carers is explored.

Chapter 8: Provides an analysis and discussion of the experiences of consumer participants in relation to recent developments within mental health and psychiatric disability support services. The discussion focuses on perspective’s and experiences related to the developing psychiatric disability support service sector including issues such as: access to services; consumer expectations of services; impact of roles and
attitudes of mental health and psychiatric disability support service providers; current consumer experiences of participation.

Chapter 9: Provides an analysis and discussion of the experiences and opinions of carers. The role of carers is discussed and analysed with respect to their relationship with consumers and service providers.

Chapter 10: An analysis and discussion of the data collected and presented in the preceding chapters focusing on the degree to which consumers and carers feel reforms to mental health services have empowered them. Summary and conclusions in relation to the findings is presented. The implications of the findings in relation to consumer and carer participation and mental health service delivery are explored. Limitations of the research and the need for future research is also discussed.

Summary.

The evolution of mental health services has taken considerable time to reach the stage at which it is currently operating. History reveals that care and treatment of the mentally ill, up until the second half of the last century was almost exclusively delivered from within institutions. It has only been during the last fifty years that the care and treatment afforded to patients has begun to change to incorporate options where services are delivered from within the community.

These options have largely become available as a result of reforms initiated by governments in response to criticisms about the care and treatment patients received in institutions. Several inquiries, investigations and Royal Commissions have been undertaken in Australia to investigate the concerns raised about hospital conditions and the conduct of service providers charged with the responsibility of providing the so called care and treatment. The most significant national inquiry into the human rights of the mentally ill was undertaken by the Human Rights and Equal Opportunity Commission.
The investigation was lead by Brian Burdekin, the then Human Rights Commissioner and culminated in a two volume report released in 1993 that highlighted significant inadequacies in the care and treatment of the mentally ill. Whether directly or indirectly associated with these inquiries, the closure or scaling down of the large hospitals and the practice of deinstitutionalisation became wide spread and common place.

Perhaps this is because deinstitutionalisation, amongst other reforms, occurred within an environment where there is an increasing recognition to acknowledge and preserve the human rights of people with a mental illness.

The increased mobilisation of consumer movements worldwide is also a phenomenon that can be attributed in part to the processes of deinstitutionalisation. By default, consumers and carers are now more involved in their own care, treatment and support. As a consequence, they have formed specific mental health consumer movements that undertake a range of activities in support of the advancement of mental health services and in particular consumer participation.

In Victoria, the involvement of consumers in research through the understanding and involvement series of projects, sought to achieve greater communication and collaboration between consumers and providers that would eventually lead to positive changes in the attitudes of providers towards people with mental illness.

The evolution of mental health services has seen consumers make the physical transition from institution to community in terms of where services are delivered. Opportunities to move beyond passive receipt of service delivery to active participation in service development and delivery has taken some time to evolve but none the less it is emerging. The background to this study attempts to place this evolution into perspective. The following chapter will lead the reader through the discussion about how consumers and carers have been affected by the changes to date.
Chapter 2: Recent Changes to the Mental Health System and Psychiatric Disability Support Services in Victoria.

Introduction.

Over the past three decades, significant change has occurred in the design, development and delivery of Victoria’s mental health system. It can be argued that the progressive policies of deinstitutionalisation are a significant contributing factor. Stakeholders have been required to adapt particularly in Victoria where the changes have occurred over a relatively short period of time. The closure of long term or chronic institutions also saw the development of psychiatric disability support services in Victoria. These services have expanded considerably over the past decade particularly as additional funding has been made available (Victorian Government Department of Human Services 1994, Victorian Government Department of Human Services 1996). Strategic framework documents outlined the strategies that intended to support consumers with increased resources and improved access to services within the community of which psychiatric disability support services were to play an important part.

The evolution of service delivery has also provided an increased opportunity for involvement by consumers to contribute their skills and knowledge at various levels within the service system. These include volunteer services where consumers occupy positions on boards of not for profit organisations as well as the provision of consumer consultancy roles. These key roles constitute both unpaid and paid positions respectively that are still developing. These roles will be explored in further detail throughout this thesis. The developing role of consumer consultants is paid particular attention and is perhaps a central tenet of the debate surrounding empowerment of individuals using psychiatric disability support services.

This chapter will discuss recent developments in the reform of mental health services with an emphasis on how services have sought to support consumers within the
community. The transition from the provision of predominantly long term institutional care to that of a more community focus has been identified and discussed throughout the literature. The developments in Victoria and what effects these developments have had on consumers, carers and providers is reviewed and presented within a national and international context.

**Recent developments and reforms to the mental health system in Victoria.**

Changes to the way in which organisations provide mental health services and the expectations of the people who receive them have progressed at a rapid rate over the past three decades in Victoria. Institutional care is no longer the only answer for the majority of people who require long term care and support for their mental illness. Victoria’s large stand-alone psychiatric hospitals have been replaced with smaller community based facilities which are either attached or annexed to general hospitals or which are classified as non government organisations (NGO’s). The majority of agencies providing psychiatric disability support services are located in the community, are publicly funded, and are managed by non-government staff. Indeed, the NMHP also indicates that Non-government organisations have:

... performed a key role in providing support services for those with severe mental health problems and mental disorders, in advocating for services to be more responsive and in educating and supporting carers (National mental health Policy 1992, p. 11).
Government initiatives in mental health reform.

National policy initiatives within Australia.

The most recent set of initiatives that proposed to set new directions for the development and reform of mental health in Australia commenced with a national agreement of a policy by Australian Health Ministers in 1992 (Australian Health Ministers 1992). The National Mental Health Policy (1992) established a mandate for services to consider and implement several key objectives. It sought to improve mental health service delivery and was proposed through the development of Australia’s first National Mental health Plan. The policy that underpins the plan, reflects a statement and commitment by Commonwealth, State and Territory Health Ministers in ensuring that appropriate services are available and accessible to all Australians with mental health problems and mental disorders and attempts to set a clear direction for future development of mental health services within Australia (National Mental Health Policy 1992).

The aims of the National Mental Health Policy are:

\[
\begin{align*}
&\textit{To promote the mental health of the Australian community} \\
&\textit{and, where possible, prevent the development of mental} \\
&\textit{health problems and mental disorders;}
\end{align*}
\]

\[
\begin{align*}
&\textit{To reduce the impact of mental disorders on individuals,} \\
&\textit{families and the community; and}
\end{align*}
\]

\[
\begin{align*}
&\textit{To assure the rights of people with mental disorders} \\
&\textit{(National Mental Health Policy 1992, p. 7)}
\end{align*}
\]

A number of priority areas were determined to ensure that the aims and objectives of the policy were addressed. One of the policy’s underlying principals indicates that services become more responsive and effective through consumer and carer participation:
The quality and effectiveness of mental health services are enhanced if the services are responsive to their consumers and communities and if avenues are created for participation and decision making about the development of services and about an individual's own treatment (NMHP, p. 7)

The initial policy also required the recognition and guaranteed protection of the rights and civil liberties of people with a mental illness. Among the policy objectives are statements that reflect consumer participation in services as a fundamental right. In this context there must be:

Respect for individual human worth, dignity and privacy
Participation in decisions regarding treatment, care and rehabilitation and;
Access to advocacy support where necessary to ensure participation in treatment decisions (NMHP, p. 8)

A recent review of the National Mental Health Policy was conducted in 1997 and has reinforced the forward moving approaches to the delivery of mental health services as well as acknowledging greater support for consumers and carers. The policies broadly encouraged a national approach to the development of mental health services, to strengthen the impetus for reform of mental health services and to provide a mechanism for addressing agreed priority issues such as consumer participation. (Vicserv 1998, p. 95)

In Victoria, these initial policy initiatives were supported through the development of a series of strategic ‘Framework’ documents. In fact, they reflect Victoria’s policies on the progress and improvement of mental health services within this state (Victorian
Government Health Department. Office of Psychiatric Services 1992, Mental Health Implementation Working Group 1994, Victorian Government Department of Health and Community Services 1994, Victorian Government Department of Health and Community Services 1996). These policies guided the reforms to service delivery. They advocated for improved outcomes for people with mental illness both in services delivered within the restructured in-patient units and within the growing community based psychiatric disability support services. They also espoused options for the provision of support to carers.

The strategies provided a platform from which to move the development of mental health services forward and in particular toward a more community orientated approach to service delivery with an increased responsiveness to consumer and carer needs. Strategies to achieve improved outcomes included changes to the way in which services were delivered and, in particular, the continued transition from institutional care to community care - the transition had already commenced with the closure of a number of large stand alone psychiatric hospitals in Victoria.

Whilst a large part of this deinstitutionalisation process involved the closure of mental hospitals and the subsequent need to find alternative housing options, it also became apparent that there was a real need to provide additional support services that would provide people with opportunities beyond just living out their lives in the community. There was a real sense that, to achieve a comprehensive process of reforms for people with ongoing serious mental illness, required adding value to basic services and not merely maintaining their existence beyond institutional care.

The discussion that follows, seeks to identify issues related to Victoria’s deinstitutionalisation policies and attempts to explain the implications for consumers and carers involved with mental health services. The debate about the impact deinstitutionalisation has had on consumers has been mixed particularly when the
discussion about resources, or lack of them, is raised (Human Rights and Equal Opportunity Commission 1993). In that context, the comprehensive investigation into the practices occurring within the mental health service system from a national perspective revealed that the closures of psychiatric hospitals that had already occurred did not in effect correspond with a transfer of resources to the community (Human Rights and Equal Opportunity Commission 1993)

In general, the savings resulting from deinstitutionalisation have not been redirected to mental health services in the community. These remain seriously under funded, as do the non-government organisations which struggle to support consumers and their carers. Whilst the movement towards mainstreaming mental health services may alleviate the stigma associated with psychiatric care, there is a serious risk it will not receive the resources it so desperately needs (Human Rights and Equal Opportunity Commission 1993, Volume 2: p. 908)

**Deinstitutionalisation and its implications.**

Predominantly, reforms have sought to move from a mental health service system that focused on institutional care to one that favours community based services. This evolutionary process became known as deinstitutionalisation and continues to evolve as a result of state run services moving toward a more community oriented approach to service delivery (Short et al 1993). There was a need to change the philosophy that:

state run services were responsible for a clients total basic needs (Victorian Government Submission 1990)
Several factors have determined the continuation of deinstitutionalisation policies. These included advances in drug therapy, especially major tranquillisers, which reduced the need for long stays in hospital; the acceptance of concepts of normalisation which tried to make patterns and conditions of everyday life close to those found in mainstream society; and the emergence of human rights issues which stressed the need for the least restrictive environment as a guide to community based care (Victorian Government Submission, 1990: p. 1). These re-socialisation policies have been firmly adopted by governments not only in Australia but also overseas. There has no doubt been considerable thought given to the costs of providing ongoing treatment and rehabilitative institutional care, by almost all financial managers involved with providing these services. The emphasis of providing more for less has been a developing culture as governments struggle to reduce spending and increase services both of which are required to respond to different forces.

Ethical considerations of deinstitutionalisation.

Considerable debate has taken place about the management and care of people with a psychiatric illness and subsequent disability associated with their illness. (National Mental Health Policy 1992, Victorian Department of Human Services 1994, 1996). Much of the discussion has centred around issues related to ‘where’ care should take place. The debate generally includes issues related to whether a person with a psychiatric disability should be cared for in an institution or whether they should be cared for in their own community environment with the support of specialised services designed to meet specific needs. The question of whether a consumer has the choice of being treated in a psychiatric facility or within the community when they become ill contributes to the debate about who should or does hold the power to enforce or allow either of these treatment options to occur.

The Mental Health Act (1986) mandates that treatment should occur in the least restrictive environment and certainly this interpretation is very much dependent upon the
mental state of the individual at the time of assessment and the clinical knowledge of the medical officer. A number of criteria set down in the Mental Health Act indicates what constitutes a mental illness and then regards these as a basis to determine whether a person with a mental illness can or should be admitted to a psychiatric facility as either an informal or involuntary patient. An important aspect of the Mental health Act (1986) is its emphasis on patient rights where it is desirable for the patient to consent to voluntary admission. As Happell (1994) points out:

There is no longer an automatic assumption that a mentally ill person does not have the capacity to make their own decisions (Happell 1994, p. 84)

Happell (1994) gives an account of the process of admission of a person, within Victoria, who has been diagnosed with a mental illness. The medical officer will determine that admission is desirable and that the person will benefit from admission. Where the mentally ill person is unable to or refuses to consent to admission, the decision to admit rests with the medical officer.

However, as mentioned earlier, Victoria’s peak body for psychiatric disability support services (Vicserv) have raised some real concerns about the confusion which exists in relation to clinical treatment of a mental illness and psychiatric disability support (Vicserv 1998).

The discussion regarding the best place to provide care and treatment of a person with mental illness is not limited to simply location, whether it is a long term institution, an acute facility or the persons own home. Care and treatment carries with it more profound questions related to what is proper, what is responsible and most importantly what is ethically and morally appropriate for stakeholders including consumers, carers and the broader community (National Mental Health Policy 1992).
There are varying opinions regarding what is perceived to be best options for the care of mentally ill people by different sectors of the community. Generally, planners and providers of services will confess to making decisions in the interests of consumers and based on what is morally and ethically correct at the time rather than what consumers or carers actually want. However, although the ethical and moral aspects of those decisions are often given considerable weight they appear to parallel and in many cases are overshadowed by different agendas related to finance and other resources (Victorian Government Submission 1991).

Deinstitutionalisation became the often used term of the 1980’s where the focus was placed on restoring ‘normality’ to patients who had spent much of their lives living in an institutional environment. In Victoria, a decision was made to restore this ‘normality’ by reforming and systematically dismantling the State Mental Health System. A National Mental Health Policy, published in 1992, and to which Victoria was a signatory, underpinned the radical reforms which, in part, involved the decommissioning of large psychiatric hospitals and the establishment of smaller more locally located facilities. The options of cluster and group homes were also well supported with the intention that these facilities would provide only minimal day to day supervision (National Mental Health Policy 1992)

**Royal Commissions and Inquiries.**

Throughout the process of current reform, a resurgence into the investigation of practices within the State’s mental health system gathered momentum and was relentless in its pursuit to improve the quality of services. These investigations were not new. The provision of mental health services has, since 1858, been in a continual state of review in response to allegations about scandalous conditions, particularly in some of the larger mental hospitals. (Dax 1961)
A number of Royal Commissions and Australian State Government departmental reports have been undertaken over the past decade and a half, to investigate the conditions of psychiatric and mental hospitals within Australia. (Health Department of Victoria - Report on Lakeside Hospital Ballarat 1990, Health Department of Victoria - Report on Aradale Hospital: 1991, Human Rights and Equal Opportunity Commission 1993, Ward 10 inquiry in Townsville, Chelmsford Royal Commission in New South Wales). These inquiries confirmed that patients were living in unsatisfactory and in many cases, appalling conditions in some of the larger ‘Chronic Institutions’.

Within Victoria, Boards of Investigation were established by the State’s Chief General Manager of the Victorian Health Department. One such Board of Investigation was established to:

_Inquire into certain clinical and management practices at Lakeside Hospital Ballarat, with specific reference to the death of Patient x and the ward 22 outing of 30 August, 1990 (Health Department Victoria February 1991)_

This report uncovered a number of deficiencies and a global lack of appropriate and necessary care by staff of the hospital for patients within the hospital. The report culminated in a number of recommendations to the then Victorian Office of Psychiatric Services (OPS). Whilst no recommendation was made at that time to close the hospital, the Board of Investigation concluded that the physical environment of Lakeside Hospital, particularly ward 25, was inappropriate.

_The board concludes that physical environment is an important part of patient care and that delays in updating these conditions:_

Contradict the stated objectives of OPS and the Mental Health Act;
Reinforce the custodial benevolent attitudes of staff towards patients,
And project negative images of people with psychiatric disabilities (Health Department Victoria February 1991, pp. 75-76)

An investigation conducted at Aradale Hospital in Victoria also resulted in a discovery of poor care and treatment practices and a neglect for the basic rights of patients. (Health Department of Victoria. November 1991).

Nationally an ongoing Human Rights Commission more commonly known as the Burdekin Inquiry has comprehensively placed the issues of the human rights of the mentally ill on the agenda. (Human Rights and Equal Opportunity Commission 1993). Brian Burdekin, who at the time was Australia’s Human Rights Commissioner, led the investigation and tabled many reports in parliament which condemned the mental health system and its failure to provide adequate care and treatment for people with a mental illness. Many large institutions at the centre of investigations, were named as providing extremely poor management and care practices which led to employees of the public service system facing criminal charges. Every large psychiatric facility in the state of Victoria has been decommissioned since the reform commenced.

Fiscal benefits.

The moral and ethical implications of deinstitutionalisation provided in the initiatives described earlier can then be said to have certainly attempted to address quality of life issues for the individual. It has also, however, successfully achieved huge reductions in hospital admissions and bed days, made substantial savings in the operational costs of large institutions, scored political points during election campaigns and assisted in
rationalising health services through the integration and mainstreaming process. In
addition, it can be assumed that there has been large scale realisation of capital through
the sale of prime real estate on which many of the institutions were situated.

Whilst financial considerations need to be taken into account particularly in the utilisation
of available resources needed to administer mental health and psychiatric disability
support services, there is little doubt that the necessary resources that needed to follow
consumers of these services into the community following deinstitutionalisation did not
occur (Human Rights and Equal Opportunity Commission 1993, p. 908). This factor will
continue to place hardship on developing services and may necessarily result in a number
of potential consumers missing out on services and programs that have the potential to
significantly improve their lives physically and socially.

Shifting the burden of care.

Whilst the term ‘burden of care, is unacceptable to consumers, who do not accept that
they are a burden on anyone, it has been used here to indicate the burden with which the
mental health system is faced. The term is used only in the context that the mental health
service system and the bureaucrats who work within it, continue to struggle with the
internal and external forces which contribute in shaping the service system in the interests
of consumers. Therefore, and in that context, one may discuss the outcomes of shifting
the burden of care particularly as it relates to consumers who have moved from institution
to community. Criticism of this transition has centred around the concept that more needs
to be done to ensure that support services are available and accessible within the
community for people with mental illness, a concern which had been shared in the early
process of deinstitutionalisation.

More recently psychiatrists involved in the delivery of public mental health services have
also commented supporting the view that:
Public psychiatry has been run into the ground under the mantra of 'de-institutionalisation' not only in South Australia but across the whole country. Specialist public psychiatric hospitals have been closed without ensuring that alternatives are effective, or properly funded (National Association of Practicing Psychiatrists (NAPP, Nov 1997)

NAPP believes that whilst deinstitutionalisation was appropriate many patients clearly have lost the sanctuary and security of a large specialist hospital.

*I think those of us who were involved in the early stages of deinstitutionalisation and community care were over optimistic. We thought ... stop the damage inflicted by the old institutions, free people from the oppressive environments of the chronic asylums, give them decent accommodation and proper support in the community and they will cope well. What has happened traditionally is that because they're awkward patients, they're ungrateful patients, they're objecting and sometimes quite threatening, they get less care, not more* (Four Corners Feb 1999, Excerpt from I/V - Prof. Paul Mullen, Victorian Institute of Forensic Mental Health)

The often complex issues associated with community treatment and support for people with psychiatric disability has been recognised by the Victorian Government who have continued to expand community psychiatric services and fund psychiatric disability support services. (Victorian Government 1996). Although efforts have been made to provide additional resources, there still exists the lack of adequate funding for further
development of community services and this is a significant concern to consumers, carers and advocates (Human Rights and Equal Opportunity Commission 1993, Short 1993).

The need for adequate resources to be made available to the community following deinstitutionalisation has been well documented. “British studies have shown that if deinstitutionalisation is to be successful, as much money and resources have to be made available in the community as were formerly channelled into institutions (Roth and Knoll 1986 in Short et al 1993, p. 132)

Mainstreaming and integration of services.

Other reforms which impact on the delivery of mental health and psychiatric disability support services include the mainstreaming and integration of psychiatric services (Healy 1992), and the reconfiguration of Victoria’s metropolitan hospitals into large health care networks that occurred on August 1, 1995. The concept was considered to achieve rationalisation of services where:

... there is now the opportunity to facilitate the integration of health services across metropolitan Melbourne and allow more localised, detailed rational planning of a range of services for both the community in its broadest context, and for specific communities of interest (Metropolitan Hospital Planning Board 1995)

The mainstreaming (delivery of services from within a general hospital system) and subsequent integration (specialist network of inpatient and community care psychiatric services) became the trend and additional outreach services auspiced by general hospitals were also rapidly developing. The suggestion espoused in all
these circumstances was that patients were far better served living in their local communities where they were less isolated, have access to a greater range of health and other services and the assimilation would assist in reducing the stigma attached to mental illness. It was widely accepted by many that with such a move patients were able to achieve the previously stated ‘normality’ and that this existence was qualified by the phrase ‘improved quality of life’. The notion of continuity of care appeared to be the main rhetoric however the practice could be described as an alternative to institutional care which presumed to have failed in providing that continuity.

The large hospital networks across metropolitan Melbourne were reconfigured through the disaggregation of some networks during 1998. However, the concept of mainstreaming services prevails on a local level.

**Consumer and community consultation.**

The question which needs to be asked is whose purpose did these initiatives serve and in whose interest were they ostensibly applied? A draft report titled National Goals, Targets and Strategies for Improving Mental Health was released in February 1994 and sought to clarify the platform on which decisions of reform of mental health services were placed. Specifically these national goals targets and strategies sought to:

> ... identify areas in the community where changes and improvements in service delivery and attitudes to mental health will improve the health of Australians (Mental Health Implementation Working Group 1994)

The report conceded however, that its development was:
... aided by limited consultation with key individuals and lead agencies in mental health on the understanding that it would provide a basis for broad community consultation at a later date (Mental Health Implementation Working Group 1994)

The reference is an example of consultation with consumers taking place following a policy decision. It is certainly not wrong that Government planners should reap any fiscal reward that followed from a successful move to improve outcomes for mentally ill persons. But has the radical reform agenda, with its main focus on deinstitutionalisation, achieved the desired improved outcomes for individuals, many of whom ended up living in conditions condemned by earlier inquiries? Rather than simply decanting large hospitals of their patients following this exposure, would it not have served both the interests of the patients concerned and the governments reform agenda to improve substantially the care within these facilities? Perhaps the patients themselves should have been consulted on these important and considerable life changes with which they were about to be faced. In response to this rhetorical question, there is no evidence to suggest that patients of the former large psychiatric hospitals were actually questioned about their preferences. That is, did they wish to move from their current environment which some had known for several decades. The changes were made in the so called interests of better care and once again by a group with the power to make such decisions for and on behalf of all individuals within these institutions who presumably did not have the power.

**Institution to community.**

None the less the closure of large isolated psychiatric hospitals which had for some time provided what the public thought to be asylum for the chronically mentally ill, has taken place. Commencing with the decommissioning of Willsmere Hospital in Kew Victoria in 1989 the transition from institution to community was effectively underway with the closure of all other large psychiatric hospitals in the state following over the ensuing
The paradox is in the definition of asylum provided to patients and this is worth exploring in more detail.

The Oxford dictionary defines asylum as follows:

_An institution for shelter and support of afflicted or destitute persons, especially the insane; shelter, refuge; sanctuary_ (p. 44)

The move away from the term ‘asylum’ has been a deliberate one in order to achieve the transgression from institutional care to community care. The connotation attached to asylum, when the debate about the care of people with psychiatric illness was continued and throughout the periods of investigation, is contrary to that defined by the Oxford dictionary and suggests an environment of isolation, rejection, difference, indifference, routine and to a large degree, stigma. This is not surprising when one examines the terminology associated with the word asylum in the Collins Thesaurus which list such descriptive words as:

... _old-fashioned funny farm, loony bin, madhouse and nuthouse_ (Collins Thesaurus 1991, p. 43)

It is the use of this terminology which seems to arouse more enthusiasm for human interest stories so frequently sought by the media.

**The paradox.**

The paradox, in terms of the Oxford dictionary’s definition of asylum, is that the contemporary use of the term asylum describes an environment, which stigmatises an individual, is less than ideal and one which has derogatory overtones. The use of the term asylum in this way has facilitated sensationalist journalism and in a number of cases
not accurately reflected what was happening within the institution nor focused on the
benefits the individual derived from being there. The negative use of the term has also
sought to further stigmatise mental illness. Clearly the definition contained with the
Oxford dictionary, describes the true meaning of asylum as a place which provides
comfort, safety and belonging. The term has been applied to refugees who seek asylum
(asylum seekers) who have fled their country of origin citing oppression of the worst
kind. There does not appear to be any confusion about the plight of these refugees when
referring to them as asylum seekers.

Quality of life issues.

In what context then can one discuss an environment which is not literally considered to
be an asylum. One where the alternative to asylum offers an individual new experiences
in an environment which may provide less support but a far greater autonomy to make
the choices about everyday activities of living. One which may not be able to offer
shelter, refuge and comfort and which is perceived to be devoid of apparent boundaries
offering safety, a sense of belonging and an opportunity to develop. It is a reasonable
assumption to make that the nature of deinstitutionalisation suggests fewer physical
constraints and boundaries, a more demanding immediate environment and a change in
the relationship between the client and carer. The direct implications on the individual,
issues of responsibility and a moral duty of care to those who may not be in a position to
make reasonable judgements about their own welfare, need to be given paramount
consideration.

Consumer choice.

The matter of consumer choice and decision making has become a political platform
from which many policies, ‘in the interest of the public’, can be launched. Should an
individual suffering from a chronic or acute mental illness, who is not in control of their
faculties, and who may be a danger to themselves or others, be given a choice of where
treatment of that illness should be received? In general terms and in consideration of sections of the Mental Health Act (1986), the least restrictive environment determined by one may become the most restrictive for others. It is the opinion of the author that the very nature of psychiatric illness has determined this outcome.

It is simply not good enough to suggest that the shift from asylum to community care has created a dramatic improvement for individuals merely because of the transition itself. Community support services are evolving to a level where independent living has greater support both financially and in terms of community acceptance. This evolution in many aspects has been demanded and mandated by Government. The reform of the mental health system in Victoria, represented largely through the closure of mental hospitals, has been almost certainly associated with the outcome of the many Royal Commissions and Inquiries undertaken to date. It is inappropriate to argue that positive action in response to the outcomes of the reports should not lead to action in providing a better environment for all persons with mental illness. What has been determined and accepted by many for centuries to be a place of asylum for sufferers of mental illness has turned out in some instances to be a place of misery and maltreatment. The abysmal state of the many institutions subject of the inquiries indicates, in the first instance, a need to react by closing the offending institutions which has already occurred. The real knowledge of the outcomes for individuals, in the absence of asylums, will be evidenced in years to come.

**A clarification of mental illness and psychiatric disability support services.**

During 1989/90 the Victorian Government provided funding to non-government agencies for the provision of psychiatric disability support services. Initially, 46 such services received funding to provide supported accommodation and residential rehabilitation, outreach support to individuals, centre based day programs including the development of living skills and social and recreational activities, vocational/employment support services, consumer and family mutual support, individual and legal advocacy and

A review of the literature on psychiatric disability support services currently available through Non Government Organisations (NGO’s), indicate that services are targeted to meet the needs of both existing and potential consumers. These support services include consumer advocacy services, day programs, employment, recreation, housing programs, self help and mutual support groups, planned respite care and support for carers. (Department of Human Services 1997, Forum-Vicserv, Psychiatric Disability Support – A resource Book 1998). In spite of this generally held view, there is limited research that fully explores the impact on consumers and carers (their actual and perceived level of empowerment) with respect to the rapid and continuous changes to the mental health service system overall and to psychiatric disability support services specifically. Components of service delivery related to psychiatric disability support services change continually under the banner of providing improved client outcomes and an investigation of the extent of consumer and carer involvement in these changes is considered important.

Vicserv, the peak body for psychiatric disability support services within Victoria, stress that there are fundamental differences between acute services delivered to people with a mental illness and support and advocacy services delivered to those who, as a consequence of their mental illness are faced with a psychiatric disability. This, Vicserv attributes to the longstanding method of treating people who, once diagnosed, continue to receive treatment based on clinical assessment and treatment plans. Once a label has been attached the service system in its current form seems incapable of offering alternatives to treatment in the form of non clinical social support for example.

*People diagnosed with a mental illness have been locked into the clinical service system where all aspects of their*
Integration back into social circles and the community is an important aspect of the recovery for people with mental illness particularly as it has already been determined that most forms of mental illness are extremely debilitating, stigmatising and cause individuals to isolate themselves from others. Therefore an identity other than being ‘mentally ill’ is required to facilitate community reintegration for people with serious mental illness.

Summary.

Just as the reforms that guided the move from institution to community realised a certain liberation, the change of environment has impacted significantly on the lives of consumers and carers. Changes in the way services are delivered continue to evolve as services that have predominantly been provided within institutions are being replaced with those that deliver from within the community. Both consumers and carers must adapt to these changes. How they adapt will largely be determined by the capacity that consumers and carers have to effect change from which they can benefit. Reforms have already been underpinned by the growing recognition that consumers should participate in their own treatment plans a principle that is espoused by the World Health Organisation. In Victoria, the establishment of frameworks around national goals and strategies linked to the WHO charter, have seen the introduction of increased participation by consumers and carers in line with this charter.

In-patient services that have developed as a result of mainstreaming and integration of services are still an important component of the mental health service system. However, as the principles of rehabilitation and disability support continue to gather momentum, and as these services are primarily delivered with the community, there is a recognition
that resources must be directed where this activity is taking place. Non Government Organisations delivering psychiatric disability support services continue to grow and there is little doubt that that growth should attract additional resources.

The discussion regarding the consumer movement and the concepts of power and empowerment are discussed in chapters three and four respectively. These discussions will attempt to shed some light on consumer participation particularly in relation to consumers capacity to do so and the mechanisms that allow their participation. It is important to understand how the reforms will impact on consumers and carers if they are to assume more responsibility for their own care and support.
Chapter 3: The Consumer Movement.

Introduction.

The mental health consumer movement is central to this study as it identifies and locates the position of consumers within the mental health service system as it currently exists. Consumers have identified an increasing need to form alliances, to speak out and to be involved in reforms that continually attempt to rid them of the stigma and the associated experience of powerlessness mental illness and its consequences have thus far determined for them. Consumers and their advocates are taking steps to establish change, particularly in the way that they as individuals are accepted and acknowledged within communities.

Consumers of mental health services, like consumers of other health services, have varying degrees of incapacity that often prevent them from participating at the level they desire within the community let alone the service system with which they are involved. The capacity for involvement for some is contingent upon a number of factors that come into play at varying times. In relation to mental health the capacity for involvement is contingent upon the degree to which consumers are experiencing psychiatric symptomatology. These varying degrees of capacity are not always debilitating according to Morgan (1998) but rather they can be stimulating and rewarding. In describing a conference that was entirely user run Morgan stated:

*The prevailing mood was a combination of chaos, energy, creativity and realism. A room full of people with varying degrees of mental health needs at varying stages of health or ill health can be an unpredictable environment* (Morgan 1998, p 183)

The numerous inquiries and studies that have taken place over the past decade, have uncovered practices that allegedly have violated consumers most basic human rights
(Human Rights and Equal Opportunity Commission 1993), but they have also identified opportunities for progress. Opportunities that have been created through deinstitutionalisation policies both in this country and abroad. There is a sense from consumers that now there is an opportunity to correct the power imbalance that has existed for so long between consumer and provider. A sense that through their own activity, those consumers and their advocates are willing to take up the challenge and speak out about how they want to shape the system that purports to provide them with support without involving them. Opportunities that seek to prevent community and outreach services from becoming institutions themselves. The mental health consumer movement is about these and many other issues (McLean 1995, Spink 2000, Mizrahi 1999)

To understand the relevance of consumer movements and how and why such movements contribute to the development of empowering strategies, and particularly as they apply to consumers of mental health services, it is important to first take account of the origins, concepts and constructs of consumer movements generally. For the purposes of this study, the debate focuses on how consumer movements began, what the consumer movement is and what it can and has achieved for individuals.

This chapter will provide an analysis and discussion on the origins, development and mobilisation of consumer movements on several fronts including what is occurring locally in Victoria, nationally in Australia and internationally. It is the intention here not to present in detail the mechanisms of each individual movement, but rather to establish the representations made by consumers in forming their movements and what these movements purport to achieve for them.

Specifically, this chapter will discuss the following:

1. Definition and explanation of consumers and the consumer movement
2. Origins of Consumer Movements
3. The Mental Health Consumer Movement
4. Terms used to describe consumer consumers and consumer movement.
5. How the mental health consumer has been mobilised to action in Victoria, Australia.

Consumers and consumerism – a definition and explanation.

We begin here with a discussion on the definitions of various terminologies used to describe the relationship between people who use services and those who provide them.

The Macquarie dictionary (1990) defines “consumer” as:

\[ n. \text{ a person who buys or uses goods or services (opposed to producer)} \] (p. 221)

And “consumerism” as:

\[ n. \text{ a movement which aims at making consumers aware of their rights and also protecting their interests from dishonest trading practices} \] (p 221)

The definition, in part, of the word movement is provided by the Macquarie as follows.

\[ n. \text{ A group or a number of groups of people working for a particular cause or purpose: the conservation movement} \] (p. 682)

Sluzki provides the origin of the term consumer:
The word consumer derives from the Latin composite ‘consumere, that is, to use up, to take up wholly ... a person or organisation that uses a commodity or service (Sluzki 2000)

The terms consumer and movement are explicit in their meaning both singularly and together. That is, the former can serve to describe a person who uses or has use for a product or service and the latter a description of a group of like consumers working together toward a common cause to achieve similar ends.

Consumerism has been a term that has often been applied to describe, in a positive way, the efforts of the consumer movement (Swagler 1994). Swagler discusses the various applications of the term consumerism and points out that the term is relatively new in comparison to the history of the consumer movement, which he states can be ‘traced back for nearly a century’:

... the term consumerism was apparently first used in a manner which is only tangentially related to contemporary usage. The original usage reflects the important role of cooperatives in the consumer movement through the 1930’s. Moreover, the link to that earlier reformist tradition may help explain reactions to consumerism when the word re-emerged in conjunction with the consumer movement of the mid 1960’s (Swagler 1994, p. 348)

Swagler (1994) suggests that as early as 1965 in the US, the term consumerism was linked to the emergence of an advertising publication called Printers Ink (PI), and that this publication used the derivative form of the term (consumerist) to describe Federal protection initiatives (p. 348).
Efforts to promote consumer protection were characterised as statist, bureaucratic, anti-competitive and paternalistic. That is an auspicious beginning to a word which, in a slightly different form, would soon gain currency (if not clarity) in both the popular press and the professional literature (Swagler 1994, p. 348)

The meaning of the terms consumer, consumer movement and consumerism as they apply to the mental health consumer movement do not require further clarification to progress the debate about consumer involvement and participation. If the term is applied in the context of a general understanding by both consumers and providers that consumers have a role in determining and protecting their own interests, then there is little benefit in 'playing semantics' to find further exact literary meanings.

The title consumer and consumer movement is relevant in describing consumer association with the mental health service system. Tower (1994) asserts that the clients of human services should be regarded as similar to customers who wish to acquire products from suppliers. However, she qualifies her explanation of the fundamental differences between these groups by stating that consumers within human service systems are more knowledgable about their own needs also implying that customers who seek an understanding of products they wish to purchase may not necessarily have this knowledge:

Fundamentally, clients of the human services are consumers in the same way as are customers who acquire the services and products of a grocery store. Their consumption bears an actual cost that consumers pay either directly or through third-party payers, means tested
transfers or charitable funding. Most providers however do not conceptualise their services as consumer products. In addition, consumers often do not understand the rights and responsibilities they bear for the management of their own lives. The basic doctrine of consumerism within human service systems is that individuals who have direct experience with a particular life condition (for example, aging, disability, mental illness) are more knowledgeable about their own needs and interests than are their professional counterparts. When individuals redefine their role from that of patient, client or recipient of goods and services to that of consumer, their sense of control over their own lives is elevated (Tower 1994, p. 192)

Tower (1994) explains that the transition from ‘patient or client’ to consumer creates a sense of power and control for consumers and therefore implies a more balanced relationship between consumer and provider. Conversely, according to Sluzki (2000) adopting the term consumer or consumerist and applying these terms in the context of the consumer movement, does not always imply a position of power or control. In his article, ‘patients, clients, consumers: the politics of words’, Sluzki (2000) provides a colourful description of the use of the words consumer and consumer movement. It is more appropriate here to debate his meaning on the words in the context that his explanation of consumers can also be taken to include mental health consumers because they also use services. Sluzki states that:

We could argue that the usage of that word (consumer) has been inspired by the noblest of contexts, the socially responsible consumer movement, namely “a modern movement for the protection of the consumers against
useless, inferior or dangerous products, misleading advertisement, unfair pricing etc”... the movement not only advocated on behalf of the weak, the helpless, and the suckers, but championed their cause by actively defending them. For that purpose it created the role of the consumerist “also called the consumer advocate, a person who is dedicated to protecting and promoting the welfare and rights of the consumers (Sluzki 2000, p. 1)

Sluzki’s portrayal of the scenario in which consumers and their advocates find themselves paints a picture of a less than healthy relationship between consumer, advocate and provider. The power differentials he describes occurring within these relationships can be applied to the mental health sector where there is:

The assumption that there is an implicitly dangerous, exploitative relationship between a naive consumer who needs protection by a benign advocate against conniving exploiters ... where ... the actors that represent these three characters in the current mental health scenario: the (until recently called) patient, the (recently created) managed care representative and the (until recently called) doctor, or professional, now called provider (Sluzki 2000, p. 348)

This analogy perhaps represents a cynical view that consumers and providers have yet to establish the real purpose and benefits that a relationship principled on the provision of mutual care and support whilst acknowledging a degree of consumer control, can provide. That each may need the other to exist or to do their ‘job’ is not argued. The relationship between the actors as espoused by Sluzki (2000) however, may determine the reason for movements to exist in the first place, in that consumer movements seek to
achieve a certain power and control over their own destiny, and that these groups can work toward changing the dynamics that may exist between them for the particular benefit of the consumer.

None the less, if we adopt the more acceptable and pragmatic approach to defining the relationship between consumers of services and providers willing to include consumers in their attempts to achieve self determined outcomes, there is a realisation that power and control can be conferred upon the consumer.

The origins of consumer movements.

The consumer movement, in any form, seeks to ensure that consumers have a choice in decisions which essentially affect or implicate them (Green 1998,) thus creating an opportunity for consumers to take control of their own lives. A similar term used to describe this phenomenon is consumer direction and subsequently the consumer direction movement (Nadash, 1998 and Kosciulek, 1999). The term consumer self help (Breakey 1996, Carling 1995, Spink 2000) is also used widely in the literature.

The fundamental paradigm of the consumer movement is to achieve fair and reasonable outcomes for consumers in an environment that is often structured and organised in favour of the provider. The literature dealing with consumer movements identifies several labels that have been placed on the activities of individuals and community groups who are involved with the mental health service system, as they determine their strategies to achieve control over their own lives. Among them includes the terms consumer champions, self help and advocacy, self determination, community activists, consumer direction and consumer movements. They have, as their primary aim, a desire to assist individuals to achieve a recognition that they can and do have control over events that influence and determine how these services should shape their lives:
Clients as consumers suggests they have real choices as to where and how they seek help. What's new today is that "choice" increasingly is being eroded even for middle-class people, as managed care takes over health and mental health care. Nevertheless, the positive aspect of the promotion of the consumer concept is that it establishes a different set of expectations and a more empowered relationship between the service recipient and the service provider (Mizrahi 1999)

The modern consumer movement began in the United States during the sixties and then quickly spread around the world (Crawford, 1998). According to Crawford, the consumer movement in that country was in part responsible for making government agencies more accountable and reactive to a range of issues that were affecting ordinary people every day. The consumer movement was able to effect real change. Whilst ensuring that they received the appropriate responses to their claims, consumer groups were also concerned with a fundamental need that they had to be more in control over their own destiny. Being in control meant being empowered, not just in decisions about treatment but also in decisions about almost every aspect of a person’s life. (Chamberlain 1990, McLean 1995)

Consumer movements around the world have served to strengthen and unify groups of individuals who challenge the ideology of services, and the way services are developed and delivered. They have begun to play an increasingly visible role. (Carling 1995). In many cases, the visibility that consumer movements have achieved can be attributable directly to a champion who works tirelessly, often behind the scenes to bring about change.
Consumer champions.
It is often difficult to determine exactly the specific origins of many movements and in a number of cases, a movement is given the auspicious status by virtue of the individual who has determined to be a primary figure around the time of its inception. As a result, many authors in various countries offer up what they consider their own ‘consumer champions’, those who were believed to be instrumental in changing the balance of power through fighting and conquering oppression. (Hibbert 2000). These champions may not be the driving force alone behind organised voices but they do generally represent a starting point for at least some representation and advocacy and several people around the world have been awarded such distinction.

Consumer champions are, however, presented in different ways and often regarded as community leaders. It is not the intention here to seek out all those individuals and compare their activities but rather to discuss the ways that some individuals have influenced others to follow in their footsteps and become part of a phenomenon however defined.

In India, Mahatma Ghandi was acclaimed as the person who called upon the nation to ‘boycott anything that smacked of irrelevance, exploitation or untruth” and it is claimed that consumer movements the world over began with such boycotts (Desikan, 2000). Ghandi’s paradigm of self regulation sought to place individuals in control of their own destiny and thereby create within each individual an inner strength and discipline with which to achieve their life’s ambitions. The creation of this inner resolve to achieve better outcomes for themselves and their communities can perhaps be attributed, in part, to the central tenet that people have choices and they should and must exercise their individual and collective strength in order to move forward and seek a better existence.

Ralph Nader has been accredited with starting the general consumer movement in the United States. (Inlander 1998, Green 1998, Tower 1994). He is described by some as
having ‘jump started’ the movement with a report delivered to government on the safety of cars – Unsafe at any speed (Nader 1966). This report eventually lead to the compulsory instillation and wearing of seat belts in all vehicles across a number of states in America (Green, 1998), These changes spread to other parts of the world and there is evidence that Australia was eventually influenced by these changes in the late 1970’s. Nader’s prolific association with many consumer activities within the US, has been well documented over several decades and these activities have lead to claims that the American consumer movement has become a powerful force for protecting the health and welfare of Americans (Crawford 1998). It is further contended by Crawford and others that as a result of Nader’s activities, the consumer movement within that country has actually influenced and given rise to many other consumer movements around the world (Crawford 1998, Green 1998, Bodner and Dovel 2000).

Pagan Jr 1989, supports the notion that often there is a single person behind a movement. The energy displayed by a single advocate to right a wrong, he suggests, tends to attract ‘people of conscience’ to join the cause. It is not difficult to accept if this is the case, that before long a small group can grow to become a significant force:

> For the most part, activist movements are people's movements, initially amorphous but soon coalesced and then organised around a commonality of interests and concerns. An articulate advocate for an emerging concern can soon become the linchpin of a movement. People of conscience are quickly attracted to those who are willing to devote all their energies to righting a wrong (Pagan Jr 1989)

The women’s health movement for instance, according to Inlander (1998), gathered force in the early 1970’s with the objective of not only advocating and protecting the rights of
women on several fronts but also to ensure their equality within a substantially male dominated society. The movement has continued to evolve with many champions being created who have influenced the direction of its activities.

As mentioned earlier, different reasons exist for the emergence of different consumer movements. In some cases it is not just about equality or human rights but about recognition that a certain group is and must be a force to be ‘reckoned with’. For example, an interview conducted with a women’s health expert, Susan Merrill, revealed that women’s health services have emerged as a growing component of the health care system over the past two decades. This emergence equates to, among other things, the large proportion of health care products that women consume. When questioned on whether there was a time when it became obvious that women were becoming a force in the market Merrill responded:

*From a statistical perspective, women have long been a major force in our society, but the male dominated sectors (including health care) were reluctant to accept this fact. After a while, however, it’s hard to ignore the numbers indicating that women are consuming the lions share of health services, spending two-thirds of the health care dollar, and serving as the gatekeeper for a lot of other people. Frankly it took the aggressiveness of baby boom women to make this point, so it wasn’t so much the industry recognised women as distinct, but rather that female consumers imposed this perspective on the industry* (Interview: unknown author, 2000)

Here, Merrill also suggests that the impact of the number of women using the health care system is dominating the market and by virtue of this fact creating a voice that must be
heard. None the less it is significant in itself, that whatever the mode of recognition, a
voice is developed.

The consumer health movement.
The origins of the consumer health movement can be linked to the commencement of the
general consumer movement as suggested by (Crawford 1998) and others, to have
occurred in the 1960’s. (Inlander 1998, Green 1998). Early discussions regarding the
reasons for establishing active consumer participation in the United States in the health
care service system, also suggests that there was a reaction to the rising costs of health
insurance coverage and the costs of medical expenses for ordinary Americans.
Additionally there was national concern over the rising incidences of ‘malpractice and
incompetent physicians allowed to practice in different states’. Inlander contests that, ‘by
1985, numerous consumer health advocacy groups had sprung up’. (Inlander 1998).

Australia’s reported consumer champion, Hilda Bastion, is the Chairperson of the
Consumers Health Forum of Australia. Bastion advocates that Australia leads the way in
the provision of consumer representation of health care services, policy and research and
that involvement of the community regarding the development of health services in
Australia began earlier than in many other places:

Consumer representation in health care services, policy
and research is extensive in Australia by international
comparison. Indeed, it is difficult to find an example of
such far reaching health consumer movement anywhere
else. ... Certainly, seeking community input into the
development of health services began earlier in Australia
than in many other places (Bastion 1999, p. 1)
Bastion’s view clearly enunciates the position of consumers within Australia and is supported by other authors who hold the premise that consumer health participation worldwide is in its infancy. (Bastion 1999, Inlander 1998, Wyke 1997). The purposes of the consumers health forum in Australia is to achieve similar outcomes for consumers to those of their counterparts in the United States. Among other issues it includes reforms that have included consumer participation in the evaluation of pharmaceutical evaluation process and in reforms to general practice (Bastian 1999).

Bastion believes that interest in consumer participation is increasing mainly as a result of a ‘well funded health consumer lobby’. Her contention is that without the establishment of a formal forum such as the one in which she is involved, there is a lack of opportunity for ordinary health consumers to understand their rights with respect to treatment options as well as being informed about risks and benefits of treatment. Through this forum, consumers are afforded and accept responsibility for their own outcomes by being involved in lobbying activities as well as significantly informing the debate about how best services should be developed and delivered. Bastion’s views are not without merit. However, her association with the consumer health forum as chairperson must be weighed up in terms of bias with respect to the plight of the ordinary health consumer. It would be naive not to consider that there may be a particular perspective or agenda that is being pushed through Bastions comments as chairperson of a national forum.

**Mental health consumer movement.**

The mental health consumer movement has adopted a set of similar principals to the general consumer health movement such as establishment of forums and lobbying. However, there are some notable differences in the mechanisms by which consumers become actively involved. Peak bodies within Victoria such as Vicserv, often coordinate consumer and carer conferences, that are in their own right a type of forum. Not for profit non government organisations advocate for consumers and support consumers in their attempts to obtain additional funding for various programs as well as lobbying
government. Consumers themselves however, have become active at a grass roots level, in their involvement with self help programs that tend to form the basis of their movement.

For consumers of mental health services, the term self help describes both the ability to take control of their own lives and to make choices. (Mclean 1995). It inherently proposes that consumers actively pursue and reinforce their rights to make choices that affect them. Self help therefore adequately describes what consumers do and how they do it.

The human rights violations that have been reported have occurred in various forms and have led to consumers determining for themselves that the consequences of such violations impact negatively on every aspect of their lives. (Mclean 1995). Although these perceived violations were not the only precursor to the major reforms to mental health policy world wide, they did present a focal point for consumers to begin to publicly denounce the mental health service system as harmful and to lobby governments about their gross dissatisfaction. They did this by forming grass roots movements that were primarily aimed at assisting consumers to focus on opportunities to help themselves. (Mclean 1995) An era of self help and advocacy had been born.

Consumers of mental health and psychiatric disability support services advocate for themselves and are armed with the belief that they are always going to struggle to get what they want and need. Whilst according to Tower (1994) the transactions between consumers of mental health services and associated providers is conducted in much the same way as customers acquiring other products and services. Mental health consumers organise themselves into a movement because of their individual and collective personal experiences of loss through disenfranchisement and feelings of powerlessness. Their reasons for forming their movement is largely based on their experiences of oppression,
loss of control over their own lives and subsequent dissatisfaction with the ways in which mental health providers administer services. (Mclean 1995).

The nature of mental illness and the often accompanying symptomatology have been difficult for people to understand. The definition of mental illness, what it is and how it affects people is elusive. As a result people with mental illness have assumed a number of labels that have served to reinforce the myths that accompany the illness. Terms such as split personality to describe schizophrenia for instance do little to represent the illness for what it is and the effects it has on the individual. Other terms used to describe the behaviours of people with a mental illness also contribute to a further misunderstanding of various illnesses and associated symptoms. Consequently, the very nature of the illness allows for their judgement, no matter what the circumstances, whether individuals are in the midst of a psychotic episode or fully recovered, to be questioned.

Consumer participation through self help and advocacy has been the most acknowledged form of mental health consumer activism and the mental health and psychiatric disability support services sector has become more familiar with the term consumer self help as a way of describing consumer activity. (Spink 2000).

The rights of individuals to make choices which affect their own lives and the consequences of not achieving this aim, has driven consumer movements to continually evolve and change their focus from merely protecting its membership, to becoming strong political lobbyists and human rights activists. This phenomenon is not localised and transgresses all boundaries as groups of people band together for a common purpose.

Self help groups can incorporate a range of activities. Carling (1995) outlines the results of a survey conducted by Specht in 1988 and lists a comprehensive and diverse range of groups including:
Individual advocacy related to services and entitlements, and consumer rights, advocating for systems change by educating legislators, producing new legislation, pushing for new or increased funding, becoming involved in mental health policy development, promoting research, engaging in class action litigation, and educating the public, providing crisis intervention and short term crisis shelter, offering peer mutual support through the twelve step programs, buddy systems, rap groups, and peer counselling, operating drop-in centres and clubhouses, providing case management and housing services, evaluating and monitoring services, and community organising (Carling, p. 275)

These activities constitute a virtual support system for consumers. They cover almost every need that consumers may have as they seek support either directly through delivered programs or indirectly through government lobbying. It is apparent that had many of these services been delivered to the standard expected by consumers, the movement may not have grown as quickly as has been reported. Many observers have linked the progressive consumer movement with the deinstitutionalisation policies, that commenced in the 50’s and 60’s. (Flynn 1993,).

With the growth of deinstitutionalisation, self help groups are bridging the gap between hospitalisation and community living for expatients and self help groups have developed to replace the natural support networks that have been lost or have become disconnected as society has changed (Spink 2000 p. 7)
According to Spink (2000) it is through the reported self help movement that consumers:

... have had a significant effect on the development of psychiatric disability support services and advocacy for service user and carer rights (p. 7)

Although some consumers were focused on improving their own mental health through self help initiatives, others were determined to focus on alleviating the associated consequences that forced treatment and institutionalisation had on their lives and that of their families. Mclean (1995) further contends that through mutual support and self help, consumers, in sharing self help alternatives, discovered that their participation led to an elevated self validation and self esteem that actually promoted their recovery.

Consumers and ex-patients shared feelings of disenfranchisement and powerlessness resulting from their perceived abuse by service providers and their experience of human rights violations in being institutionalised through involuntary commitment and forced treatment. Thus they declared consumer empowerment as their fundamental goal. Empowerment was evoked as a means to correct those violations and the pervasive debilitating consequences of their encounters with the mental health system. Thus empowerment came to mean self determination and control over their entire lives, not just their treatment. Consumer alternatives, by engaging persons as producers of their own activities (eg. social change, self help, advocacy, information exchange or running a business), conceptually rejected reliance on professionals. Instead they endorsed the principles of self-
McLeans’ (1995) contention that empowerment is manifestly achieved through the principles of self-determination and the desire for consumers to ‘take control of their own lives’ is evidenced through the current rising popularity in consumers involvement in service delivery and research (Reference Group 2000). The reference group and its contribution to this research is acknowledged and discussed in chapters five, six and seven.

**The various terms used to describe mental health consumer movements – do they all mean the same thing.**

The terminology that currently exists to describe the various forms of self determination principles espoused earlier can be confusing. An attempt will be made in the following section, to highlight the common terms that are used to describe mental health consumer movements and their activities.

Firstly, it is worth making a distinction between the way in which consumers often prefer to refer to themselves. In the United States, the descriptions of consumers who became involved with the self help movement varied depending on how consumers wished to identify themselves and their association with mental health services. Mclean (1995) adopted the term consumer as the basis for depicting those involved in the consumer movement. She recognised and discusses what she refers to as ‘subtle but distinct political variations’ each group portrayed:

*Persons who identify themselves as consumers, clients or patients tend to accept the medical model of mental illness and traditional mental health treatment practices, but work for general system improvement and for the addition of*
consumer controlled alternatives. Those who refer to themselves as ex-patients, survivors or ex-inmates, reject the medical model of mental illness, professional control and forced treatment and seek alternatives exclusively in user controlled centres. The contemporary ex-patient/survivor movement in the United States was promoted mainly by this latter group. Despite these variations, all groups shared an empowerment ideology and advocated for protection of their legal rights and support for user controlled alternatives to the traditional mental health system. ... Because of their dislike of the term consumer, some movement activists have retained the cumbersome but politically more encompassing construction consumer/ex-patient. I fully appreciate the importance of the political distinction between the two terms. At the same time, I feel consumer is appropriate for characterising a movement by individuals whose motivations have been guided by the negative experiences they had or have has as consumers – regardless of whether or not they were consumers by choice when this occurred (McLean 1995 p. 1054)

It is worth stressing that although variations did exist in the way individuals chose to identify themselves in terms of their use of and association with the mental health service system (McLean 1995), they shared a ‘common ideology’ that underpinned the principles of their movement and that was that:

... all groups shared an empowerment ideology and advocated for protection of their legal rights and support
In the context of the Victorian experience, the terms used by McLean and the distinctions between them are probably not dissimilar. The distinctions lie somewhere beneath the surface and have not been explored in the literature within Australia to any great degree. Consumer, ex-patient and survivor all appear in the literature that has been compiled for various projects on consumer participation, consumer feedback and other research projects.

Of significant note is the research project titled ‘The Ultimate Exit Survey: Survivors of Psychiatric Services Speak Out (The Melbourne Consumer Consultant Group (MCCG) (1997), in which a number of discussions between consumers were audio-taped and reproduced to allow the reader to gain a first hand understanding of consumer experiences with the mental health system in Victoria. The title makes reference to consumers as survivors, perhaps to attract attention to its significance. The content discusses first hand experiences and perspective’s of consumers who have had significant involvement with the States mental health system.

None the less the term consumer appears most frequently in the texts that were developed in Victoria over the past decade, where the term consumer takes on the perspective of active and willing involvement by individuals associated with the mental health system. Understanding anytime (McGuiness, M. and Wadsworth, Y. 1991), Understanding and Involvement: A projects beginnings (1994), Understanding and Involvement: A project Unfolds (1996), Understanding and Involvement: A project Concludes (1996), Consumer feedback and staff-consumer communication (1996), Why don’t you ask? (1996). (Epstein and Wadsworth 1991, 1994, 1996)
**How the mental health consumer has been mobilised to action in Victoria, Australia.**

It can be argued that Victoria leads the way in Australia in advancements to reform the States mental health system. Continuing research is robust as evidenced by the number of projects that have been developed over the past decade. Whilst there are several organisations that exist to support the provision of self help and advocacy, for example (ARAFEMI, VIMIAC, SFV Vicserv to name a few) these organisations have also provided support for numerous research projects undertaken through establishing consumer participation initiatives as well as providing valuable funding support. In essence these organisations have supported the growth of the mental health consumer movement within Victoria and established benchmarks for other Australian States to follow.

In reference to the discussion about consumer champions appearing earlier in this chapter, there can be genuine similarities drawn between the efforts of those portrayed to be consumer champions and the consumer consultants engaged to participate in the development and direction of mental health policy within Victoria. Their developing role and the contribution they are making is discussed further in the following section.

**Consumer Consultants.**

The role of the consumer consultant within the mental health and psychiatric disability support service sector has been explored and discussed more fully in Chapter six. However, it is the intention here to make mention of the perspective and involvement of consumer consultants within the mental health field broadly and as catalysts who have championed the consumer movement. As has been mentioned earlier and supported by such authors as Pagan Jr (1989), there is often a single person who is behind a campaign and the driving force perpetuating a cause or movement. Consumer consultants individually and collectively can be regarded as that force who have lead the way with respect to involvement and reform of mental health services within Victoria. Their major contribution to ensuring the movement continues to be progressive, has seen consumer
consultants more active on several fronts within the mental health field since 1997. Their involvement has not been limited to tokenistic contributions on voluntary boards or committees. Rather they have been an important part of many of the action research and evaluation projects conducted in Victoria since the early 90’s (Epstein and Wadsworth 1996)

The introduction of meaningful dialogue transpired between consumers and providers during the first Understanding and Involvement Project (Epstein and Wadsworth 1994) at Royal Park Hospital, an action research project that was ground breaking. That project had a second and equally important historic significance in that it was responsible for the formation of the Melbourne Consumer Consultants Group, now an incorporated body. (MCCG 1997). The stated mission of this group is:

To pass on consumer information to all who contribute to, impinge on, and shape the experiences of consumers, realising that there is a widespread need for the consumer voice and a consumer perspective to be heard. Practically, this sees our members sitting on committees, contributing to seminars, forums and conferences, actively participating in research projects (my emphasis), and now, helping to elicit consumer views as Area Mental Health Consumer Consultants (MCCG, p. iv)

As individual consumer consultants, they have been employed by a number of in-patient, community and psychiatric disability support services throughout Victoria since their initial involvement with the understanding and involvement projects conducted at Royal Park Hospital. (MCCG p, iv). As their mission states, consumer consultants assist with the development and delivery of services and programs and perform a range of functions including the dissemination of information. As stated by Breakey et al (1996):
It is now widely accepted that nobody understands the experience of mental illness better than the patients and their families, who have lived through it (p. 160)

Consumer consultants have lived the experience and are in a position to speak from that experience.

The Melbourne Consumer Consultants Group have been involved in a number projects since its inception and many consumer consultants have taken a further step to individually embark on their own research on consumer and provider activity. The recognition of their contribution has been recognised and acknowledged through various publications released by the Department of Human Services in Victoria. (MCCG pp. iv). This involvement, either as a group or as individuals continues to reinforce to the community, providers and other consumers, that consumers can play a significant role in shaping the development of mental health services through their active participation.

As mentioned earlier it has not been just a case of direct involvement with services. Consumer consultants are also conducting research on a range of issues. For example, some particularly pro-active consultants are undertaking important research and presenting papers at various conferences both in Australia and overseas. This type of involvement that important aspects of mental health and psychiatric disability are placed in the public arena especially in the areas of service development and changes to legislation affecting all consumers.

Some consumer consultants have delivered unpublished papers that are of significant importance to consumers and providers alike. One such paper was developed and delivered by Allan Pinches (Pinches, June 2000). This paper provided a short history including time lines of Victoria’s Mental Health Services, Government policy directions
and the consumer movement. Considerable investigation had gone into the preparation of this paper with the result being a succinct composition of activities related to mental health services in Victoria since 1949. Not only does this provide valuable reference material for other researchers, but it also demonstrates the ability of consumers to engage in and share their understanding of the developments of mental health services from a different perspective not just as ‘survivors’ of the mental health system but as pioneers of it.

Summary.

Consumers have expectations about how services should be developed and delivered. However these expectations have not always been met. Consumers were not in a position to challenge providers with what they considered to be unacceptable outcomes in terms of their (consumers) expectations. In the mental health services sector, deinstitutionalisation policies introduced over the past three decades together with greater opportunities for direct involvement with services and a self determination by consumers to have a say have created a more balanced relationship with providers and their service system. It is perhaps more the perspective of the consumer that the power imbalance is now being rectified. In some cases this still creates a threat for providers, especially those who have had a long standing association with the psychiatric hospital system and find the cultural and attitudinal changes difficult to achieve.

Consumers are working to change the dynamic and to achieve for themselves a recognition that they can improve services through their direct involvement. More and more, consumers of services are demanding better outcomes in terms of their standards of living, and in the services they demand and expect but also, they want recognition that they are capable and have demonstrated that they can make a significant contribution to the development and delivery of mental health services. The most significant way that this accountability by providers has been brought about, is through consumers
demonstrating a collective voice, united in their endeavours to achieve the response that they seek. A movement by consumers who rally together for a common cause.

To this end they seek what other consumers in different sectors seek with a commonality of purpose. However, it is acknowledged that consumers are still starting from a position of relative weakness in comparison to consumers of other services. Unlike consumers of other services, mental health consumers are required to overcome a number of additional barriers in order to achieve their goal of at least being heard. These barriers are associated with stigma, lack of understanding by the community, the consequence of mental illness on cognitive functioning and the life circumstances such as lack of employment, income and accommodation problems with which a large number of people with a mental illness and psychiatric disability are faced. Although there should be no more difficulty in consumers with mental illness accessing services in comparison to those people accessing general health services, the reality, because of societies perception of mental illness, provides a different picture. Mental health consumers do find accessing services more difficult and this has been exacerbated in an environment where providers still need to change their attitudes towards people with mental illness. Whether services are paid for directly by the consumer, or funded indirectly by the tax payer, providers have been called to be more accountable in the way that services are developed and delivered.

Consumers want protection from the threat of being further disempowered. Once again, this exploitation may be in the form of promised but undelivered goods purchased, or it may be in the form of promised services that have led consumers to believe they will receive appropriate levels of commitment by providers. There is little doubt that purchases of goods and consumers of services enter into similar contracts and relationships with providers in order to achieve certain outcomes for themselves. If these outcomes are not realised to the satisfaction of those consumers concerned, some form of action is required. With consumer groups in place to monitor actions and activities by
providers, there is often the opportunity for consumers to take the necessary steps to correct problems or speak out on different issues if and when they arise.

The opportunity for consumers of mental health and psychiatric disability support services to form groups that can achieve change in the way that services are developed and delivered is a relatively recent phenomenon. Although there has been some debate about whether consumers of mental health services who from the consumer movement actually have the power to influence providers and subsequently change the balance of power (Sluzki 2000), others believe the recognition of the transition form patient or client to consumer actually restores that imbalance and creates a sense of control and power for consumers. The question that consumers ask is about the reluctance of providers to accept that consumers are capable of contributing to service design, development and delivery at several levels including policy. Consumers seek to be empowered so that they can control events that impact upon their day to day lives. As individuals, achieving a state of empowerment is often difficult particularly in context of the barriers mentioned earlier.

Consumer movements, however defined or described, seek to empower individuals. They do this by creating the opportunity for individuals to campaign for choices that they can and should be able to have over the activities that shape and direct their lives. When people are allowed to make choices about issues that have the potential to dictate every aspect of their psychological, sociological and biological existence, they begin to belong to a society that has come to expect that individuals take responsibility for themselves. That people with a mental illness have not had the responsibility for their own lives over a considerable period of time can be attributed to institutionalisation practices that effectively removed their rights to do so. It is important to note however, that consumers living within institutions as described earlier, were disempowered because of a number of reasons, and cannot be attributed to the presence of walls and boundaries that surrounded the institutions. Staff within these institutions contributed considerably to removing power and control from patients because they had assumed the authority to do so.
conferred upon them by the regulatory processes of state governments and through relative legislation.

There is support for the notion that were it not for the enthusiasm and vision of some individuals who championed a cause, consumer movements would not be what they are today. Many examples have been given in respect of those individuals, Ghandi and Nader in generalist terms and Burdekin in relation to human rights to name a few.

Consumer consultants positions were first conceived during the understanding and involvement projects at Royal Park Psychiatric hospital in Melbourne in January 1994 (Wadsworth and Epstein 1996 p. 47). It can be argued that this group of consumer consultants and those who have since followed in their footsteps have been the true champions of the development and progression of the mental health consumer movement over the past decade. It is not necessary to single out any one person within this initial group. Rather it is important to recognise that a group of mental health consumers, survivors, ex-patients, have been able to contribute enormously to not only mental health policy development within the state, but also in bringing credibility to their activities as members of treating teams, program developers, advocates and researchers.

The mental health consumer movement has achieved considerable progress like no other movement in the past decade. Not only has there been a recognition that deinstitutionalisation practices have finally achieved a greater autonomy for consumers, consumers have now also come to expect that they will receive the support they need at varying stages of their illness within the community. This support must go beyond simply recognition and acceptance of mental illness and psychiatric disability and move to embracing the unique skills and experiences that people with a mental illness can bring to the service system.
The opportunities to enable consumers to share their experiences and to assist in further developing services that meet other consumers' needs has already been realised. To build on this recognition, all research into the mental health system should be welcomed as an opportunity to bring mainstream society into closer touch with the people who have mental illness and a psychiatric disability. The ability, opportunity, and willingness for consumers themselves to take a greater role in research is particularly relevant to this study and one that will continue underpin the activities of the mental health consumer movements.

The concepts and strategies that facilitate and enable the participation of consumers in services will be explored and discussed further throughout the discourse on power and empowerment presented in chapter four.
Chapter 4: Power and Empowerment.

Introduction.

The question of power and empowerment and how it is perceived and understood by consumers of psychiatric disability support services and their carers is paramount to this study. The recognition of power and who holds it, or who is perceived to hold it, is also important in determining who has and has not the mandate to make strategic decisions about policy which ultimately affects the lives of consumers of mental health services and their carers. The struggle for power dominates business strategies and involves acquiring and relying on leading edge resources such as technology, information and customer services (Morgan 1986). Customers are central to the success of a business for without them there can be no business, no transaction and no ability for achieving greater market share.

The rhetoric attached to consumer and carer involvement in the development and provision of mental health services provides a stark contrast to what appears to be occurring within our communities. There has been, and will continue to be much discussion surrounding the value of consumer and carer participation in the management of relatives and friends who have a serious mental illness. Of significance is the debate about whether lay management of people requiring specialist intervention for their mental illness actually succeeds in improving outcomes for the individual. These questions will be explored through the extensive literature available, and through directly interviewing consumers and carers. Of equal importance is the degree to which consumers and carers wish to participate in every aspect of intervention. The question of responsibility and who should have it arises as the most predominant here particularly during the more difficult periods of a persons illness. What is important is that there needs to be a collaborative and cooperative approach between consumers and carers and professionals which needs to be clearly defined yet flexible. We can begin to understand how this may occur only
when we have explored the concepts and practical aspects of achieving empowerment and what it means to experience it.

**Definitions of empowerment: understanding the concept.**

*Only empowerment can invest people with the sense of self-efficacy, which enables them to act in productive ways. Only empowerment can encourage risk taking, unleash energy, stimulate creativity, instil pride, build commitment, prompt the taking of responsibility and evoke a sense of investment and ownership* (Guba and Lincoln 1989, pp. 226-227)

The assertions of Lincoln and Guba go a long way toward successfully describing what individuals have to look forward to as they strive for and move to an empowered state. It suggests that, empowering people requires a number of inter-related and perhaps inter-connected experiences which, when taken in context, create an empowered state where individuals feel in control of their own lives.

In order to firmly understand empowerment both as concept and practice, it is necessary to discuss the terms, references and meaning of power and empowerment. The concept of empowerment assumes that ideologies have generated the need to consider conferring power upon mental health consumers. The practical application provides for those ideologies to be translated into tangible ways of implementing systems which recognise the contributions of consumers and carers. In this chapter, the views of a number of authors who have investigated the concepts of empowerment and its implications is reviewed and discussed. In particular consideration is given to the relationship between power and empowerment. The general and perhaps often inappropriate use of terms such as power, empowerment and empowering in the name of conferring authority and control.
by a person or group to another person or group is analysed and discussed. In addition, a
discussion of the specific ideologies associated with empowering consumers and carers
involved with mental health services is also included. This generalist discursive approach
is favoured in comparison to simply providing a collection of definitions of
empowerment because of the many aspects of life situations and environments which
appear to contribute to achieving (or not achieving) an empowered state.

According to Meekosha and Mowbray (1996)

*The concept of empowerment is located within the
discourse of community development and is connected to
concepts of self-help, participation, networking and equity.*

*Empowerment is the taking on of power, at both the
individual and social levels* (p. 60)

**Perceptions of empowerment – understanding the practice.**

Understanding power and empowerment and their effect on individuals, communities and
groups is important in knowing how to develop and facilitate applications which achieve
an empowered state. It is equally important to grasp an understanding of the relationship
between the concepts and the various applications which seek to empower individuals
and groups. It would not be sufficient to only distinguish between the meanings and
concepts of power and empowerment, nor to summarise these meanings into possible
applications without first reviewing the context in which power and empowerment are
grounded in theory. This review requires the development of a framework which, as a
core contribution, assists the reader to a better understanding of the distinction between
terms and practices related to power, empowering and empowerment and the empowered
individual or group. Here, it commences with a discussion of how power is described,
achieved and transferred.
Foucault (1954) proposes that power:

... means ... a more or less organised, hierarchical, coordinated cluster of relations despite the fact that it is never localised here or there ... never in anybody's hands, never appropriated as a commodity (Foucault in Cheater 1999 p. 3)

His concept further suggests that power is:

... vested, even created in discourses of truth and knowledge rather than in any Weberian command of potential force (p. 4)

In relative terms, this ideology suggests that power is inherently possessed by all individuals and the degree to which power is exercised by an individual depends predominantly on factors related to their capacity to do so. For an individual to actually feel empowered or be empowered therefore, they must have the capacity to feel or be in control of their own lives, which Foucault points out, is achieved through knowing oneself and one's environment. If this theory is extrapolated out to involve the user of mental health services then in order to understand and utilise this concept, there is an opportunity to value the contribution that consumers and carers can make through their knowledge of issues and experiences which have directly affected them. Furthermore, through their active participation in organising support and advocacy for other people with a mental illness, there is considerable scope for further development and understanding of issues, which were once primarily the domain of the mental health professional. To this end, and in keeping with Foucault's discourse on an individuals inherent possession of power, a group of individuals has emerged to drive the voice of mental health consumers. The role of consumer consultants was first established through
the conduct of an action research project undertaken in an acute admission ward of a psychiatric hospital in Victoria. (Epstein and Wadsworth 1994). The research considered options for effective feedback by consumers and service providers so that a more balanced approach to treatment and care of consumers during their hospitalisation could be achieved. The role of a consumer consultant and the consumer movement will be dealt with in more detail in a later chapters, however, it is necessary to acknowledge here that the emergence of a significant few has perhaps seen the creation of a new movement advocating for mental health services. The knowing of oneself and ones environment as Foucault so aptly put it, finds consumers with a realisation that these advantages clearly allow consumers to be empowered.

Barnes (1988) describes power as a theoretical term referring to distributions of capacities, potential’s and capabilities. However, he proposes further that the practice of empowering individuals is achieved through the genuine conferring of power from persons in relative power to their subordinates, a process he describes as 'downward delegation. In conferring this power the empowered agent has

\[... \text{a discretion to use the given resources to further the objectives of the power holder and is considered generally to be a power holder in his own right} \text{ (Barnes 1988, p. 71)}\]

Elaborating further on the concept of empowerment, Barnes (1988) suggests that distinctions are required to be made between what he has described as 'downward delegation' and 'authorising'. In the latter, an entity is authorised to carry out a particular task(s) which, through this practice, leaves little latitude for an entity to use his own discretion and judgement. In delegating authority, the power holder continues to direct the actions of the entity to whom the authority has been delegated and this authority can be retracted at any time. In enabling the agent to be truly empowered, the power holder risks the loss of control over subsequent strategies and structures which were initially
designed and developed to realise plans and objectives the power holder has put in place. In addition, there is also a perceived risk of loss of individual power. The delegation of authority clearly establishes a mandate which indicates that the original power holder stays 'in touch' with the proposed empowered entity to ensure that the discretionary power conferred upon it can be effectively recovered. Judge (in Cheater 1999) would agree that empowerment is about making the most of peoples potential. But he opposes Barnes view of the way empowerment is achieved by stating that ‘empowerment is not delegation’.

In making this assertion, Judge, describes the power plays between managers and staff. Although an Organisation may consider that employees have been empowered, there is an inherent difference between managers and staff usually made clear through who holds the power at any given point in time. In other words staff are continually reminded that there are power holders within the Organisation who have greater status. In this context Barnes and Judge have treated power as a commodity and their discussion about how it is owned is in opposition to the view espoused by Foucault.

Dhal, suggests Chakerian, supports Barnes view and states that:

*Power is a set of resources such as money, credit, jobs, expertise, influence and social influence* (Chackerian et al 1984, p. 132)

In the context of how power is achieved Morgan (1986) also supports Dhal’s view of power as a commodity and suggests that:

*Power involves an ability to get another person to do something that he or she would not otherwise have done* (Morgan 1986, p. 158).
For some, explains Morgan, that this assumption is made is determined by the:

... conditions under which one person, a group, or an organisation becomes dependent on another while for others it leads to an examination of the historical forces that shape the stage of action on which contemporary power relations are set (Morgan 1986, p. 158)

There are significant differences between the views on the concepts of power and empowerment proposed by Foucault, Barnes and Judge. In particular, the way in which individuals and groups achieve their empowered state is a continual focus of the debate and arguably of considerable importance. Despite the obvious differences there exists an opportunity to understand how people with a mental illness and their carers might experience an empowered state. The path to empowerment, whether through delegation, the conferring of authority or the personal potential manifest in each individual, may at the end of the day influence the extent to which true empowerment can be achieved.

**Perceptions of empowerment: Do consumers and carers want to be empowered?**

In determining that empowerment is a real responsibility, consideration should be given to the nature of and extent to which consumers and carers wish to be empowered at all. (Mascull in Cheater 1999), remarking on empowerment of employees considers empowerment to be the following:

_Empowerment, an ugly transatlantic neologism which suggests that ordinary workers want, enjoy and benefit from being empowered. Of course, with power comes responsibility, and it is not clear that workers who warm to the former, are equally happy about the latter. Also, the_
Empowerment of one group usually means the disempowerment of another group (Cheater 1999, p. 3)

Having power conferred does not necessarily mean that the individual is now empowered by some unusual occurrence. Or that a person has now been transformed into someone, who was just a short time ago, a less empowered person. The term itself suggests a choice in the matter, whether to accept more power or not. But the acceptance or non should not be construed as powerlessness as the concept of free choice prevails.

Empowerment in response to deinstitutionalisation.

It is clear from the literature that whenever changes to the mental health service system occur and new policies are developed the recipients of those services, including consumers and families, should be involved at several levels in both the planning and implementation stages (WHO 1990, HR&EOC 1993). The devolution of pre-existing institutional care, which was largely authoritarian in nature, has indirectly conferred power on consumers and carers to take more responsibility for their own care and treatment. Rather than delegating direct authority to take this responsibility, consumers and carers are now tacitly empowered to become involved with the changes. (Dickerson 1995).

Constructionists of social policy have provided analyses of community order and power for decades. They also agree that the trend of empowering consumers and carers to be involved in the management of their own health, is continuing and that this trend is largely due to the deinstitutionalisation policies that have been instituted. (Heflinger and Nixon 1996, Meekosha and Mowbray in Craig and Mayo 1995). That is, the empowerment has occurred as a direct response to deinstitutionalisation and the associated need for greater self care within the community.
Other authors have contributed to the debate regarding consumer response to deinstitutionalisation and the way in which it has contributed to empowering people with a mental illness (Dickerson 1998, Furlong and Leggatt 1996, McClean 1995, Braye and Preston-Shoot 1993, Freund 1993). They agree that individuals have become empowered as a direct result of deinstitutionalisation and related policies which impact upon individuals and the community as a whole. It is perhaps this notion, which I will call reactionary empowerment, which sits most comfortably with the consumer movement as it implies that consumers are able to respond positively to forces which have contributed to their struggle for better mental health services. In addition the concept also holds consumers up to be capable competent people who have the ability to make choices about their own lives and in some cases, the lives of those who they perceive would share their views.

The meaning of empowerment – A shared concept and practice.

The term empowerment is used often in psychiatric literature. The numerous authors who have discussed empowerment and the mental health system have contributed considerably to clarifying some of the fundamental attributes and applications associated with empowerment practice. (Gutierrez et al 1995, Freund 1993, Rappaport 1984, McLean 1995). In the broadest possible terms, they aim to improve the mental health system. In doing so they subsequently attempt to improve outcomes for the same group as well as create a necessary debate about how this is best achieved. As with any debate, there are positive and negative outcomes both real and perceived for consumers, carers and health professionals. Understanding the often marked differences of opinion regarding power and empowerment and how it is achieved is essential in determining the way in which consumers and carers are ultimately empowered to take responsibility for their own lives.

Of significant note is the work of Guterreiz et al (1995) who suggest that:
The concept of empowerment has become popular within the human services professions, but little agreement about its meaning or dimensions has been displayed (Gutierrez 1995, p. 534)

Clarifying this dilemma would seem a significant step forward in understanding the construction of strategies and structures which would underpin successful empowering practices. Human service organisations attempt, at various levels, to translate the concept of empowerment:

... understood to mean: the ability to get what one needs; the ability to influence how others think, feel act, and behave; and the ability to influence the distribution of resources in a social system such as family, organisation, community and society (Gutierrez 1995, p. 535)

The application of this concept in practical terms is represented in various ways including the development of goals, processes and intervention techniques. However, according to Gutierrez et al (1995), it is this practical, even tangible aspect derived from the very concept of empowerment which has the propensity to establish a 'working definition'. Their development of a framework, which clearly identifies the parameters of an empowering practice, indicates that, through recognising the components central to developing a workable model, a greater understanding of the relationship between concept and process is achievable. They summarise the necessary ingredients that bridge the gap between a conceptual model and its propensity to be applied by "organisations and individuals". This summary is represented in the following table as presented by Gutierrez et al (1995).
Empowerment is a theory and practice that deals with issues of power, powerlessness and oppression and how they contribute to individual, family, or community problems and affect helping relationships.

The goal of empowerment is to increase personal, interpersonal or political power so that individuals, families or communities can take action to improve their situations.

Empowerment is a process that can take place on the individual, interpersonal and community levels of intervention. It consists of the following sub-processes: development of group consciousness, reduction of self blame, assumption of personal responsibility for change, and enhancement of self efficacy.

Empowerment occurs through intervention methods that include basing the helping relationship on collaboration, trust, and shared power; utilising small groups; accepting the clients definition of the problem; identifying and building upon the clients strengths; raising the clients consciousness of issues of class and power; actively involving the client in the change process; teaching specific skills; using mutual aid, self help or support groups; experiencing a sense of personal power within the helping relationship; and mobilising resources or advocating for clients.

Source: (Gutierrez et al 1995, p. 353)

Of critical importance here is recognising and achieving the goal of increased actual power for the individual or group which demonstrates that

\[
\text{action can be taken to prevent or change the problems they are facing} \quad \text{(Gutierrez et al 1995, p. 353)}
\]

Braye and Preston Shoot (1993), suggest that the way forward for practitioners to empower their clients involves four key components of which the development of a conceptual framework is one. The other three components include a personal will, an
organisational commitment and a developed practice base. They describe their frameworks as 'frameworks for understanding' where one is required to understand and take into account: power and equality, internalised oppression, and choices for practitioners.

**Attitudes of health professionals on empowerment and treatment.**

A recent review on the attitudes of health professionals in the development and delivery of mental health services, was commissioned by the Mental Health Branch of the Australian Commonwealth Department of Health and Family services. The resultant document (Frank Small and Associates 1998) discusses a number of issues about the relationship that consumers and carers have with professional mental health service providers and the barriers to effectively providing consumer driven services. It made progress in identifying predominant themes which expose the nature and extent to which professionals perceive and achieve ‘working relationships’ with consumers and carers.

Central to this investigation is the discussion contained within the document which relates to the:

*Conceptual and practical problems that surround the use of terms like empowerment* (Frank Small and Associates 1998, p. 78)

Referring to a number of researchers who have contributed to a greater understanding of what empowerment actually means Frank Small and Associates (1998) discuss this in context with an historical background on the development of the mental health service system nationally in Australia and abroad. The debate does not necessarily focus on what the term empowerment actually means, although Gutierrez et al (1995) provide a substantial working definition of one version and Fisher (1994) provides a second. The discussion suggests that a central tenet in understanding the benefit of conferring power
and thereby empowering consumers and carers to have more responsibility for mental health service development and delivery, has been missed by mental health professionals. The willingness to empower has been confused by the mental health professional with the view that to do so would be to lose power and control rather than become a driver of change. There may be the belief present that empowering consumers would result in a direct loss of power by the provider however a more fundamental issue of not having the power to confer in the first place appears to underpin this notion as stated:

Relatively few providers seemed to advocate consumer empowerment, one of those that did wryly remarked "we need to empower consumers but staff needs to be empowered before they can empower clients" (Scheid 1994 in Frank et al 1998, p. 58)

Other studies, which have examined the attitudes professionals have toward their clients and more broadly, to issues of mental health generally, have revealed that some major misconceptions are present about mental illness and its causes. For instance, Premamatha et al (1990), undertook a study which investigated the attitudes of professionals working in primary health centres in India. The questionnaire designed for the study had 35 items and included topics such as psychosis, epilepsy and mental retardation. A training program, which sought to improve the understanding and knowledge of mental health workers and to dispel the myths related to mental health and how one is affected by it was the focus of this study. The sample were required to respond to the questions specifically developed for the research, before and after training had been instituted. The researchers conclusions suggest that professionals working in the field required specific training in order to improve their attitude and subsequent level of care for people with a mental illness. Of significant importance was the finding that despite undergoing the training, many trainees "continued to have reservations whether mentally ill persons could indeed be managed at primary care settings". The issue of cultural belief, in this
case, is an obvious barrier to improving outcomes for people with mental illness, however questions must also be asked about the usefulness of the training program and what it set out to achieve. (Braye and Preston-Shoot 1993)

For the group of trainees who were unable to respond to the need to change their attitudes in relation to their beliefs about mental illness, the concept of empowering consumers would be difficult to achieve. Yet by empowering consumers there is the opportunity for providers to understand different ways of providing treatment:

*Empowerment has the potential to ultimately challenging the status quo and leading radical new ways of understanding and approaching the treatment of mental illness* (Scheid 1990, pp. 679-683)

The Understanding and Involvement projects, A projects Beginnings (Epstein and Wadsworth 1994), A Project Unfolds (Epstein and Wadsworth 1996) and A project Concludes Epstein and Wadsworth 1996) undertook to explore the relationship between service providers and consumers and how best evaluative feedback between consumers and providers could be achieved. The series undertook, through an action research methodology, to uncover the attitudes of health professionals working in an acute admission ward. These projects have been discussed in an earlier section in this chapter, however it is worth reiterating here that they provide one example of the benefits achieved through the application of practices that have effectively empowered mental health consumers to action.

**The relationship between consumer and professional - traditional practice.**

The perception that the empowerment of the individual is achieved through the process described by Guteirrez warrants further investigation. Rappaport (1987) suggests through his definition of empowerment that:
built into the term is a quality of the relationship between a person and the community, environment or something outside oneself (Rappaport 1987, p.129)

To this end, there is now an opportunity to discuss how power is actually conferred from one person or group to another so that an empowered state is achieved and recognised. The explanation of a working model by Guteirrez et al (1995) suggest that this state is achieved spontaneously following the recognition and understanding of the concepts behind the empowering process.

The relationship between consumer, carer, and provider has been referred to by many authors who suggest that providers and clinicians must be sensitive to a number of issues with which consumers are faced including: stigma, disenfranchisement and social circumstances. (Dickerson 1998, Freund 1993, Mclean 1995, Guterriez et 1995).

Freund (1993) describes the importance of the relationship that staff have with consumers. His assertion is that without this relationship, a realistic model of empowerment cannot be developed. Through his experiences with consumers involved with rehabilitation services he describes a process of empowerment through individual development where a link is made between the ability to truly empower and the staff members personal belief that "managing ones life is primarily the result of internal motivating factors". (Freund 1993, p. 67). He explains that an aspect of successfully understanding the transference of power from the professional to the consumer, requires staff to have a 'high internal locus of control' (Freund 1993, p. 67), a belief also shared by other practitioners. (Dickerson 1998). Professionals with this high internal locus of control are "sensitive to consumers needs to learn from their experience and to chart their own course". (Freund 1993, p. 67). The distinction is made between working with consumers which requires flexibility and spontaneity and working for consumers where
structure and discipline have been pre-determined and presumably one would deviate little from this structured course. Throughout the process, a great deal of consideration and attention is given to the need for staff to de-emphasise their professional role as the symmetry within the group and the dynamic of the group changes. The process itself provides a good explanation of the overall role professionals play in developing self help and support groups. The ability for the professional staff member to gradually relinquish the responsibility for some, if not all of the leadership tasks, Freund believes, communicates a clear message that the group members can and should have control and they have therefore been empowered.

The gradual move from dependency to independence or interdependence (the latter term is used by Freund to describe the relationship between group members) which according to Freund empowers consumers, occurs in three phases. The phases included dependence, self assertion and inter-dependence. A brief explanation of each phase follows.

In the dependence phase consumers join a rehabilitation program where some structure is offered by professional staff in the form of orientation to the program. Consumers, already during this phase of the relationship begin to be empowered through their engagement with staff who encourage and guide them through the new process where dialogue is essential. Dialogue between the professional and consumer includes discussions about the importance of the consumers choice and the ideas and suggestions they are prepared to put forward. The professional can be described as a subtle facilitator in linking consumers interests and thereby foster a desire in consumers to take more control.

Self assertion, which is the development of the second phase of the relationship between professional and consumer, proposes that consumers move further away from a structured process and where they become more assertive as individuals and as a group. The
professional has a role here of mediating on issues between group members and this is seen as increasingly important depending upon how assertive consumers become.

The third and interdependent phase, sees consumers within the group establish a greater dependence on each other. This phase describes the political environment in which fully formed groups grapple with factional separation and come to agreement, or reach a common ground on hotly debated issues.

Freund’s (1993) description of the transition consumers and professional make during their working relationship, suggests that the power once held by the professional is conferred upon the consumer in gradual steps. However, during each phase, it is assumed that the consumer is empowered sufficiently to make decisions and take control of the given situation. The benefits of this empowering process described by Freund, provides assumptions about the needs of the consumers. Do consumers require that their lives be organised in such a fashion that they are given increasing amounts of responsibility depending upon their level of understanding, ability and knowledge of what they (consumers) must do to improve the quality of their lives?

**The relationship between consumer and professional – alternative practice.**

It has been argued however, that there is a need to move away from the traditional practices within the mental health field where an assumption exists that the practitioner/professional holds the power and control. In the US over recent years, support has increased for alternative approaches to developing programs which are run entirely by consumers and ex-patients of mental health services McLean (1995). This response according to McLean, has developed because consumers and ex-patients have felt increasingly disenfranchised and disillusioned with the mental health system, citing issues related to forced admission and treatment as human rights violations. The consumer movement has continued to evolve and has led to the development of extensive self help practices where consumers were able to share their feelings of these perceived
human rights violations. The context of realising empowerment through self help is described by McLean as individuals having:

\[
\text{self determination and control over their own lives, not only their treatment} \quad (\text{McLean, p. 1053})
\]

It is a direct response where consumers attempt to correct those violations and the pervasive debilitating consequences of their encounters with the mental health system. McLean’s attempt at defining empowerment is grounded in the theories on the relationship between power and empowerment espoused by Foucault (1980) and Szasz (1990). In relation to conceptualising a working model wherein empowering consumers is achieved through understanding the negative and positive aspects of power, McLean's description more than adequately provides a fundamental basis on which to build a successful empowering practice. While her discourse lends some uncertainty to which perceived understanding of empowerment practice is accepted, McLean (1995) contests that the:

\[
\text{array of assumptions is ultimately political in nature} \quad (\text{McLean 1995, p. 1056})
\]

Anthropologists continually studying the effects of power balances on individuals and groups would agree that there are limits to community power which can be directly attributed to the extent of that power held by social institutions for example:

\[
\text{power adheres to institutional roles which give the people who occupy these roles control over valued resources} \quad (\text{Dye in Waste 1986, p. 29})
\]

In a collection of studies related to community power, he suggests that:
communities, like nations, are governed by tiny minorities. The community itself, and the lives of the people who live in it, are shaped by a small number of people (Dye in Waste 1986, p. 29)

Dye also discusses ‘elite theory’ which he suggests puts into perspective the power and control of institutions:

it helps us to identify what is truly significant about community life. It helps us to understand communities by describing, clarifying and simplifying politics, by suggesting explanations of political events and public policies and by directing inquiry and research in community studies (p. 29)

Dye further asserts that:

at the national level, the study of elite’s involves the identification of positions of authority in large national institutions – institutions that control the economic, governmental, educational, civic, and cultural resources of the nation (p. 30)

The shift from traditional institutional care to the more accessible style of community support brings with it specific challenges. The discourse on elite theory suggests that the power and control owned and exercised by the large institutions such as the former mental hospitals may simply be transferred to community organisations that have replaced these institutions. Therefore, they have the propensity to become institutions in their own right. If this is the case there is a real risk that the attitudes of providers
considered to be pathological with respect to practices within the former mental hospitals would again have a negative impact on consumers within the community.

**Literature related to consumer and carer participation.**

Information for this research was retrieved by a number of methods and they are briefly outlined below. Firstly an electronic search of online catalogues and available CD-ROM’s using the University of Melbourne’s Buddy search engine was conducted. Both abstract and full text journal articles were retrieved through this method. This initial search yielded a large compilation of relevant information from Australia and overseas. Abstracts were reviewed for their relevance to the research topic before a decision to access the full article was made. There was obvious benefit in being able to access the growing number of full text journal articles that are now available on web addresses such as medline and proquest. Those that were not available in full text were accessed manually through the University’s library. A review of mental health and psychiatric disability support services web sites was also conducted to investigate the current content of online advertising and presentation of information for consumers and carers.

A manual search and retrieval of catalogued and unpublished sources of data within libraries and from individuals was undertaken. This included unpublished papers that were presented at mental health conferences and discussion papers developed by psychiatric disability support services and peak bodies.

A review of the literature related to this research indicates that some studies revolving around the importance of consumer participation in mental health service delivery have already been conducted. In a study conducted by Honey (1999) in Sydney Australia, 17 consumers and 10 occupational therapists discussed a range of issues related to effective consumer participation. This study explored the ‘uncertain’ relationship between consumer and providers, in this case occupational therapists, through a discourse on the relationship between empowerment and power and consumer participation in services.
The need for creative ways of addressing and resolving concerns was proposed by the authors as was the need for further collaboration between consumer and provider.

Other studies regarding the concepts and practical aspects of empowerment conducted outside of Australia have involved discussions about consumers but these studies have not sought to directly involve them in the research as participants. (Chamberlin et al 1989, Braye and Preston-Shoot 1993, McLean 1995, Dickerson 1998). These studies although in part responsible for highlighting the benefits of consumer participation, were also concerned with exploring the strategies and programs that foster empowerment. At the same time the authors identified the negative perceptions and stereotypes of mental health consumers and barriers that continued to exist between consumers and providers as a result. These studies made a valuable contribution to understanding the plight of consumers however the discourse about consumer concerns did not directly seek the opinions or experiences of consumers.

It is worth reiterating here that the Understanding and Involvement action research projects undertaken at Royal Park Hospital in Victoria (Epstein and Wadsworth 1994) did contribute significantly to fostering a more collaborative relationship between consumers and providers. These projects coincided with the reforms to the mental health system both nationally and within Victoria where consumer and carer participation were enshrined in government policy developed in 1992. The importance of these projects has already been discussed and they have been referred to frequently throughout this chapter.

The issues related to carers of people with a mental illness has received little attention in the available literature save for the references to them about the benefits of their participation. No actual research has been conducted that attempts to explore the experiences that carers have in their role. The difficulty in recruiting carers and the lack of response to expressions of interest by carers to participate in this study is discussed in chapter five.
This research therefore represents a significant contribution by both consumers and carers in that it seeks their experiences and perceptions of the mental health service system on which many have come to rely. That there has been little available literature that presents consumer and carer experiences and perspective’s on their participation in an evolving mental health service system indicates that through this research another important milestone in the history and progress of mental health services has been reached. It is hoped that further research involving consumers and carers associated with mental health and psychiatric disability will be conducted and further progress made towards understanding and facilitating their needs.

Summary.

The question of power, its definitions and nuances, who holds it and how it is distributed is paramount to this research. There remains a variety of definitions and concepts illustrated by Foucault (1954), Barnes (1988), Lincoln and Guba (1989) and others that help tease out the essence of power and empowerment.

The idea that power is desired by consumers and carers is explored. The effects of recent major reforms including deinstitutionalisation and what this has done to the power base is discussed.

The attitudes of providers on empowerment is discussed with an emphasis on the barriers that exist to providing consumer driven services. The notion that to empower is to lose the power oneself is an issue hampering providers from fully entering into or supporting consumer participation in mental health service delivery.

Traditional relationships between consumers carers and providers are threatened by the relatively new concept of the empowered consumer and carer. On the one hand there are
the barriers to empowerment affecting consumers such as stigma, disenfranchisement and social isolation. On the other hand consumer experiences reveal that providers desire to maintain the status quo.

Despite the barriers, there is a definite indication of a move away from traditional institutional power based practice to individual and community based power.

In order to thoroughly explore issues related to consumer and carer experiences and to discuss these in the context of current mental health and psychiatric disability support services trends a qualitative methodology was adopted for this research. Chapter five presents the use of this methodology in detail.
Chapter 5: Methodology.

Introduction.

Qualitative methodology was selected as the most appropriate mode of investigation for this study. The purpose of this research is to uncover in as much detail and as accurately as possible, the experiences of informants who are receiving care, treatment or support for a mental illness and psychiatric disability. The experiences of carers and their involvement with consumers and the mental health service system is also investigated. It was determined that the investigation into the experiences of consumers and carers could be best facilitated through in-depth discussion with participants because of the broad focus of the research topic. This approach constituted the primary method of detailed data collection from respondents and is further discussed later in this chapter.

By contrast, quantitative methodology, which focuses on the analysis of statistical data collected through survey, would not adequately achieve the construct of data rich in discursive content. Responses to questions that provided statistical information would limit the extent to which respondents could elaborate on particular issues of concern.

The study design is flexible and emergent and based on the description of experiences provided by the respondents through in-depth interviews. Primary experiences of consumers and carers was considered, in this case, to elicit a range of diverse responses that could only be adequately dealt with through this method. Consumers and carers have contributed to the bank of knowledge required to place the current understanding of their experiences into context, particularly as they relate to the capacity and opportunity for consumers and carers to achieve a state of empowerment.

An exploration of the literature ranging from socio/political text to government inquiries and historical information discussing the development of mental health services and the development and progress of psychiatric disability support services was sourced for this
study, and is presented in preceding chapters as a background to the current realities and perceptions of consumer experiences. The activities of the consumer movement in relation to consumer and carer activity was viewed as an important phenomenon that needed to be explored in order to place their experiences in context. Therefore a wide search was conducted and literature reviewed on the emergence and development of the consumer movement both within Australia and abroad. Generalist movements supporting consumers and based on economic rationalist principles in addition to more specific consumer health and mental health movements have been included and discussed as a precursor to discourse on power and empowerment. Other documents, both published and unpublished were also sourced to gain an insight into the varied opinions of authors who have written on the attitudes of service providers specifically and the broader society in relation to people who have a mental illness or psychiatric disability.

This chapter will discuss in detail the methodology used to complete the research and provide a clear sequence of events that allowed themes to effectively emerge as mentioned earlier.

**Research design.**

Qualitative methodology has been presented and discussed by a number of authors (Guba and Lincoln, 1985, Guba and Lincoln 1989, Lackey and Gates 1997, Leininger, in Carr 1998, Creswell 1998, Beanland and Schneider 1999, Patton 1987) who have written extensively on the development and implementation of qualitative research. The fundamental tenet of qualitative research has been that humans contribute best to the understanding of a phenomenon by sharing their experiences in a naturalistic setting. Although Lincoln and Guba, (1985 & 1889) have given a detailed account of what has become known as naturalistic inquiry Beanland and Schneider (1999) sum up what it means to take a qualitative approach to research in a naturalistic setting:
... qualitative approaches embrace the wholeness of humans, focusing on human experience in naturalistic settings. The researcher using this approach believes that unique humans attribute meaning to their experiences and experiences evolve from life context. Life context is the matrix of human – human – environment relationships emerging over the course of day-to-day living. From this perspective, one person’s experience of pain is distinct from another’s and can only be known by the individuals subjective description of it (Beanland and Schneider, chapter 9)

This research follows a naturalistic pattern of inquiry where a description of the experiences of both consumers and carers within their own environment is given and discussed. To this end the approach taken for this research design allows for information to emerge through the collection of data from a number of sources but primarily through in-depth interviews.

Other sources such as literature obtained from service providers and representatives of peak bodies in addition to unpublished conference presentations was also utilised for the purposes of background data and for comparison with that information collected from consumers and carers. In this way, the themes that emerged at each stage could be compared and contrasted to identify specific areas, important to participants, on which to focus discussion.

As in-depth interviews were a primary source of rich data collected for analysis, it is worth discussing the benefits of such interviews further. The use of in-depth interviews constitutes a prolonged engagement and is an essential element of naturalistic inquiry because it provides significant benefits in facilitating the acquisition of important
information. (Guba and Lincoln, 1989). Among these benefits is the opportunity to respond to information immediately it is received and for further inquiry and clarification of responses. There is an opportunity to reflect on participants responses so as to effect further probing of relevant issues not only as they arise during the interview, but also in subsequent interviews. The variable responses obtained in one interview from one particular respondent may provide a point of discussion at subsequent interviews and also stimulate further inquiry with different respondents. Prolonged engagement provides the time for researcher and respondent to become comfortable with the interview and allows a trusting relationship to develop so that respondents will provide information which is honest and thoughtful. Respondents are encouraged to engage in thoughtful discussion and contemplate and organise their ideas more fully and it is therefore more likely that they will provide honest and open and accurate accounts of their experiences.

As has been suggested by Beanland and Schneider (1999), interviewing allows the sharing of information. In-depth interviews therefore allows the individual to explain to the researcher in his own words, what being in a certain situation means to them:

This method of data collection permits an exploration of a person’s feelings, ideas, attitudes and thoughts in the words of the individual and not in the words of the researcher

(Beanland and Schneider 1999, pp. 294)

In reflecting on the benefits of an emergent design, the preferred mechanism for identifying and sorting themes for discussion, Guba and Lincoln (1989) contend that naturalistic studies are virtually impossible to design in any definitive way before the study is actually undertaken. That is not to say however that there is no benefit in formulating a hypothesis at the outset of the research. Broad questions developed to guide the interviewer will assist in establishing patterns of engagement with respondents so that recurring responses can be validated and further inquiry held. Although there is no
preconceived notion of what specific information respondents provide, some structure, by way of general questions asked, will allow patterns or themes to emerge as the interview unfolds:

... naturalistic studies do have a characteristic pattern of flow or development (Guba and Lincoln 1985, p. 187)

By conducting in-depth interviews, there is an opportunity to establish a rich data set where a complete picture of the issues as they relate to the claims, concerns and experiences of respondents about their involvement with psychiatric disability support services emerge naturally and can be explored and discussed. (Lackey and Gates 1997, Leininger, in Carr 1998, Guba and Lincoln 1985).

By seeking to understand the nature of the respondents experiences an opportunity exists for the construction of a basic tenet where the aim is to discover and describe the structure of the given as experienced, even when experienced reality is not always rational. (Giorgi 1989). There is also an opportunity to understand and evaluate the perceptions and life experiences, as they exist for the individual, in the case of this study in relation to care and treatment of mental illness and psychiatric disability support encountered or experienced. In other words, the ‘patterns and structures’ of the experienced phenomenon can be studied (Giorgi 1989 p.50).

The techniques employed through this qualitative study approach are particularly adaptable in the context of a naturalistic inquiry where a focus of attention on specific topics can be established. In this way, respondents offer information that they believe is important and as a consequence of their own experiences and in raising these issues, actually assist in constructing relevant themes for discussion and interpretation.
... claims, concerns and issues of stakeholders serve as organisational foci (the basis for determining what information is needed) that is implemented within the methodological precepts of the constructivists inquiry paradigm (Guba and Lincoln 1989, P. 50)

Further, Guba (1990) states that through an emergent design, there is an opportunity to discover experiences as they naturally occur (as opposed to being contrived or fabricated) and in the context of human experience – “lived or felt or undergone by the participants in that experience” (Guba and Lincoln 1989, p. 50). In this context, the use of a qualitative framework has been further reinforced by respondents throughout the conduct of the research. An example of this can be clearly articulated. Although there was an initial intention to clearly focus on the experiences that respondents had with psychiatric disability support services, there was a desire by them to relate their experiences more broadly to the mental health system. In responding to questions and elaborating further through inquiry by the researcher, respondents preferred to place their experiences with psychiatric disability support services in context with other aspects of the mental health system. Respondents placed little importance on the need to separate acute services from rehabilitation or support services. Most also placed little importance on the need to make distinctions between their mental illness and their experiences with services specifically related to treatment of their illness and psychiatric disability support and the services that offered them support for their disability. By adopting an emergent design, the researcher was able to respond to respondents desires to relate to their own important issues rather than attempt to confine respondents to a specific, pre-determined area of study.

Investigation that places factual information in context with the experiences of respondents offers the opportunity to view the whole picture and takes account of the numerous other elements that have helped shape or construct the environment for the individual:
It is our intention to define an emergent but mature approach to evaluation that moves beyond mere science – just getting the facts – to include the myriad human, political, social, cultural and contextual elements that are involved (Guba and Lincoln 1989, p. 8)

An integral aspect of the research is to derive the meaning attached to, and the definition of data collected from respondents as they function in everyday life and in their association with psychiatric disability support services and other mental health services.

The concept of power and empowerment is underpinned by the perception that consumers and carers have of the mental health system and what their relationship is with it. Data provided by respondents will be compared to existing theories about power and empowerment as well as the way in which empowerment strategies are applied or practiced.

As mentioned earlier, the use of quantitative methodologies would not have adequately represented the views and opinions of respondents because of the limitations that statistical information presents in terms of experiential discovery. The characteristics of qualitative methodology that establish the meaning of experiences was determined to be essential in gaining a more comprehensive understanding of those experiences upon individuals. This could not adequately be achieved through the process of a quantitative study where the researcher must have some knowledge in advance of what is being researched.

Sources of data.

At the outset of this research, a plan was constructed where approaches would be made to services that had significant contact with consumers of psychiatric disability support
services and their carers. Through my own personal experiences as a registered psychiatric nurse, a belief was held that consumers of psychiatric services would be interested in participating in this study because any attempt to uncover issues that would lead to improved understanding and knowledge of consumers experiences would be welcomed. An assumption was made that consumers of psychiatric disability support services generally sought support from advocacy services and associations. As this was only an assumption at the early stages of the research, it was determined that this would be an appropriate avenue to attempt recruitment of participants.

Vicserv, the peak body representing psychiatric disability support services in Victoria, were initially approached for such advice. Their support for this research was encouraging and they provided advice on the appropriateness and relevance of other organisations that may be able to assist in recruiting participants particularly those that sought to actively promote consumer participation.

Following the advice from Vicserv, representative psychiatric disability support services were contacted and consultations held with key personnel within these organisations. Services such as the Association for the Relatives and friends of the Emotionally Ill (ARAFEMI) and the Victorian Mental Illness Awareness Council (VMIAC) were approached to determine whether they were able to assist in or facilitate the recruitment of suitable and consenting subjects for in-depth interview. These organisations had contributed significantly to the development of mental health services within Victoria and the status of consumers and carers. This they achieved through the direct and indirect delivery of psychiatric disability support services including support of carers as well as through their significant involvement with mental health research projects, the substance of which is discussed in the review of literature throughout this thesis.

Further investigation, however, following initial discussions with Vicserv and subsequent approaches to recommended organisations identified consumer consultants as a group
who have had significant involvement with research projects within Victoria. All organisations approached supported the view that the involvement of consumer consultants would significantly enhance the conduct of the research in so much as they are currently actively involved either with these organisations as members or are performing their roles within other areas of mental health service delivery.

Respondents.

The Reference Group

The concept of establishing a reference group consisting of consumer consultants and carers who could assist in guiding this research was discussed with service organisations and subsequently developed. Their contribution to this research is significant. Firstly, the group’s contribution provided advice on the conduct of the study and the most appropriate methods of data collection and sources of information. Their influence as consumers and carers within a growing movement, also added a new dimension to current issues within the field. The establishment of the group and an account of what transpired at subsequent meetings of the group is provided in chapter six.

More importantly however, the reference group, with its experienced consumer consultants and carers were enthusiastic about contributing their own experiences to this research, not only as consumers, but also as educators endeavouring to provide an example of what constructive involvement can achieve. A detailed analysis of transcripts recorded through specific and separate sessions with the reference group is provided and discussed in chapter seven.

During the process of introducing reference group participants, consumers and carers to the purpose and objectives of this study, documentation regarding background information to the study in addition to the research proposal was presented and discussed and these initial discussions yielded significant support for the project. Additional
documents such as ethics approval and the requirements regarding necessary consent and explanations of the methods, which were proposed to be used in obtaining suitable data, were also made available to those organisations that had indicated their support for the project.

All sessions and interviews with members of the reference group took place within interview rooms at the university. This appeared to be most suitable as all participants were employed at the time of interviews and this venue offered a relatively central location in addition to being quiet and offering few distractions. In this case, as with the in-depth discussions with primary consumers and carers, an opportunity to probe for additional information through prolonged engagement with the reference group about their experiences added a further dimension to the data already gathered.

Consumers.
A total of twenty-two consumers agreed to participate in an interview following an explanation of the process that would take place. Dates, times and venues were discussed and agreed generally during the first contact. Of the twenty two consumers who initially agreed to be interviewed and following the setting of meeting arrangements, seven did not present for the interview. Only one consumer phoned to provide an explanation for not attending, and another interview time was agreed. However, he did not present at the interview a second time and did not make any further arrangements. The other six consumers in this group did not contact again. By virtue of the fact that participation was entirely voluntary, no return contact details were requested and no attempt was made to make contact with the callers. It was deemed not appropriate to attempt this as to do so may be interpreted as undue solicitation for their participation.

Fifteen interviews were therefore conducted. All interviews took place at a time and location suitable to the consumer. All but three consumers wished to be interviewed at The University of Melbourne despite the difficulties that some had in taking public
transport to and from the venue. In most cases the university was chosen by the consumer because that location provided an inconspicuous venue for them. Other reasons given by consumers for choosing the university as the most appropriate venue included quiet surroundings and proximity to transport. Of the other three, one preferred to conduct the interview at home because she had a young child and was not able to meet the costs of additional child-care and stated that she felt more comfortable at home. A second consumer preferred to be interviewed at home because she felt more comfortable in familiar surroundings and was rather uncomfortable travelling to what she considered an ‘over-populated’ area. The third consumer preferred to be interviewed at a facility that provided psychiatric disability support services in the form of support groups. The reason given for this choice was familiarity with her surroundings and also that she felt more comfortable in sharing information in this environment.

Consumers were asked to allow between one and a half and three hours for the interview with the possibility that a follow up interview may need to be conducted to clarify issues further. All interviews conducted were within the specified time with the average time being about two hours. Some additional information was sought from respondents by phone and there were no second interviews required.

Of the fifteen consumers who did present for interview, five contacted and advised that they wished to withdraw from the study. They requested that all identifying information they had provided be destroyed and they wanted assurances that they would not be identified in any way. They all agreed, however, that the information that they had given, could be referred to without me actually using direct quotes. In other words, they were allowing me to paraphrase what they had said so that I could support, with examples, the experiences of other consumers, without actually using their specific data. I restated that participants may withdraw their consent at any time during and following the interviews and that their decision would in no way affect their continued involvement with services. Assurances were again given that they would not be identified. These consumers
conveyed their suspicion that they would be identified and needed to be convinced that no information would be published that would identify them in any way.

All consumers who travelled to the university to participate in the interviews were reimbursed for their travel costs.

In addition to tape recorded interviews, five consumers who volunteered for interview requested that they not be taped. A number of reasons were given for this decision. Amongst the most significant was that they feared that ‘someone might get hold of the tape’ and derive the wrong idea about their participation. They felt that as a result, the services that they receive or are attempting to receive, would be withheld or compromised because they may be seen as ‘whingeing about the service system’. This view is not entirely without credibility as the issue has been raised on tape by some consumers during the course of other interviews. These and other aspects regarding the prevailing attitudes and the culture of mental health services are discussed in chapters 7, 8 and 9. Notwithstanding this however, these participants were happy to respond to the semi-structured questions prepared for the interviews, and for me to take notes about their responses.

Carers.

Recruiting participant carers for interview proved to be difficult. Despite information being made available to carers in much the same way as consumers, only five carers volunteered for interview. That such a small number of carers participated in individual interviews raises several concerns not least of which is the significance of their responses. However, it was felt that their contribution was important and perhaps reflected the way that other carers felt about the mental health service system.

A greater response was received from carers who were prepared to be involved in group interviews and there were subsequently two group interviews held. These group
interviews proved to be most effective for a number of reasons. Firstly, because it was not possible to recruit a larger number of individual carers for interview, having up to eight people involved over two sessions provided the opportunity to illicit a range of responses not otherwise able to be achieved through individual interviews (Beanland and Schneider 1999). Although there were only a small number of interviews with individuals, the information provided by the group added substantially to the data collected from those individuals. Secondly although questions were prepared as a guide, and this assisted in facilitating discussion of various issues, the group were able to share their experiences resulting in several aspects of a topic being vigorously debated. This can obviously not take place when conducting individual interviews. In addition, the opportunity to gain consensus on issues was also an advantage within a group as responses could be interpreted during the interview without having to compare data from transcripts of individual interviews (Grbic 1999, Happell 1994).

There are also some disadvantages associated with group interviews. In particular, the reluctance of some group members to participate fully in the discussions. As with all groups, there was the propensity for the more vocal members of the group to dominate proceedings and therefore stifle the potential for others to represent their own views fully. There is also the reluctance for some group members to relate their experiences fully for fear that their views may be divergent and they may not accord with the majority. Fortunately, on both occasions, there was not one member who dominated the group. All group members were sensitive of the issues that others raised and allowed ample time and opportunity for all those who wished, to have their say.

Two carer group interviews were held with eight participants at a time in each group. Participants were made up of those carers who, in addition to their current role as carers, were either facilitators of their own carer support groups or had some other significant involvement with carers and support groups. They therefore had a collective knowledge and understanding of the mechanisms of carer support groups and functions and provided
a wide cross section from the community, as well as bringing their own experiences with respect to caring for someone with a mental illness and psychiatric disability.

An account of the discussion with carers in both individual interviews and within the two groups is provided in detail in chapter 9.

Structure of interviews with carers.
Both individual in-depth interviews and those held with carers within the groups were used as references to discuss carer experiences in this chapter as many of the salient points raised were supported by both individuals and those involved in group discussions.

Interviews were conducted in much the same way as consumers. A series of questions were prepared to guide carers through the interviews however it was important to allow carers the opportunity to discuss the key issues that they raised. All carers agreed to the interviews being tape recorded including all respondents within the groups.

Other respondents.
In relation to participating organisations, a package of information was provided which included an outline of the research proposal, evidence of the universities ethics approval, an explanation of the research in plain language for both consumers and carers (Plain Language Statement for Consumers and Carers), an example consent form and a flier introducing the research to potential participants. Organisations suggested that they would table the information contained within the package for their respective committees of management or boards with a view to gaining approval to circulate this to consumers and carers.

Service providers were sourced for initial consultation regarding their in-principle support for this research and for their assistance in recruiting participants. The services targeted were organisations involved with the provision of mental health services
The process of interview.

As discussed previously earlier, in-depth interviews were conducted individually with current consumers of psychiatric disability support services and their carers. Participants were interviewed as they responded to the expressions of interest circulated through fliers and word of mouth. There was no intended relationship or correlation between consumers and carers and any relationship between individuals of these two groups would have been coincidental. The criteria for selection for interview was, as stated above, their current involvement with mental health services and their expressed interest and consent to participating in the interviews.

The style of interview was a combination of semi-structured and informal conversation between the respondent and researcher. (Patton, 1987). Following review of literature, initial discussions with service providers, and guidance from the reference group, a list of questions was constructed as a guide to questioning respondents. The interviews commenced with this semi-structured approach and points of interest were pursued further as they emerged. There was an opportunity for respondents to raise what they felt were important issues and these additional issues were carried over and raised with subsequent respondents. Respondents were given the opportunity to provide a considerable amount of information, however, at times there was a need to get them to refocus on discussion that was relevant to the overall study.

The interview guide ensured that each interview followed a consistent approach and that all respondents were asked similar questions, even though they had the opportunity to
deviate from these main points. In this way responses could be interpreted and grouped into themes. This aspect of thematic analysis of the data recorded will be further discussed later in this chapter under the heading of Data Analysis. Additionally, the list of questions also assisted in bringing the discussions back on track should respondents deviate excessively from the main points raised. There was a continual opportunity to reflect on what been discussed so that new areas could be explored. A sample guide used for discussions with consumer participants and carer group participants appears in appendix one and two respectively.

**Data analysis and representation.**

Both consumers and carers of psychiatric disability support services were invited for interview to gain a thorough grounding in what their personal experiences of their association with these services and programs currently are or have been. A detailed account of experiences by selected respondents was tape recorded and transcribed as soon as possible following interview. The transcripts were made available to participants who were given the opportunity to clarify the contents and encouraged to relate any issues they may have about the information contained within them. Notes were also scribed during the interview so that the meaning attached to some responses which were felt to be of importance could be recorded in context. Not all interviews were taped recorded however. As discussed earlier, some respondents were not willing to consent to this arrangement but were happy for me to scribe notes including the quoting of some material.

Tape recordings were transcribed as soon as possible following interview so that an accurate interpretation of the data could be made whilst the information was still fresh and new. As can be expected, the transcripts and field notes taken during the course of interviews yielded a considerable amount of data. The approach taken to deal with this data was to identify and organise recurring pieces of information and categorise them into specific themes that could then be analysed and discussed in an orderly way.
The interviews followed a semi-structured approach with a list of questions constructed to guide the interviews as mentioned earlier. The questions provided the opportunity to develop major headings that correlated to the themes which emerged.

**Thematic analysis.**

The importance of thematic analysis is discussed by Creswell (1998). Creswell introduces the concept of a data analysis spiral to explain his concept of how qualitative researcher deals the research matter. Here he describes a number of stages that are transgressed from initial data collection to representation of information. The process according to Creswell can best be illustrated using an upward spiralling diagram. Once data is collected the researcher moves in analytical circles that eventually lead to an ‘account or narrative’. During the process the researcher sorts and manages data, describes, classifies and interprets and finally presents.

It is within the describing, classifying and interpreting loop of the spiral where the researcher develops the themes through a classification system. According to Creswell:

*In this loop, category formation represents the heart of qualitative data analysis. Here the researcher describes in detail, develops themes or dimensions through some classification system, and provides an interpretation in light of their own views or views of perspective’s in the literature* (Creswell, 1998 p. 144)

Creswell (1998) further asserts that the main aim of classification should be to develop categories of information. These should then be used to identify five or six different themes that Creswell states will be used to write the narrative. Keeping the number of categories to about twenty five to thirty, will assist the researcher to ‘winnow’ the data
where important pieces of information are sorted and grouped and other data discarded. This approach he suggests is useful regardless of the size of the data base. (Creswell 1998 p140). Without an approach such as this there is the propensity for researchers, according to Creswell to end up with too many categories:

Those researchers who end up with 100 or 200 categories – and it is easy to find this many in a complex database – struggle to reduce the picture to the five or six that they must end up with for most publications (Creswell 1998 p, 142)

In the context of this research the significant volume of data collected required management in much the same way as described by Creswell. The development of themes was an appropriate approach for this research as many of the issues raised by respondents could to some degree be dealt with by grouping them for discussion and presentation.

Audit trail.

All direct quotes used in this thesis were extracted from transcribed tape recorded data. Because the tape counter was considered to be unreliable due the propensity for varying tape speeds, all interviews tape recorded were transcribed and then printed. Once printed, a copy of the transcript was forwarded to the interviewee to verify its accuracy.

Coding methods used varied slightly between consumers, cares and the reference group and are explained below.

In the case of consumer and carer participants tape recorded, individual transcripts were coded and then page numbered separately. For example CH: 81-86. This code refers to statements made by Consumer – H between lines 81 and 86 on that transcript.
Carers were coded similarly except that carer group interviews were also included. An example of a statement by a carer or member of the carer groups is: Carer Y: 513-527. This code refers to statements made by Carer Y between lines 513 and 527.

For the reference group, sessions recorded were transcribed and page numbered consecutively. Each subsequent session followed on from the previous one and page numbering continued. Reference was therefore made to the pages from which quotes were used. Original tape recordings and transcripts have been retained for audit if required.

In relation to the audit trail, the researcher wished to convey the extent to which the validity of data collected could be audited. All transcripts and other material used for the purposes of compiling the thesis are available for review in accordance with the Ethics Committee requirements of the University of Melbourne.

**Trustworthiness.**

**Credibility.**
The main focus of this research centred around the experiences and opinions of consumers and carers. The in-depth interviews with participants provided an opportunity for prolonged engagement where rapport could be built with participants (Lincoln and Guba 1989), even though these interviews were conducted once only.

There were no time constraints placed on either individual consumer interviews or interviews with carer groups. The open ended structure of general questions provided the opportunity for a trusting relationship to develop between respondents and researcher particularly as there was the opportunity to clarify responses as they were received. This was particularly important for group interviews where a significant number of varied responses was elicited by members of the group. Although there was no predetermined
expectation to gain consensus amongst the group in terms of their individual responses, there was the opportunity to clarify those responses when consensus was assumed.

**Persistent observation.**
Categorising data and developing themes for presentation and discussion was determined to be the most suitable approach in dealing with the research topic (Creswell 1998). Persistent observation is the process whereby themes can be identified and pursued at subsequent interviews. The in-depth interviews with consumers facilitated the emergence of data that could be further pursued with other participants. Carer group interviews were conducted twice and important issues were explored in the subsequent interview.

**Triangulation of data.**
The process of triangulation involves the cross-checking of data from a number of sources (Lincoln and Guba 1989). Interviews with consumers were conducted once only although for a substantial length of time of up to two and one half hours.Whilst the views and opinions they expressed reflected their past and current experiences with mental health services, it was important to compare this data with other sources available such as field research already conducted, conceptual and practical applications related to empowerment and government policy. The data provided by both consumers and carers provided an invaluable opportunity to compare their collective experiences with the mental health service system. Whilst opinions differed between consumers and carers, there was potential to substantiate claims and concerns both positive and negative which were common and had an impact on both groups.

Consumers and carer participants of this research are recipients of mental health and psychiatric disability support services who have had individual and various experiences with the mental health service system. The intention was to gain an overall understanding of their experiences and to present an objective view of their situation.
Peer review.
On a personal level as a researcher, the conduct of the research was important. That is, it was felt necessary to obtain the views of other people so as to maintain the direction of the research and its objectivity. Because of the volume and nature of data that emerged, it was both necessary and beneficial to frequently seek clarification about the direction of the research. Participants interviewed all offered different points of view even though in some cases they may have been only slight variations on a theme. Discussions with the reference group participants assisted me in understanding the bigger picture as they were able to place in context what was emerging from the interviews and what was occurring in the field.

Also significant was the opportunity to present the progress of the research to other higher degree students and lecturers either through individual presentations or student seminars. Feedback from these groups facilitated opportunities for reflection and consideration. Some students were familiar with the subject content of the research whilst others were not. It was important to illicit feedback from peers who were not as close to the research and who were able to raise questions about validity of the method used. Their perspective's provided an invaluable opportunity to consider different approaches to data collection and investigation of subject matter. In addition regular communication was established with another higher degree student investigating consumer and carer participation in mental health services. These communications assisted in keeping the focus of the research clear, while remaining open to new interpretations of the data.

Similarly regular discussions with my supervisor provided me with objective opinions about the structure and development of the research. Ensuring that the information was presented fairly, accurately and was readable and understandable by the target audience, were issues that were continually addressed during the course of the study. Additionally, as this was a lengthy investigation, it was also important to be able to debrief about my concerns and problems with the research. My supervisor proved to be a constant support
throughout the research. She was particularly aware and responsive to the many dilemmas one faces when one has undertaken qualitative research, not least of which is the frustration felt when avenues of investigation are thought to have ground to a halt.

**Member Checks**

Member checking is a process that involves the researcher feeding back to respondents the information they have provided. The process ensures that the information the researcher receives is that which the respondent(s) intended to provide and is accurate in its content. Member checking in this research was conducted primarily in two ways. Firstly, the main issues that were raised by respondents in both individual and group interviews were fed back to respondents at the time of interview. For example “It appears to me that you are saying … is that correct?.” Seeking clarification in this way minimised the propensity to misinterpret responses.

Secondly and following transcription of tape recorded data, copies of the transcripts were forwarded to respondents. Respondents were asked to review the transcripts and advise me on the accuracy of the content, and whether the record was an accurate account of the interview. Qualitative research relies on a true account of the perspective’s and experiences of respondents. It is necessary to ensure that respondents themselves believe that they have been represented accurately and fairly.

**Transferability**

The provision of thick descriptive data in the form of detailed information presented in this thesis, enhances the opportunity for this material to be transferred to other similar situations. The account of the experiences given by consumers and carers is recorded in detail and there is sufficient information to adequately inform others who wish to undertake similar research. It is hoped that this research will stimulate interest and provoke thought on ways that will continue to enhance the lives of people with a mental illness and psychiatric disability.
Summary.

A qualitative method was used to investigate the experiences that consumers and carers have had with mental health and psychiatric disability support services. The use of a qualitative method was justified in the context that data collected primarily from in-depth interviews with respondents provided a rich source of information for presentation and discussion. It was felt that this method was more suited to facilitating a deeper understanding of respondent’s experiences and one that went far beyond that which could have been interpreted from review of a responses to a questionnaire for instance.

The emergent design adopted for this research enabled consumers and carers to fully present their views as they saw them, on a range of issues that they felt were important. Qualitative methodology for this type of research was supported by many authors throughout the literature. Their views have been presented to provide supporting evidence of the benefits and challenges of qualitative research.
Chapter 6: The Reference Group.

Background.

This research attempts to uncover the experiences of consumers and carers who have been involved with psychiatric disability support services. The research involved, among other activities, the development of a comprehensive data set surrounding current activities within the psychiatric disability support services sector and recent and current trends within the consumer movement. These trends would then be related to data collected through in-depth interviews with consumers and carers who have been involved with the psychiatric disability support services sector.

In addition, the research initially set out to identify issues related to power and empowerment and the significant struggles consumers and carers have faced in attempting to address the well documented ‘imbalance’ or in many cases, absence of power by the consumer in the consumer/provider relationship (HR&EOC 1994).

The relationship between consumer and provider impacts considerably on the lives of consumers and carers because of the perceived power differentials that exist. Relationships that have been formed could include the range of options available and suitable to consumers including accessibility of services, choice of treatment options and voluntary involvement in social rehabilitation programs following acute illness. This involvement may be further extended to include involvement in the design, delivery and evaluation of mental health and psychiatric disability support services and the representation of consumers and carers through advocacy.

Introduction.

The value of consulting consumers and carers throughout the conduct and development of the research was determined to be crucial in ensuring its credibility. The participation of individuals who use and rely on psychiatric disability support services and who expect
these services to improve the quality of their lives is perhaps an even more important factor in determining that their direct inclusion in the project was essential. Their involvement in fact has already been acknowledged and reinforced through the policies that have been developed and are in place within Victoria and other Australian states as well as abroad (The Victorian Department of Human Services 1996 & 1998, Human Rights and Equal Opportunity Commission 1993, WHO 1988). Contained within these reports is the recognition that in order to continue to develop psychiatric disability support services that effectively meet the needs of consumers and carers, they need to be given the opportunity of being involved with the process of service development, implementation and evaluation at several levels. Participation in program development and delivery is paramount to achieving not only better services but creating opportunities that effectively empower individuals (Reference Group 2000). At the very least, consultation is determined to provide a healthy way forward as well as allowing consumers and carers an important opportunity to provide feedback and advice on aspects of services that directly affect them.

Wadsworth (1991) in her discussions of human service Organisation evaluations, uses the term ‘critical reference group’ to describe all those groups that are, for the most part, involved in receiving the efforts of human service activities. She includes a number of individuals and groups to whom the term is applied and states how they can benefit from this involvement or what their relationship might be relative to any evaluation being conducted.

*The words critical reference group* try and capture the ideas that:

*This is the group whose members values and practices stem from their shared interests and who are thus the source of the most decisive and critical questions.*
This is the group to which services and providers (as well as the group itself) must refer if they are to identify accurately what the group’s needs are, and what are the best solutions.

This is the group who must finally judge and decide (critical comes from the Greek ‘to judge’ or ‘decide’) whether the services or actions ‘got it right’ and their needs are met or their problems overcome, etc. (Wadsworth 1991, p. 7-8)

Wadsworth’s presentation and interpretation of the activities and responsibilities of a critical reference group are very much in keeping with those espoused by the reference group established for this research. Although she discusses these issues in the context of evaluative processes, they are, none the less, applicable to the way in which each individual in the reference group contributes his or her knowledge derived from actual experiences gained within the psychiatric disability support service sector field. Although participants in the reference group acknowledge that improvement to service delivery, and changes to policy may be actually achieved as a result of this research, they themselves may or may not benefit directly from the outcomes. This is an important point raised by Wadsworth who suggests that.

It is important – if starting from a critical reference group’s concerns – to identify the sorts of services that might be relevant to them, or – if starting from a service – to identify their critical reference groups (Wadsworth 1991, p. 8)
In this case the latter applies as the reference group for this research was formed following the identification of a critical core group of people who have successfully emerged to consult for people with psychiatric disability within the community.

Further, it is also important to ensure that representatives of critical reference groups have the opportunity to present issues with which they are primarily concerned. In other words, the reference group participants should be able to share their knowledge as broadly and as much as possible:

... the efforts must be made to seek out the expression of critical reference groups’ will – and all possible barriers to this continuously addressed. ... Nor can we rest with the idea that a few representatives of critical reference groups can make everything go according to their will by sitting on a committee of management for a couple of hours once a month, contributing to a consultation once every few years. These are necessary but highly insufficient ways of hearing the voice of the critical reference group. We must look to our constant every day ways of doing this. Every time there is contact for example, between service users and providers, users must have channels for ‘voicing’ their experiences and needs, and providers must have – and show they have – ‘ears’ and ‘eyes’ to hear and see (Wadsworth 1991, p. 8)

The reference group for this research has indicated that they wish just that – a constant interaction between their role in this group and their role as consumer consultants within the community. They have remarked from the outset (commencement of the inaugural meeting) that there is a need for them to continually improve their own professional
development so as to achieve better outcomes for constituent group they represent. This continual interaction, they believe, is a vehicle that will assist in achieving their aims.

The contribution that can be made by a reference group such as this one has been discussed earlier, however, it is worthwhile elucidating further the benefits of such an arrangement in the context of the outcomes of any research project designed to understand the real life experiences of participants. Whilst individual consultants may achieve an acceptable outcome in response to an evaluation, Wadsworth (1991) remarks that this may be a chance occurrence. Without the relevant knowledge or participation of service providers or users Wadsworth states:

> The chances of such an evaluation ‘getting it right’ for consumers may be slim however – especially if neither the consultant or the department have much familiarity with the service or its local context........However, such a outcome – while successful in the short term – must be considered a long term risk both on methodological grounds and practical grounds (Wadsworth 1991, p. 10)

This is because the reference group, by virtue of the individual and collective experiences of members of the group, are able to contribute from a user perspective and not solely from a point of view that provides for assumptions about certain practices or experiences.

> A participatory and democratic evaluation process is a better way of increasing the chances that critical reference groups – through their participation in the evaluation – both determine the descriptions of the world which are used as the basis for evaluation, and also are able to judge the value of these images or descriptions if the evaluation is
intended to contribute to the improvement, change, and development of services. These ways of participating go well beyond conventional notions of representation on evaluation committees, and penetrate deep into every day fabric of service provision ... (Wadsworth 1991, p. 10)

The importance of a collaborative process between service providers and users is emphasised by Wadsworth who has provided one perspective of the function of a critical reference group for the purposes of a collaborative evaluative process. She discusses a number of criteria needed to realise this collaborative effort. This perspective is reinforced by the reference group for this research, who reflect continually on the need for sustained collaboration between all parties, particularly as they (consumers) endeavour to overcome the barriers associated with adequate representation in services which directly affect them.

In summary, the perspective alluded to refers to the values placed on critical reference group participants and to the value of having them share their knowledge and experiences about the service or sector they purport to represent. As stated earlier, their initial intent was to help guide this study so as to establish its credibility and impact on policy makers and service providers. Whilst the reference group work in parallel with the criteria set down in Wadsworth’s perspective’s, their relationship to the research as an advisory group continues. Their connection has been made much more legitimate because of their experiences and current roles as consumer consultants and active carers who are working within the field.

This chapter will further explore what specific contribution consumers and carers have made to this research through considering the involvement of a reference group, that was originally established to provide guidance and support to the researcher throughout the conduct of the research.
**The concept of a reference group.**

The concept of a reference group being involved in assisting to guide this research is perhaps unremarkable. The involvement of such groups as research panels, advisory committees, Boards of Management and other bodies have been introduced to oversee specific activities and provide support of individuals or another groups affairs and conduct. In relation to the reference group established specifically to guide this research, this chapter will uncover the transition the group had made in a relatively short space of time, from support group advising on the progress of the study, to active participants who, considered themselves primary informants to the study because of their significant experiences within psychiatric disability support services and the mental health field. Information about the project was provided to each participant and draft terms of reference developed which were to be discussed with the group at its inaugural meeting. At this stage of the research there was no clear agenda about how reference group meetings would be conducted and in what way the group would provide support over the term of the study. The terms of reference however, elucidated a number of objectives which the researcher thought to be necessary from the point of view of planning more effectively the time frames and milestones required to be reached. These terms of reference are also more fully discussed later in the chapter. The discussion that follows tracks the groups activities and its contribution to this project.

**Formation of the reference group.**

The section commences with an outline of the reasons and methods of engagement of participants and then provides an account of what has transpired as the group met and vibrantly discussed their experiences related to mental health issues.

A decision was made to establish a reference group following presentation at and discussion with the researchers confirmation panel and the researchers’ supervisor. The
group was to consist of consumers and carers who were active within the psychiatric disability support services sector and who may wish to be involved with the research.

Representative psychiatric disability support services and peak bodies were contacted and consultations held with key personnel within these organisations. In particular, Vicserv, the peak body representing psychiatric disability support services in Victoria, provided advice on the appropriateness and relevance of those organisations that may be able to assist in recruiting participants so that a reference group could be formed. Specific organisations were approached as a result and in the context of recruiting consumers. All were willing to at least hold preliminary discussions about my requirement without obligation. Documentation regarding background information to the study in addition to the research proposal was presented and discussed and these initial discussions yielded significant support for the project. Additional documents such as ethics approval and the requirements regarding necessary consent and explanations of the methods, which were proposed to be used in obtaining suitable data, were also made available.

When canvassed for names of people who may be interested in forming a reference group as well as suggestions of ways to go about selecting and recruiting participants for the group, the general consensus was that consumer consultants would be able to provide valuable advice and support.

All respondents identified consumer consultants as being suitable for the role because of their depth of knowledge in the field and their willingness to be involved with mental health research. All service providers had actual experience in working with consumer consultants at various levels including involvement with projects, program delivery and as members of voluntary service boards or committees. In discussions with these service providers, all stated that consumer consultants had particular experiences with psychiatric disability support services and that this factor would further provide clarification with respect to the researchers interpretations of current activities within the field. It was felt
that, because of their activities, the researcher would be able gain access to other consumers willing to participate in the data collection phase of the study. This advice was given by key providers in recognition that, since the commencement of the consumer consultant role, they (consumer consultants) have increased their involvement with a number of aspects of psychiatric disability support services program delivery.

Many key service providers were also directly involved with the consumer consultant role through their association with their own, or other Psychiatric Disability Support Service committees on which consumer consultants were representative. One service provider, The Victorian Mental Illness Awareness Council (VMIAC), was perhaps the Organisation that has provided the most significant support for consumer participation, through its auspicing of research projects such as The Report of the Lemon Tree Learning Project (Epstein and Shaw 1997), and The Understanding and Involvement Series of Action research Projects (Epstein and Wadsworth 1994 to 1996) which influenced the emergence and development of consumer consultants’ role. Potential participants, particularly consumer consultants, did not have to be persuaded to participate and no consumer consultant invited to participate refused the invitation. The response to the invitations and indeed the reaction to the request to participate in this research as ‘educators’ was warmly welcomed by consumer consultant participants. In contrast, carers who were initially approached responded hesitatingly. This hesitation was found later to indicate a consistent trend, during the attempts at recruiting other carers for interview about their experiences with psychiatric disability support services, and this phenomenon is discussed in more detail in chapter nine.

**Consumer Consultants.**

As discussed above, the idea of consumer consultants was first conceived during the first phase of a consumer evaluative project conducted in an acute ward of a psychiatric hospital, Meduna Ward Royal Park Hospital. The series of three volumes titled Understanding and Involvement (U & I) – Consumer Evaluation of Acute Psychiatric
Hospital Practice commenced with … a projects beginnings. (Epstein and Wadsworth 1994) This first evaluation discussed the methods whereby consumers evaluative feedback could be provided to staff and the notion of establishing a Consumer Consultants Group arose. As reported in the second volume of the series “a project unfolds”, (Epstien and Wadsworth 1996) a Consumer Consultants Group Implementation Group, consisting of consumers, was formed in November 1993 and was formally transformed into the Consumer Consultants Group in May 1994. The group, whilst an agent for the Understanding and Involvement project series, also saw itself as a much greater resource. The group felt it could respond to the broader mental health issues raised publicly and in this respect they wanted a greater freedom to speak independently about the agenda raised through the U&I project. In other words, the creation of this significant consumer voice should allow them to pursue agendas in addition to and separately from the U&I project. The emergence of an empowered group through consumer consultants represented the voice of consumers and lent credence to the concepts of power and empowerment espoused in earlier chapters. In particular power was conferred on consumers to act in a role that they had previously as consumers not been able or rather not permitted to achieve. Their status was recognised and indeed personified by the importance of allowing consumers the autonomy to use their individual and collective knowledge and skills. One of the group’s aims and objectives, within its documented background principles is to:

Demonstrate that the people who use mental health services have the skills and knowledge necessary to improve services in ways which maximise empowerment

(Wadsworth 1994, p. 51)

In addition to this newly empowered state, and as bona-fide consultants, the right to expect appropriate remuneration for each individual providing their respective expertise, was being sought. Further, as an apparent and direct consequence of the consumer
consultants group and its activities, the role of consumer consultants has been further developed since the Understanding and Involvement projects. This is now being evidenced through the employment of a number of consumer consultants for specific roles within the mental health system in Victoria although. Employment options range from permanent part time to casual employment in psychiatric disability support services programs, and the engagement of individuals as consultants for research projects such as this.

**Remuneration for consultancy.**

In recognising their role as consultants, however, the need for adequate remuneration, as discussed above, was important to all reference group participants and discussed at the first reference group meeting. All agreed that whilst they were keen to participate and share their knowledge and experiences of the Psychiatric Disability Support sector and the mental health system generally, their significant involvement should attract a consulting fee as earned by other health professionals. During the discussion regarding suitable fees, there was a strong sense that they (consumer consultants) were clear about their right to adequate remuneration and why payment for consulting services would further reinforce their status amongst other professionals within the mental health field.

**Opportunity for professional development.**

Whilst the discussion regarding remuneration was an important agenda item amongst the group at the inaugural meeting, there were other equally important aspects of involvement by consumers in this research which were raised. Their involvement was also determined by them to be an experience whereby they could reflect on their own practice within the field and in so doing, improve their own understanding and knowledge of current issues and allow them to become better informants for other consumers. In terms of quality, the opportunity to participate in their own professional development through discussion, reflection and clarification of issues with their peers,
was considered by all in the group to be of paramount importance. There was a strong sense amongst the group that their contribution to the development of psychiatric disability support services could be further enhanced through participating in research projects on virtually any issue related to mental health and its reform.

Carers.

Victoria’s mental health framework documents in addition to such reports as compiled by Burdekin in particular, suggest that more should be done to consult, include and support carers in mental health service delivery. At the outset of the research, carers were identified through their significant involvement through their support of consumers. Carers could and have been regarded as consumers themselves because of their use of psychiatric disability support service supports during and following recovery of those for whom they care. In this respect and as an adjunct to the compilation of a data set which included carers, their involvement with the reference group was also seen as extremely important.

Carers proved more difficult to recruit for the reference group. Although there is considerable anecdotal information suggesting that carers are currently dissatisfied and disillusioned with mental health services generally as it lacks support for them, this rhetoric had as yet not been validated at this stage of the research and will be further investigated during the in-depth interviews.

The process of sourcing and recruiting carer participants for the reference group followed a similar route to that of recruiting consumer consultants. Most representative psychiatric disability support services organisations canvassed provided the names of potential carer participants whom it was thought would be keen to be involved in the reference group. One service provider however, which was known for its development of advocacy services for carers caring for individuals with recurring episodes of psychiatric illness, declined to be involved with the research. The explanation given by the provider revealed
that they could not support the research because they were not directly involved with its conduct or method of collecting data. More specifically, there was no real benefit for them as an Organisation to be involved and assistance is only lent to projects auspiced by them. Whilst this was disappointing from the point of view that as many avenues to recruit suitable participants for the group was desirable and the response by consumers was significant, it is difficult to determine with any accuracy whether this had a direct impact on the poor response to invitation of carers generally, discussed earlier. Assumptions can only be made about the negative effects that such an Organisation has on the further progression of the understanding of experiences of both consumers and carers. In addition, the attitudes of providers must be further scrutinised with the knowledge that not all organisations and providers see merit in advancing the opportunities to involve consumers and carers in the development of the services on which they rely. Again, the key issues related to the attitudes of providers is discussed with both consumers and carers and reported in this thesis.

**Objectives of the reference group in guiding the research.**

It was originally planned to have two consumers and two carer representatives on the reference group. A decision to commence anyway was made with the group now consisting of 3 consumer consultants and one carer. The group met four times following its formulation.

The first meeting of the reference group was convened in August, 2000. Prior to this meeting participants were made aware of the objectives for the establishment of the group in broad terms and that these would be further discussed at the first meeting. Four objectives were initially identified:

- To determine the terms of reference of the group: which included such items as membership of the group, frequency and length of meetings and venues.
• To discuss the formalities of the conduct of the research; which included such issues as confidentiality, consent to participate and recording of data collected from participants in the in-depth interviews.
• To critically review and discuss the research proposal.
• To review the general questions which would be used as a guide for interviewing consumers and carers and those for other key informants.

The first four objectives were conducted with relative ease. It was clear on commencement of the session and following introductions that the consumer consultants and the carer involved with this reference group had had significant experience in and involvement with formal protocols related to groups and their conduct. They all appeared comfortable within the group and were able to demonstrate a professional approach during the discussions that ensued.

Presentation of the research proposal to the reference group.

Of significant importance was the fact that the group spent some time on reviewing the research proposal, initially with a view to correcting terminology within the proposal. The close examination of the proposal and the comments made about its wording have had a significant impact upon the researchers understanding of how consumers see themselves in relation to what policy makers and service providers think of them. The terminology that the researcher assumed was standard for the field in describing the relationship between consumer and service provider was not acceptable to the group. It also indicated that consumers were sensitive about the way that consumers are portrayed, particularly as it portrays the power imbalance that they see still exists. For example, the wording which reflected the management of people with a mental illness was not acceptable to the group as one of the group members stated quite clearly that he did not wish to be managed in any way:
... the management of people in the very first statement. I hate people managing me. They can assist me to manage the symptoms or they can assist me in managing problems or difficulties or something like that but you don’t manage people (Reference Group, p. 2)

This comment was met with great support from the other members of the group who all stated that the wording should read “assistance with the management of their own illness or disability.

The proposal also discussed the transition from institution to community and how this transition shifted “the burden of care” as a result of this initiative. Whilst this comment reflected terminology used in policy documents and was not necessarily the view of the researcher, it was included to indicate the changes with respect to deinstitutionalisation and put into perspective what this process has actually succeeded in achieving. One member of the reference group commented as follows:

This terminology really bugs me. If society was to start knowing what we know as far as intervention and prevention (was concerned) it could go a long way to learning from us and finding that we are not a burden or we can shift from their society perception of being a burden of care to actually leading the way in reforming the pro-active health prevention’s that can prevent people from experiencing serious episodes of mental health problems (Reference Group, p. 2)

Another issue concerned the lack of reference to the report conducted by the Human Rights and Equal Opportunity Commission, commonly known as the Burdekin report, in
my initial research proposal. Of significant concern to the reference group was the outcome and recommendations of the report which consistently referred to the benefits of consulting with consumers and carers and of having consumers and carers participate at various levels in their own care and treatment. Although the researcher explained that references were made to the Burdekin report throughout the literature review, particularly in relation to background information on consumer and carer involvement, it was suggested by the group that these be included in any introduction or abstract and referred to as a major catalyst for reform of the mental health system. This was necessary, according to the group, to convey accurately that the human rights violations uncovered by the inquiry, is an important factor in the whole debate about the necessary involvement of consumers and carers.

\[... it needs to be mentioned when you are talking about ... transition from institution to community and deinstitutionalisation, ... the findings of the Burdekin Report which we all support – every single thing that the Burdekin Report found – but nothing has changed as far as that goes and what has happened is that there has been a major rationalisation of services in the shift to community supports and there has been more reliance on the disabilities support sector and carer organisations and self help groups to take up the lack of resourcing for community services (Reference Group, p. 1)\]

The ‘Burdekin’ Report (Human Rights and Equal Opportunity Commission 1993) and other investigations into the treatment and care of people with a mental illness has been further discussed in Chapter One.
In these opening remarks by the reference group however, the group members individually and collectively reflected the sensitive nature of consumers particularly in relation to the way the research proposal was worded. Further discussion however, in the early stages of the groups first meeting, and during other discussions with individual members outside of the group setting, revealed that each member wished to contribute far more to this research than merely support for its conduct. These additional contributions are discussed more fully in the subsequent section and have lead to the inclusion of important data associated with the experiences of those consumers and carers interviewed.

Several additional items were raised by the group as significant objectives in relation to their involvement with the research. They sought clarification of their level of participation in the research and what the researchers expectations of the group were in terms of their contribution as consumers and carers. The response was that although the group were asked to provide the type of guidance and support to enable the appropriate conduct of the research, the researcher welcomed their personal contributions through their experiences as consumers and as consumer consultants and carers. In the context of providing data about their experiences with psychiatric disability support services and the mental health system, participants stressed that they wished to be acknowledged for this contribution. They viewed their involvement with this research as ‘important’ to the location of the consumer consultants role in the wider provision of mental health services.

**Summary.**

An explanation of the rationale for establishing a reference group that included consumers and carers is discussed. The importance and value of having consumers and carers participate in this research was determined at an early stage. The group were initially formed to guide the conduct of the research and specific objectives were agreed between myself and the group.
As mentioned earlier, it became clear early in the group's first meeting that following our agreement on the terms of reference, discussions and clarifications on terminology and inclusions to background information in relation to the research proposal, members of the group wished to contribute more than merely support for the conduct of the research project. Their ambition was to contribute their own experiences of the service system as a way of strengthening their involvement as consumers within the broader context of the consumer movement.

Although reference group participants were not keen to separate their activities as consultants from the broader mental health consumer movement, they acknowledged that their role was leading the debate on consumer participation and involvement. It was their contention however, that all consumers and not just consumer consultants, should be able to make their own choices about what they (consumers) should or should not participate in. They none the less viewed their role and activities as consumer consultants as a constructive way forward and an example of the level of involvement that can be achieved by willing participants. They held the contention that this was in fact a representation of true empowerment.

The group were keen to also discuss in some detail, their individual knowledge and experience of the psychiatric disability support sector and what developments have occurred to date. They wished this to become an integral part of the research which recognised their contribution as consumers to the development of mental health research. Most reference group meetings convened for between two and three hours each. The length of the sessions indicate the in-depth discussions about the groups collective and individual knowledge and experience of the sector. Themes that re-emerged (according to the reference group participants) indicated a need for consumer consultants to continually be on top of current developments in the field.
With respect to the additional role the group now decided to adopt, they were behaving much more like a focus group, sharing their insights into the perceptions and experiences they have of the evolving psychiatric disability support sector. All members agreed and were comfortable in having the sessions tape recorded. They preferred to have copies of the transcripts of each meeting so that at subsequent meetings, any unclear issues could be clarified and discussed further.

This transformation of the group from support into focus group also supported individuals' desire to continue their own professional development. That their goal was to instil a more respectable view of consumer consultants in the eyes of health professionals, became more obvious as the group progressed, and further discussions on the prevailing attitudes which currently exist within the mental health professions occurred. Also, the group felt that their involvement in this research was an important function of their roles in reflecting on and responding and contributing to continual development of understanding of consumers' needs through appropriate research practices.
Chapter 7: Experiences and Opinions of Reference Group Participants.

Introduction.
In recognising the contribution that those consumer consultants and carers wished to make to this study through this reference group, an opportunity to engage them through in-depth questioning about their personal experiences arose. The group agreed to discuss their experiences with the mental health sector and with psychiatric disability support services with which they had all been involved over several years. The unique and significant contribution made to this research by the reference group through in-depth interviews with them warranted that information they provided by dealt with in a separate chapter.

This chapter deals with those detailed interviews. Information collected from these discussions was treated separately to that of the primary interviews with consumers and carers particularly as the content continued to make some reference to the conduct of the research.

The purpose of the interviews was to establish their experiences of and attitudes towards the mental health service system and the psychiatric disability support services sector given their current roles. The group were asked similar questions to those primary consumer participants who were invited for interview. In this case however, the group were asked to discuss additional themes that emerged and were developed following those primary interviews and to expand on issues raised.

Sub-headings have been used to categorise points of discussion arising from these themes rather than listing the questions that were used a guide. Specifically, the following major themes were constructed which emerged from the in-depth discussions with the group.

1. The role of carers
2. The role of consumer consultants in relation to support for consumers
3. The role and attitude of policy makers and service providers
4. The reference groups opinions of deinstitutionalisation and its consequences
5. The need for education and training
6. Empowerment and the progression of the mental health consumer movement

**The role of carers.**

In discussing what the role of a carer is from both the consumer and carer perspective, the group agreed that the role of carer is not specifically defined with limited training and education available and accessible in respect of how to support consumers through their stages of illness. The group felt that the role description of a carer and the perception of what a carer should do to support consumers, was equally as important as the way in which their roles emerged. The lack of any professional support for carers as individuals and as a group is also recognised as a major flaw within the psychiatric disability support sector:

*There has been no training put in place on how to be a carer. They didn’t provide any of that. Now there is ‘how to look after your self’ because if you can’t look after yourself, then that impacts on whether you are able to care about me and the other is an assumption that every one has carers* (Reference Group, p. 62)

And:

*Some carers are still pulling their hair out wanting to know what to do. And I don’t know all of the answers* (Reference Group, p. 63)
That the role was thrust upon carers raises questions about whether they are actually equipped with the necessary skills to provide support to consumers considering that they have been ill-prepared for the role. Several members commented on the lack of education and training carers receive particularly in light of them being involved with consumers by default or with no plan and considering the considerable expectations placed on them by the service system, as stated:

*I think the carer role is recognised as being more important than has been in the past...there is improvement there. It is often the carer who really provides the home base clinical support without any clinical training or expertise* (Reference Group, p. 61)

And:

*Unless there is some sort of support and training [for] carers, they really don’t know what to do in particular situations. If there is a crisis for example, who do you ring? How do you contain the behaviour...? Where do carers go for information?* (Reference Group, p. 61)

Without the proper guidance, education and training for carers, consumers within the reference group felt that carers tend to be misguided in their approach to consumers. Consumers do not wish to be cared for but rather cared about so as to allow them (consumers) the freedom to manage their own illness with support from carers when needed. When discussing carers specifically, the group continually reinforced this notion as they had in earlier discussions regarding the difference between being ‘managed’ and the consumers desire to be assisted to manage their symptoms. The group believed that, whilst well intended, carers tended to restrict consumers activities in the belief that they
were providing the support that consumers wanted. There was consensus that the role of a carer should be, amongst other things, a supportive one, allowing the consumer the opportunity to recover with support when needed:

> And just like service providers, carers too can hold people to a role of less than what they can achieve. I am a parent myself and I know how hard it is to let go and stand by and let someone stand on their own ...

> I don’t like being cared for and I will just only talk from my own experiences...I do know carers who need to have a child that meets their needs so they will hold me as a child to meet those needs and never let me be an adult (Reference Group, p. 62)

Comments were raised about providing support to consumers in much the same way as parents support their children when they take their first steps. Whilst there may be several other suitable analogies, the one put forward by the group serves to reinforce the notion that consumers want the opportunity to develop and learn to manage on their own knowing that they have the support from carers if and when they require it:

> The other is like being cared about. And I like carers... and a lot of us like carers who can care about us and that is where it is about putting cushions around us when we are standing up. And we might take a step and stumble but we don’t hurt ourselves too much but we can still take a step and stumble because that is where we learn ... but it is gentle and kind because it is softening the impact ... but it still allows us to take a step (Reference Group, p. 62)
Without the suitable knowledge and experience, consumers within the group agree that the role of carer, particularly in the early or acute phase of a consumers illness, is a difficult one. One consumer made the following statement:

*I am thinking from the care point of view here. Particularly when people are in the earlier stages and they are discharged before they are well ... and they really need close attention and the Crisis Assessment team might visit twice a day* (Reference Group, p. 61)

Another contributing factor to inadequate preparation for carers to assume that role is deinstitutionalisation and its consequences. The rapid process of deinstitutionalisation that occurred in Victoria has been well documented in the literature and discussed in chapter two. The reference groups experiences in respect of deinstitutionalisation have clearly had an impact on both carers and consumers particularly in relation to their (carers) ability to cope with what the group describe as relatively new experiences in dealing with acute and protracted psychiatric symptomatology.

*The first thing I think is that the service system is abusive.....The abuse... to carers is that deinstitutionalisation didn’t put in community supports necessary, and they expected the carers to take up that role and there has been recognition that that has damaged carers* (Reference Group, p. 62)

The damage is interpreted as the loss of opportunity for carers to live freer lives whilst adopting the carer role. Carers continually make concessions related to employment opportunities in particular so that they retain more time to assist consumers with their needs. The role has evolved as one where carers feel they are required to respond to a
crisis in the absence of support for consumers whilst consumers are going through an acute episode of a major illness. There was general agreement that carers did tend to place their responsibilities of providing necessary support to consumers before their own needs. Although employment would not be the only aspect of a carers life that would suffer as a result of their commitment to providing support to consumers, it was given as one of the many examples of what carers were, by default, required to forgo in their role as stated:

*Lets take an instance of that. It really affects a carers employment. They either have to give up their job or they are less able to do their job or pursue a career* (Reference Group, p. 62)

The group commented on the often held myth that all consumers had carers and that carers were generally always willing and available to provide care and support when consumers needed it. A number of factors come into play for when consumers require or want carers to provide support. These included the extent to which relationships between consumers and carers have developed in the past, particularly related to the carers ability to cope with acute episodes and the extent to which families are willing to provide support given the strength of past relationships, for example:

*I know there are a lot of assumptions that people have families. If I am out in Box Hill say, lots of people have stable family relationships. I work in an urban mental health service. The majority don't have families and ... the families that some do have are not supportive. They are actually detrimental, so you can't make assumptions about families, consumers and carers being supportive. Sometimes it is not* (Reference Group, p. 41)
And:

Also it also depends on the stage of the persons illness. A lot of the people that use psychiatric disability support services have a long term illness and have not been very well served by the system. And they have lost the fuel to cope with their family and the family have been unable to cope with them. And there are also people who are getting sick, developing an illness today who are still living at home and whose families can be helped to cope with a crisis. And even the people who are in touch with families have significant close relationships which are longer term than say the clinical service (Reference Group, p. 41)

The role of consumer consultants in relation to support for consumers.

The emergence of the role of consumer consultants and the functions of the role have already been discussed in the previous chapter. It is intended in this chapter, to provide the reference groups perspective on the role consumer consultants currently assume from the view-point of their own experiences and relationships and the way in which their role has been accepted by consumers and providers within the mental health field.

The role of consumer consultants is frequently discussed throughout this thesis because in many aspects, the role places in context the ability or disability consumers face in being involved in choices about their own care and treatment. Moreover, although consumer consultants are perhaps viewed as the relatively new wave of consumer movement and held up to be consumer champions within the mental health system, their views provide an accurate account and in some cases, reflection of what it is that they believe their role should be.
As people who have seized the opportunity of being involved with the fundamental delivery of mental health services and as consumers in their own right, the contribution consumer consultants make through sharing their experiences provides a unique opportunity to debate the benefits and barriers to involvement and participation by consumers in the overall mental health service system.

The opportunity of engaging consumers in the development and delivery of health services, whether in Victoria or elsewhere is not a new concept. That consumers of psychiatric services were given the opportunity to provide feedback in relation to the quality of services offered at Royal Park Psychiatric Hospital in Melbourne Victoria during 1993 (Epstein and Wadsworth 1994), did herald a change in the relationship between consumer and provider and will probably continue to have an impact in the future. That initial involvement by consumers who were patients within the psychiatric facility and the emergence of the consumer consultants role, has at least served to break down several barriers which had previously existed between consumers and providers. In particular, the opportunity for consumers and staff to communicate more effectively about a range of issues, brought about a greater understanding of the need to establish closer working relationships. This enabled the most effective strategies designed to facilitate patient feedback to be discussed, developed and implemented for the betterment of both consumers and providers within the service system.

Even though communication and representation may have improved, particularly as a result of the emergence of the ‘consumer consultant’ role, there exists a healthy scepticism with respect to the perceived usefulness of the role by those consumer consultants who have gone on to provide other consulting services (some to the large Melbourne hospital networks and others to the large church and charitable organisations that auspice disability services). This scepticism revolves around the notion that their role, although initially conceived to empower consumers by conferring greater
responsibility for their own care and welfare and that of their fellow consumers, has been developed to speak on behalf of consumers who choose or are not able to take an active stance. According to one participant this is a rather misguided belief:

Is everyone given the same opportunity to participate because quite often there will be a selection criteria of those who are able to participate so that it actually inhibits everyone from participating…. The consumer consultant’s role is to be the representative, to facilitate the input from every one, all of the consumers to participate at whatever level and however they want. Some like writing and sending articles, some like sitting on committees and saying ‘we should be doing this’ and our job then is to facilitate a whole range of mechanisms where everyone can participate. Whereas, if you just have a consumer representative or 2 reps, that limits participation (Reference Group, pp. 18-19)

And:

This is one of the things that I am really struggling with at the moment ... a lot of this talk about how do we get people to be representative and that is not what consumer participation is about by saying (for example) we can only have four consumers on this committee. Only the people who have the skill can be here. Because that selection criteria is exclusionary of the very people that you need there. ... It is about creating opportunity and providing the support that everyone can participate at that level. Putting
in the training, putting in the supports and creating the opportunity that every single person, even if their experiences or their perspective that they come with is only their individual one ... a service can provide to that in a quality improvement context. And everyone has the right to participate (Reference Group, p. 36)

A further example of this ‘selective participation’ adopted by the service system relates to the opportunity that other consumers have to be involved with consumer consultants and what they do. Although the group still preferred to view the role as a significant opportunity to be involved in decisions related to clinical care, support and advocacy of consumers, they were concerned that the establishment of the role may have the opposite effect to bringing consumers closer and could serve to disenfranchise consumers. They explained this by indicating that the existence of the role of consumer consultants may be interpreted by providers as the establishment of a preferred mechanism by which consumers could now communicate with them (providers, staff). The group stressed that this was not the intention of the role, citing again the preference they have for all consumers, whether consumer consultants or not, to be able to participate at a level appropriate to the individual, for example:

The notion of any consumers at all from the service system working with us on any sort of project is OK as long as it is not with staff (directly). The consumer consultant can work with staff but the consumers of the service can’t. We are employed to be the representative and the consumer participation is only as far as the consumer consultant. No further. We can talk to consumers and gather the feedback but we are the ones that have to represent that. We are the acceptable consumers (Reference Group, p. 59)
The group acknowledge that development of the consumer consultant positions and role is a starting point with which other consumers may identify, not the answer to representing all consumers who can and should have a voice on matters that directly involve and concern them. They do, however, believe that all consumers should be given the opportunity directly to discuss their issues and concerns with staff regardless of whether they are in consumer consultant positions or not.

Although the role is given some support as evidenced by the appointment of a number of part time positions in and around Melbourne Victoria, there is still the perception held by consumers that these roles are providing a tokenistic contribution because of the minimal hours of employment for which they are currently employed. Consumer consultants do acknowledge that their role is still in the developmental stage. Although some progress has been made in establishing themselves within the mental health field as consultants who are able to make a significant contribution supporting consumers, most still operate within the initial guidelines established during the Understanding and Involvement projects at Royal Park Hospital in early 1993. As the consumer consultants roles had only just been conceived during the evaluations at Royal Park Hospital, individuals would need to operate in the roles for some time before any useful evaluation with respect to the role itself could be undertaken. As no formal evaluation has been conducted since the inception of the role, it was appropriate to inquire from the group about how their roles were perceived currently by providers.

When questioned about how their role is accepted by providers and staff within the mental health field, the group responded that their role has been viewed differently at different levels. Primarily however, one major aim of the role is to stimulate discussion and to create opportunities for healthy debate about a range of mental health issues as a way of becoming part of the mental health team as one participant stated:
At different levels it (the role) would be viewed differently. The (Director of the Service) knows that he and I are never going to be friends. We don’t expect to be. And he and I are going to arm wrestle about lots and lots of things. That is what our roles are. My role is never to be silenced or intimidated by him and my role is to always say what needs to be said, whether it is the consumers giving their feedback about services that they experienced or whether it is being a consumer consultant within the service system viewing systemic processes and making comments on those or whether it is me challenging and questioning a direction that he decides to lead us to. We are always going to be arm wrestling on all those issues (Reference Group, p. 57)

The group also agreed that they saw their role as one that should not simply be tokenistic but rather one that could “disturb their (providers) comfort zone”.

It is a discomforting role. It is my job. My job is not to go in and say ’yes [name withheld], no [name withheld]. ... He knows that and the reason that he employed me is that he found out that I am not like that. He didn’t want someone to be tokenistic. I respect him as a manager that sometimes he will have more information about the broader picture ... that I don’t see (Reference Group, p. 57)

The group felt that an important aspect of their role was to be included in the treating teams, be asked their point of view on various issues much the same as a manager should ask his or her staff for information so that a considered decision could be made. They remarked on the need to have the opportunity to reflect the consumer consultants view
and that that view is regarded as being as important as other members within the service system team and one that is valued and respected. There was also the view however that even though a collaborative approach to problem solving was the ideal it was accepted that at times the person in charge of the area was responsible for the final decision:

I will question his decisions and he will explain it or not. There will be times where he can be collaborative and ask ‘what is your view on this’ as he does with all of the other managers ... as he is saying ... what are the consumer views on where we are going here. There are other times where he will have to make a decision – right or wrong – he is employed to make a decision. I might not always agree with where he is going to stand but he needs to make a decision for me to have confidence in him (Reference Group, p. 57)

Consumer consultants also, as part of their role, sought to improve the quality of services delivered to other consumers. Whether their input into the quality of service delivery is actually accepted as being that is a contentious issue for them. One group member remarked that although he had agreed to employment on the basis that his role included the improvement of the quality of services, his employer discouraged his involvement with the improvement of clinical services preferring to send the consumer on a research mission unrelated to clinical services:

It is interesting though that when I start talking about clinical things, there are times where he asked if I gathered feedback about the environment on the wards, about the food etc, and I have said no. My role and my job, and we have agreed on this, was in quality improvement of the
services. The services are clinical services. If you want me, and I am employed to do the job of improving the quality of those services, then I make comments on clinical issues, not just on other issues (Reference Group, p. 57)

And

I make comments on when a team is not comfortable with a consultant psychiatrist that they are following and has no trust at a team level. I make comments on that. I need to see whether he is aware of it. If he is aware of it, it his job to take care of it. I don’t tell him what he should do, I just say this bit is not functioning systemically, properly and I as a staff person see that. And it might be that other staff, because they have been in the service longer than me, might not see that. Like I come in with fresh eyes. At other times … he will say … I am going to cut back the resourcing. You tell me what the effect of that is by gathering the feedback … and I gather the feedback ...

(Reference Group, pp. 57-58)

In endeavouring to support consumers both directly through support and indirectly through the provision of representation and advocacy, consumer consultants view both mechanisms as key functions of their roles even though this view may not be shared with all providers within any given service.

One of the things that concerns me as far as consumers participating in their own treatment is that consumers can participate in their own treatment with case managers but
a lot of decisions are made by the team within the intake meetings and clinical reviews. And there are three things: Is the consumer they are talking about involved in those decision making processes, an advocate for the consumer is not involved in those and the consumer perspective is not there (Reference Group, p. 61)

And:

We will say if a patient in an inpatient unit wants to go to the mental health review board, I believe the consumer consultants who go, go there as a support to them...
We don’t do that because our job is purely and strictly described as not being individual advocates, so that inhibits us, but in one service that I have worked, I am a team member of the continuing care team. Each morning the team have handovers and I am present ... There are two roles I have there: One is to observe the systemic process and make comments on improving the quality and the second is to bring the consumer perspective to where it has never been before (Reference Group, p. 61)

Mention was made in the previous chapter regarding the treatment of consumer consultants as bona-fide consultants and their belief that as bona-fide consultants they should receive payment for consultancy work. Consumer consultants have been employed in various capacities and to varying degrees within Victoria and have received a set rate per hour for their services. The important factor in respect of remuneration for consumer consultants is that they are recognised as a group of people who have expertise in mental health issues and are people who are selected to sit on committees and give advice on service delivery and development.
The role and Attitudes of policy makers and service providers.

Following the introduction of the proposed research at the first meeting of the reference group, members were keen to discuss the attitudes of service providers. This occurred in the context of relating the concepts of power and empowerment and the current perception the group had of the imbalances that exist between consumers and providers. Whilst they agree that many consumers and some carers already feel empowered in certain ways because the service system is responding to increased pressure from consumers to observe their right to good treatment and care, there is a quantum leap from that state of empowerment to actual involvement in the development, delivery or evaluation of services.

The group agreed that the progress related to the changes in attitudes by providers towards consumers rests partly with the economic reforms that continually challenge providers to account for the services they propose to deliver. To this end, they largely believe that providers are themselves victims of their own bureaucracy having to conform to policy and subsequent management of the day and decisions are therefore made without due regard to what effect this has on consumers. They question the effects that deinstitutionalisation has had on changing the attitudes even though the physical walls of the large institutions are now a part of history in Victoria.

The group stated that the relationship between consumers and providers is the key to successful outcomes in terms of therapeutic benefits for consumers. The relationships needs to be a quality one where there is mutual respect and recognition that a good client provider relationship is based on trust and cooperation, for example:

*I think the most therapeutic thing, whatever the stage the person is in their recovery, is the quality of relationships with the people that are there to support them and help*
them through the process and then the quality of the relationship, things like trust, encouragement and cooperation ... these types of things, just being there. 

*Affirmation* (Reference Group, p. 31)

In addition to this the group felt that the values possessed by providers reflected the way in which they deliver services and the difficulty that consumers have in developing an understanding of how to successfully access those services because they are constantly changing.

*Can I just say something, and this is probably a gross generalisation, but I think in practice, the service delivery really reflects the values of the service deliverers. You have mostly middle class workers with middle class values present the service in a middle class framework and a lot of the consumers don’t fit into that picture* (Reference Group, p. 35)

Another member of the group added:

*I have seen some evidence already of some signs of backlash the management sources about participation. They are saying things like ... there is a natural limit to how much consumer participation there should be. As to actually paying consumers to do projects or whatever, there is no way ... yet they can find plenty of money for cars* (Reference Group, p. 36)
Members of the group also felt that these changes are not only brought about through the individual values possessed by service providers but also through political forces, particularly during and following a change in political leadership within the state. The comments suggest that there is a lack of consistency with respect to the way consumers are treated and this is dependent upon the attitude of the day. It is partly driven by individual values possessed by providers and partly due to the political forces that have a top down effect on providers required to comply with direction from above:

*The system follows the leader. The managerial attitudes and style, everyone follows. Like the change in Government from Kennett to Bracks – the whole service system changed during that government change. The way it worked – because it knew it was under a new government and to get in the good books with the person who is above you because you want to progress yourself and you become like them. And it filtered down, management to management to management, all the way down. So the person who leaves the committee of management of the psychiatric disability support services, if they have a certain philosophy or vision or a certain set of values, then all staff will conform to that and tend to follow. And I think that is where bringing in carers … to influence that to keep the bastards honest then give a different view that everyone leading it and then all the staff will start to follow (Reference Group, p. 35)*

A further point of discussion revolved around what was happening in the broader community and how this impacted upon the relationships that consumers have with providers. In particular the notion that the pressures that currently exist within society generally is perpetuating isolation and reinforcing poor communication between families
and other individuals and is extended to the less than satisfactory interactions between providers and consumers.

*I don’t think we can have a look at what is going on within mental health services and psychiatric disability support services without having a look at what is going on in society. Because it is like saying ... look at my mental state without looking at how it is connected physically, emotionally and spiritually. They are all inter-connected. And I think in our society there are pressures guiding people into isolation. For instance, the pressures of financial things so both parents have to work. Teenagers come home from school with no-one to talk to. They don’t sit down to tea and dad says “well how was your day”. There is not that communication. And kids come home from school and sit down to the computer. Very isolated. The whole family unit is splitting now. There is not that ability to interact, there is not that respect that comes from that* (Reference Group, p. 39)

**The reference groups opinions of deinstitutionalisation and its consequences.**

The consumer consultants within the group agreed that service providers had difficulty in connecting with consumers on a personal level, something they felt was an extremely important part of the recovery process for all consumers. Little has changed from the days of institutional care when the rules and regulations were bounded by solid walls. There was also the contention that, although the physical walls of the institution were now removed through the processes of deinstitutionalisation, the psychiatric disability support services sector has created an institution within the community through the development of another set of rules which some members of the group felt were destined
to continue the myths surrounding people with psychiatric illness and perpetuating stigma associated with those myths:

*I think psychiatric disability support services are like institutions when they set themselves up to keep people separate from communities. These people are special people (derogatory). They need to have special services because they are different and this is one of the biggest barriers to complete an acceptable recovery. It does perpetuate that society’s stigma* (Reference Group, p. 41)

Similarly:

*I think it is something more than shameful the way that PDS services generally fail to deliver the essential promise in their existence. Their central promise the reason they get funded is usually something along the lines this service exists to facilitate people with psychiatric disabilities are to get back into the mainstream community. They don’t do that. They are so separate. They are segregated from the mainstream in themselves as services and they provide hardly any access to the mainstream, they do almost nothing to link any of the people in those services* (Reference Group, pp. 33-34)

The belief that people with mental illness continue to receive less than favourable treatment following deinstitutionalisation practices over recent decades, is fuelled, according to the group, by comments made by mental health service hierarchy. The attitude of policy developers continues to reflect a disregard for the needs and concerns of
consumers as individuals with rights, and indicates to consumers that they are a group who must accept the decisions of government, regardless of the effect these outcomes have on them. The promises of better outcomes for mental health consumers, particularly as a result of deinstitutionalisation, have not been realised in the way consumers expect.

... they were talking about the deinstitutionalisation and shifting to community treatment. I was at a forum in psychiatric services branch and there were some heads of departments in those meetings. They were talking about the effect, or what they thought would be the effect of closing down the institutions and they spoke about the people going into the Houses and psychiatric institutions and one of the guys there said ‘we expect there will be acceptable losses of life’. I cant understand how any loss of life can ever be acceptable (Reference Group, p. 45)

And:

I would like to see the quality of services delivering on the promises they make in their mission statement. I would like to see them actually doing real things to facilitate access of people with psychiatric disabilities to the wider community to promote opportunities to be meaningfully engaged in life. I would like to see the services being vehicles for developing ones human potential in all sorts of ways – and for it not to be stigmatised. To be listened to .. and for us to help design the services that we receive ... and to be kept to the right information that is to be in place permanently .. and in a regular ongoing way ... and to have multiple
opportunities for consumer participation (Reference Group, pp. 42-43)

Education and training.

Education and training has been described by the reference group as an essential ongoing criteria required for the continued improvement of quality services for consumers in almost every aspect of service delivery. In more detail, the group discussed the importance of education and training as a way of reducing the stigma attached to mental illness and a way of continually addressing the opportunity for service providers to change their attitude towards a more accepting environment for consumers. One member offered the following insight:

*I feel that mental health and a whole lot of things are life long education. If you are say talking about depression, it is about mental health. How do we handle it in society? and then the life long education thing. That’s why at the moment, somebody calls it mental illness and it has this stigma and has been for hundreds of years and we just don’t need it that way anymore. What we want is the community to know about mental health and to learn about it and opportunities to hear about it in kindergartens or before that, and that includes things like everything from drugs, alcohol, parenting skills, relationship skills. To me that is talking about stigma* (Reference Group, p. 33)

Another member stated:
I think a lot of the information and education can start happening long before people actually need the inpatient unit ... (Reference Group, p. 33)

A way of breaking down the myths and reducing the stigma for some members, could be achieved by providing a more open and transparent service system, again, with all stakeholders involved. The community should have a much greater involvement with the psychiatric disability support services sector to achieve a better understanding of the issues with which consumers are faced. The group commented that this involvement should be driven both from the community and within the service system. Service providers must be encouraged to go out into the community as much as the community should be encouraged to participate within the service system.

... can’t be a one-way thing where people from inside the rehab section or disability support sector can just go into the community. The community has got to come into the rippling effect, because that is where you breakdown those stigmas, that is where all that prevention, a whole lot of education, community education and stuff goes on (Reference Group, p. 34)

And this statement by one member:

I don’t think one of the things is going to affect change. We have got to get it all together, the training, the policy development, the evaluations, outcomes, attitudes, the language, education and information (Reference Group, p. 37)
The notion of an integrated service system was further supported by another member who stated:

*And I think this thing of integration is a two way thing. Not just where the disability support sector is integrated into communities, but where the community is integrated to P.D.S.S. It is a two way thing, so that all those things we were talking about, education etc can go on. That integration can be a two way thing, not just us going into the community, the community coming into the services as well. There is a potential just in that to make a big change in acceptance, about understanding, about education just in that alone* (Reference Group, p. 43)

Additionally, one member commented that there are many ways for consumers and service providers to engage with the community particularly in the context of appropriate supports and encouragement.

*And looking at a social model approach, there are all sorts of ways that people, no matter what their background is, can engage with the community in a multiplicity of ways. There are lots of options that can be explored with the right sorts of supports and the right encouragement* (Reference Group, p. 34)

A belief is held by the group that the community needs to be made aware of the potential that people with a psychiatric disability have to live ‘normal lives’.
Even just letting the next generation know that if shit does happen you can still make it through. Teenagers, when they have their first episodes are still faced with this. They have never met anyone that has episodes or anything but still has a productive life. You don’t have to fit into some little narrow category of what life should be or people want to be able to do alternatives. People have all sorts of choices. There is not just one way to live your life. There is more to life than having a boat, a house, a car. There are different ways of living. There are a lot of people on the psych scene who often tend to be people who, ... one way or another have actually experimented in alternative ways of thinking, alternative spirituality, alternative values. And maybe monetary barriers have been derailed on the way and it figures that why should everyone in society be forced down this narrow little track when life can be so many things. There are many more ways to contributing to a community than going to a job and buying a house and doing your shopping at Safeway. There are many more things you can do (Reference Group, p. 34)

Education and training options should not be limited to those who provide the services or provide carer support to consumers. The group felt that consumers themselves would continue to benefit from education, particularly about their own illness and how to manage symptoms. The group felt that if consumers were sufficiently prepared through appropriate programs and support, they would be able to effectively move beyond their crisis state to, at least, their pre-crisis condition and they would have developed additional skills along the way.
There is a lot of work to be done and there is very little education people receive about their own illness, about the support services that are available, about social skills. There is such a lot more in terms of educating people beyond their crisis. If anybody gets sick there is a net loss. No matter how much they recover, there is a net loss. And there aren’t enough supports for every person to go back to the same position where they were before. We should all be able to get back to a place where we were equal to where we were or further on (Reference Group, p. 43)

The opportunity to provide support through the provision of education should be available to consumers as early as possible following initial onset of illness and subsequent psychiatric disability. The group state that this education should occur early to allow consumers the best opportunity of linking in with the services that they may need.

Consumers need education as well because they are not always able to see things globally, they just see day to day and they go where they are directed but I think it does require some sort of education - consumers particularly, at the onset of their illness so things don’t go too far before the link in with the services that are out there. That is critical because the further they go, the harder it is to access them (Reference Group, p. 17)

There was also a need for a natural progression of services to be available and that, as stated by one member, required an integrated approach where services provided information and worked with consumers for them to realise the opportunities.
The different sources have had to really work together and do some co-training, develop that sort of mutual respect on what each is providing and when that integration happens at management level, it really is to have leadership and that would really then make the flow of information and the access more natural (Reference Group, p. 50)

There is also the perception that staff, who were previously employed within institutions, were now working within the psychiatric disability support services system and they have brought with them, practices that were recognised as unacceptable. The transition from institution to community may have taken place but the culture engendered within the institutions has not changed significantly.

In my understanding a lot of people working in the PDDS system have had work in hospital and psych units and they carry with them from their earlier experiences of training, these institutional attitudes. And I remember there might have been a debate about new institutions. And it is true though and it is very hard to shift (Reference Group, p. 22)

One member commented that the service system required consumers to be ‘trained’ so as to fit in with the way in which services were being delivered rather than the service system changing to suit the needs of consumers. To fully allow consumers to participate meant that the service system needs to continually change its approach to service delivery and respond to consumers.

In my opinion as far as consumer participation and empowerment etc, a lot of times consumers have to be
trained. I think that is bullshit. I think the service system has to be trained and change the way it goes about things so that it makes a space where the consumers can step in. If not training the consumers to fit to be structures of the service system, changing, I mean really changing the service system structures so that they will be enabling and supportive of consumers just getting in to participate. And for that to happen there needs to be staff training and managerial training in that new service system of how it is now going to operate. It is not training the consumers to participate (Reference Group, p. 54)

Education would also allow consumers to challenge the value system of communities where consumers have in some way been indoctrinated by the service system to believe that they must conform to the ‘norm’ whatever that may be considered to be.

Unfortunately, those people who may have experimented or not if you ask them now “what do you want”? They want what is called the “norm” because that is what the system does. Oh you are over here and you should be here (Reference Group, p. 34)

The way that consumers have been perceived because of the programs and services offered has, according to the group, been less than flattering. Consumers are far more capable and creative people than they have been portrayed as being. Although the basic programs do serve a purpose in terms of getting consumers back into a social scene following a relapse of symptoms, the communities sense of what they are able to achieve is often misguided according to the group.
The thing that stands out in PDS services – what do you see! When you go there, you see your fantastic sculptures in paper mache, paintings, you see the writers group, you see creative discussion groups. You see the music group. People can really express themselves in different ways and creative ways and actually question some of the prevailing values in society. I mean this globalisation etc, it is not just some abstract thing that hurts at the national level or this group or that group. During the Kennett years that reached to the most intimate corners and it made such a big difference to the services that we receive. We had a community sector where there was a lot of co-operation offered, good will between services. That was all thrown out the window for cut-throat competition. Some of the good will has started to come back now (Reference Group, p. 34)

One member stated:

*I don’t think one of the things is going to affect change. We have got to get it all together, the training, the policy development, the evaluations, outcomes, attitudes, the language, education and information* (Reference Group, p. 37)

The group were questioned about whether the community would respond to education by consumers and whether communities would accept consumers speaking with them about mental health issues particularly in relation to the groups earlier comments about
education commencing at school age and factored into curriculums. One member suggested a way forward and a type of approach that may have an effect:

*I would like to see some shift towards intervention and prevention and I think the way that we could go about it is consumers who have gone through an experience could be teaching things at schools for instance ... then if teenagers did have things happen they would have knowledge of the resources and they would have met face to face with someone who made it through. We never met anyone who made it through so we didn’t know whether you could re-organise your life and stand on your feet again ... and I think that is a daunting thing towards youth and teenagers for anyone who has a first episode. You have never met anyone who has made it through and I think that is where a lot of people give up hope because they don’t know if they can make it. Consumers don’t have to have any specific training to be able to do that. All you have to be, is game enough to stand up and say “these have been my experiences and I made it through”. And that gives hope to another generation that are going to be confronted on having first experiences* (Reference Group, p. 67)

The strategy suggested by the consumer consultant included the following:

*There is a way of linking it together. I am in my mid forties, so teenagers don’t necessarily relate to me because of the age difference. But if I was to go to school with a teenager now who was accessing youth services and we*
both spoke, then the youth relate to the youth but they can hear the wisdom from someone older. And that is the way to pair it up. Because then it is accepted ... because it is coming from one of their peers ... and they are also seeing the view that they can make it through ... and you can talk about what these disability services are ... and what they can do ... and you can give the information of how you can contact them. ... this is where you go, how you access the services and it is OK ... and it should become part of the curriculum (Reference Group, pp. 67-68)

**Empowerment and the progression of the mental health consumer movement.**

During the first reference group meeting, a background to this study was presented to the group. One of the objectives of this inaugural meeting was to discuss the types of questions that would be suitable to put to consumers and carers and to gain a perspective on how to approach potential participants and collect data. At this early stage, the group commenced offering their opinions on the concept of empowerment and what it meant to them. This created the first opportunities to allow the group to elaborate on their knowledge and experiences and further discussions regarding issues of power, participation and the consumer movement occurred at subsequent meetings.

The group had strong views on the mental health consumer movement and their understanding of what constituted empowerment was often debated throughout discussions on almost all issues raised. Each interview followed a relatively unstructured format. Whilst this was the case, there was an opportunity, at times, to focus the discussion specifically on empowerment and whether or not consumers felt or believed they were empowered in different situations. Questions had been prepared by myself prior to interviews and presented to the group. However, they were sufficiently flexible to allow respondents the opportunity to raise any issues that they felt were relevant.
An opening remark from one member suggested that barriers to participation existed because service providers were not listening to consumers from the outset. This member suggested that consumers have difficulty influencing change within the service system because of a perceived wall that exists where it was felt that consumers lacked sufficient knowledge and experience to be able to participate and contribute effectively:

A general point is ... that the professionalising of the services ... and that is a really strong thing you know, you have to be qualified or the right sort of experience to get a job and you have the consumers and it is sort of like them and us. And it is a pretty solid wall in between in terms of wanting to influence the way the professionals do their job. There is a big gap there in the participation in influencing the services and even their own treatment is hard work and often consumers are disempowered by their illness or by their experience of the service not listening to them. I think that is a current situation that there really is that gap (Reference Group, p. 4)

Another view proposed by another member in her role as a consumer consultant within inpatient mental health services stated that the opportunity to influence service delivery at direct care level is starting to emerge. This person was referring to the acute inpatient facilities. It was not clear to the group, however, whether the changes were sufficient enough to influence what was occurring in the community and within psychiatric disability support services.

It would be interesting to find if it is following the same steps as what consumer participation and empowerment in
mental health services is going through. Over the 4 years that I have been a consumer consultant in those mental health services, I have found that first consumer participation could not influence what was done, but could only influence how it was done and that was the key starting point. We couldn’t change what was mapped out. We could influence though how at direct care level how it was done and that was the starting of us being involved in quality improvement. And then now after four years, we are actually influencing what gets done and consumers are now sitting on the teams that are writing the clinical guidelines for psychiatry. The acceptance of consumers being able to participate has gone to a much deeper level now, so that we are much more involved in writing the guidelines which then influences the clinical practice, so we are starting to influence what is done (Reference Group, p. 5)

Another member supported this notion:

Yes, it still has a long way to go but they were the first steps. One was influencing how things were done and then after 3-4 years it was starting to influence what was getting done. And it will be interesting to see what the disabilities support sector has done and consumer participation and things like that (Reference Group, p. 5)

One member commented about the development of consumer movements that were originally established by carers to support consumers. One such Organisation in the US,
NAMI (National Alliance for the Mentally Ill), that advocated for consumers, has created the opportunity for consumers to participate in its functions by relinquishing control and effectively instituting empowering strategies for consumers. The example was used to compare favourably with what is occurring in some support services within Victoria although the extent to which these strategies are in place is not known as one participant describes:

... And in America NAMI. We were both originally carer support organisations that started advocating for change. And then those organisations opened up to consumers and then the carers took a back seat in those organisations. They had almost done their bit of getting that perspective in the door. That’s the way they worked. The NAMI is the national line for mentally ill in America that originally was a carer group and then now it has backed off and that is what empowerment is. Creating the opportunity to stand back and let the people take the opportunity (Reference Group, p. 9)

Another member of the group reinforced the benefits of carers as advocates promulgating the consumer movement and the need for consumers to accept that carers can offer significant leadership within the field and open the way to empower consumers.

I think that the way empowerment goes, services could learn a lot from cares if you ask consumers and within the consumer movement and it is like anything, there are certain factions. But some might say that the carer movement is more politically powerful to push their agenda because they are more homogenous and they are more able
to organise themselves. And I say why don’t we learn from that so we can get our shit together. Because I do see quite a lot of times the consumer movement pulling in different areas. For instance, the deception of consumer movements that advocates very strongly for consumers being the only experts for setting up and running totally independent services, not connected to any professional stuff at all. And that is really risky stuff. I don’t hold to that at all. ... in the carer movement, they don’t think of being disconnected at all from the professional service delivery, because they know there is a need for that. That is where the expertise is. And within the consumer movement, I align myself more to the people who are willing to try and marry the academic professional knowledge with the experiential knowledge because we have the greatest knowledge base to work from and that is sort of in the middle (Reference Group, p. 9)

The importance of distinguishing between being empowered on a personal level and empowerment that comes from being part of a consumer movement was pointed out by one member of the group:

I think it is very important to make a distinction between the area of personal empowerment, which involves a whole lot of things, a whole lot of changes to their life, a whole lot of abilities or lack of abilities of being able to rely in certain ways or being able to engage in the community in certain ways. ... Separating out the personal empowerment from the group level where we are talking about power
differentials between service providers and consumers, they are really quite distinctive different areas (Reference Group. p 28)

Another member stated:

*I go back to the personal empowerment, which is really the area. I don’t really have a lot of influence on the system but we find that a lot of people that we come across are discouraged, really discouraged and empowering is about encouragement .... Empowerment is also about the right sort of confidence to have in the service provision because they are not perfect and they would expect that something wouldn’t go right in their progressing illness and so forth (Reference Group, p. 29)*

Similarly:

*A lot of consumers and carers – their experiences don’t register anywhere. You know, “we know what is wrong with you and we are going to treat you this way. You just have to provide by the rules” ... And that is so dis-empowering, it really is (Reference Group, p. 29)*

There was a consensus amongst the group that consumer participation at any level within the service system empowered consumers. There was a caution, however, with regard to this statement as consumer consultants felt that in some cases, providers were selective about who got to participate and this negated the opportunity for true empowerment. Consumer consultants saw their role as being more beneficial to be able to construct an
environment whereby all consumers have access and all consumers can be involved through participation at every level. Consumers had a choice as stated:

*Consumer participation is about everyone being able to be given the opportunity to participate at any level they choose to. And that is empowerment* (Reference Group, p. 59)

**Summary.**

The groups view of carers reinforces the importance of the caring role particularly in light of what the group describe as gaps in support services. The role is a particularly difficult one because as explained by the group, every individual consumer’s circumstances are different and the issues need to be approached in different ways. That carers find the role difficult has been exacerbated by the lack of adequate support for themselves in a role that was often thrust upon them and one which they continue to grapple with on a day to day basis.

The lack of training and education emerged as the most important criteria for carers to develop their role and therefore provide meaningful support to consumers. In several cases, when the issues surrounding education and training were discussed, it was apparent that some members had had an opportunity to undergo some training in various forms and to varying degrees. However, it was agreed that the training and education was not available in the way that carers wanted it to be nor was there a systematic approach to offering programs or a ‘universal’ knowledge of how carers may access these.

Consumer consultants felt that their role was important in the continuing struggle for all mental health consumers to have an opportunity to be empowered and to take control of their own lives. The group agreed that the role was not an easy one. There were mixed comments regarding the acceptance of the role by providers within the service system.
and not all group members were convinced that the role had been fully accepted as part of the mental health treatment team. In some instances, they used the words tokenistic to describe how they believed some providers viewed their involvement. Although this may be the case, the group still had definite views on the importance of their roles and were positive in their resolve to continue to develop the role further.

In discussing what was actually involved and what was expected of them as consumer consultants, they described the role currently as already having a number of responsibilities. Firstly, the role offered consumers a place to at least start to be involved in their own decisions about treatment and care and a vital step in communicating their needs and rights as individuals to various providers. To some extent, the role provided an example of what consumers were able to achieve, even though the reference group indicated strongly that full involvement with one's own treatment options should not be conditional upon consumers aspiring to the role of consumer consultant or any other role.

Quality improvement within services was also considered to be a necessary function of the role particularly as opportunities existed to improve the relationships between staff and consumers with timely and relevant feedback. According to one participant, the quality of services within the mental health service system should extend to all areas within the service system including clinical care. He formed the view that when he was first offered the role of consumer consultant, his contribution to informing the service on clinical issues was necessary for that service to improve its quality. Instead, his involvement was extremely selective and determined by what was asked of him by his manager, not what he had been made aware of by consumers using the service.

Providing support to consumers through representation and advocacy, was seen as a necessary criteria of the role particularly as this was discussed in the context of the choices that consumers should have open to them. That consumers choose to use consumer consultants as advocates and representatives indicated to the group that issues
related to communication and consideration of the needs of consumers is still not fully understood by providers. One major concern for the group was the notion that even though consumer consultants felt that their role was a significant step forward in bridging the gap between providers and consumers, there was a risk that providers would effectively negate direct communication with consumers, particularly in inpatient units, now that consumer consultants were placed in positions to speak on their behalf. Although not specifically stated, the group implied that this sort of manipulation of consumer consultants role only served to actively disempower consumers further. The group stated that this was not and will not be the intention of the role and that this situation would only serve to create a wider gap between consumers and providers.

Attitudes of service providers continues to be point of contention with consumers. Consumers still feel that they are not well accepted and that not enough importance is placed on the development of a good relationships between them and providers. The relationships must provide for mutual respect and not be judgmental as some within the group experienced.

Of significant note also, were comments made by the group about the value systems of providers. Providers were still not able to or chose not to develop an environment in which consumers felt they belonged or in which they had a right to be. Consumers state that providers have become even more protective of their jobs, particularly since the rapid progress of deinstitutionalisation. The community environment in which psychiatric disability support services are delivered has evolved and developed, particularly since deinstitutionalisation impacted on services to the degree to which it has in the recent past. Consumers stated they felt that this situation has made it more difficult for providers to respond and adapt to the needs of consumers. Consumers wonder whether the attitudes that reflected the practices within the large institutions of the past were continuing within the community today.
One group member also made broad statements about the condition of today’s society and stated that the additional pressures of everyday living threatened to erode the relationships within families which will subsequently further isolate consumers. The age of technology posed one possible threat to communication between families where human interaction and activity has been replaced by individuals consumed with computers and televisions. It would seem that in this particular situation, the relentless evolution of advanced technology specifically the personal computer, has had a significant negative impact on the ability for society to manage interpersonal relationships and solve problems.

This issue represents a bigger picture with respect to consumers and their relationships with the broader community in that it serves to highlight the consequences and effects of any deterioration in communication between groups.

To many people, the concept of deinstitutionalisation meant that care normally provided in an institutional setting would subsequently be delivered in a different form and within a community setting. Whilst to a large degree this is occurring for mental health service in the form of psychiatric disability support services now established participants felt that there was a real risk of psychiatric disability support services becoming ‘the other form of institution’. Their view was that psychiatric disability support services are failing to deliver on promises of supporting and assisting consumers to get back into the mainstream community following their acute illness. Psychiatric disability support services have set themselves up to be just as separate and isolating as the institutions discussed earlier. This, according to consumers assists in perpetuating the stigma and myths surrounding mental illness and psychiatric disability. Policy decisions are generally still made with little consultation with consumers and little regard to the needs of consumers despite the various innuendo about inclusion.
The reference group indicated their strong support and need for relevant and timely education and training for all stakeholders within the mental health field, including consumers, and the importance of an integrated approach and collaboration with their communities. They believe that the training and education should be underpinned by the need to provide ‘life long’ education about mental health and mental illness in much the same way as health education is delivered regarding the long term effects of smoking or poor diet for instance. Not only would this have the effect of preparing people in dealing with symptoms of acute mental illness, should this occur, but education about resources would also instil at least some confidence in individuals who may have a pre-disposition to mental illness and assist them to cope with the stress of a psychiatric disability at some point during their lives. Further, life long education would create a continual opportunity to break down barriers that exist within the community and significantly reduce stigma that is so often prevalent and a great protagonist and reinforcement of the myths and misinformation surrounding mental illness and its consequences.

The availability of information and educational programs about a range of topics from resources to accessing of services currently exists for many public and private services. They exist to guide consumers through the often ‘mind boggling’ array of service available as well in some cases to guide consumers to specific and unique areas within a field. There is no reason, according to the group, why extremely visible and accessible information cannot be available for consumers, in the same way and well before consumers actually have need of them. For many, this could be their first episode where consumers would require information about in-patient services, how to access them and what to expect as a consumer of psychiatric services.

Whilst their views differed marginally on the ways that education and training should be delivered and where the responsibility should lay for the delivery of education and training programs, they agreed that all the stakeholders should have an opportunity to contribute. Involvement by all stakeholders also reinforced the recognition that
consumers should be sufficiently empowered to share their ideas on the ways that improve quality of services and subsequently achieve better outcomes. Of significant note were the comments about the need for education and training to be a two way street. Both service providers and the communities must collaborate so that relevant and timely education involving all stakeholders can take place.

The group further stated that all aspects of the service system need to be brought together to maximise outcomes for consumers particularly as there exists opportunities to share knowledge with a broad cross section of stakeholders. The terms used reflected the current ideology of integrated service systems, however, in this case the group were talking about the need for greater interaction between service providers and the community. There belief is that it is not simply a case of advertising services to allow people to get to understand what mental health and mental illness are about, but rather, to encourage service providers to actively break down barriers by educating communities about the range of issues with which consumers are currently faced, thereby creating an environment of acceptance.

Although the group discussed a number of ways that education would impact on services provided, they emphasised the changes to attitudes by service providers that are necessary to achieve an acceptable power balance for consumers. One member, a consumer consultant, raised concerns regarding what he believed to be the necessary training by service providers of consumers, so that they would fit into the service system. His experiences suggested that not enough was being done by service providers to respond to the needs of consumers and carers, but rather, service providers wished to maintain the balance of power and consumers were expected to conform.

Early intervention and health education programs delivered within schools would achieve a better understanding of mental health issues at an early age and provide the resources in the form of information on how to access services if and when they were required. In this
respect, the group asserted that ‘life long’ education on mental illness, psychiatric disability and accessing services should be available to all within the community.

The message provided to people through education of mental illness and psychiatric disability support, particularly in their formative years, should clearly indicate that with appropriate knowledge, understanding and support, potential consumers will equip themselves with essential strategies required to survive episodes of mental illness and lead to more productive lives as they manage their psychiatric disability.

Successful and effective education programs relied on a number of criteria proposed by the group. The need for collaboration between government in developing policy, service providers, consumers and communities, was seen as essential in ensuring that consumers and potential consumers received the best possible outcomes as could be achieved through educational interventions.

There was unanimous agreement by the group that the recognition and implementation of empowering strategies by the service system and service providers was a necessary part of achieving a voice for both consumers. Opportunities for participation in a range of activities and at a number of levels by consumers within the mental health field was seen to be the basis of this empowerment. The choice of participation in services by consumers would assist in changing the attitudes and practices of service providers and lead to a greater acceptance and improved outcomes for consumers.

To this end, the mental health consumer movement had a role to play in continuing to support the inclusion and participation of consumers in mental health and psychiatric disability support services activities. The group had clearly stated earlier, that as consumer consultants and carers, it was not their sole responsibility to only represent consumers but to also facilitate their participation and involvement.
One specific barrier to participation by consumers was the notion that consumers were seen by the service sector as not sufficiently qualified to participate in decisions made about services generally. One member stated that consumers found it difficult to influence service delivery because they were viewed by service providers as not having qualifications or experience necessary to contribute. Another member stated that the opportunity to influence service delivery in terms of ‘how’ things were done on a clinical level initially emerged and then that lead to consumers being able to influence what was being done.

There were mixed responses about whether consumers were able to influence what was being done about their own situation in terms of treatment and management of their symptoms and subsequent disability. The group, through their own experiences, were divided when discussing their views on this issue. For some, there was a strong belief that changes reflecting the greater influence that consumers have within an acute setting were starting to occur. These remarks indicated that some service providers were listening and responding to consumers preferences in terms of treatment options within that setting. The question raised for all however, was whether these shifts were having an impact on providers within the psychiatric disability support services sector and for the most part their opinion was that the same was not happening in the community.

The benefits of including carers was also raised by some members of the group. The perceived influence that carers have within the political arena was seen as a distinct advantage and some group members related their knowledge about how consumer movements both in Victoria and in other countries, were actually started by carers. Consumers were subsequently empowered by gradually taking more and more responsibility within the movement.

One consumer consultant stated that carers have demonstrated that, as a group, they are better able to organise themselves and that consumers should learn from this. He further
added that at times the consumer movement was ‘pulling in different directions’ and described these different movements as deceptive. Here he was making the point that some consumers advocated for services run entirely by consumers and that this approach was “risky stuff” and he would not support the notion. In his opinion, carers were not thinking of being disconnected from professional service delivery because they needed expert advice and assistance in supporting those for whom they care.

There were some distinctions made about personal empowerment and strengths that consumers achieved through organised consumer movements. The group recognised the differences by describing personal empowerment as the need for consumers to achieve personal growth which involves changes to their lives as individuals. One member stated that being encouraged on a personal level inspires confidence. Their discussions indicated that as individuals, achieving a state of relative empowerment depended on their capacity for personal growth and their willingness to participate in current and future service development and delivery.
Chapter 8: Experiences and Opinions of Consumers.

Introduction.

This chapter presents the opinions of consumers who have had access or are currently using psychiatric disability support services within Victoria. The purpose of these interviews was to gain an understanding of the experiences they have had or are having with psychiatric disability support services and how these experiences have affected their lives. Particular emphasis was placed on discussing opportunities for participation in service development and delivery.

Participants were asked to allow between one and a half and three hours for the interview with the possibility that a follow up interview may need to be conducted to clarify issues further. All interviews conducted took between the specified time with the average time being about two hours.

Analysis of the data from interviews revealed the following themes:

1. Participants experiences in acquiring information, contacting and introduction to psychiatric disability support services.
2. Consumer understanding of psychiatric disability support services, how they operate and what they provide.
3. Consumer perspective’s on the roles and attitudes of providers.
4. Consumer involvement and participation in services
5. Education and training
6. Empowerment and the Consumer Movement.
Consumer experiences in acquiring information about psychiatric disability support services and mental health services.

Participants discussed mixed feelings when recalling their initial experiences in getting in touch with psychiatric disability support services. Each had a different story to tell and each described their recollections of their respective experiences differently. Most participants regarded their first contact with psychiatric disability support services as involving either an acute assessment team or an area mental health service. That is, they were not able to clearly define the differences between acute clinical services and those related to psychiatric disability support services such as advocacy and drop in.

A clear definition of the perceived differences between acute mental health services and psychiatric disability support services was not given at the start of interviews, however, details of the types of services that consumers might expect to receive through psychiatric disability support services was outlined in the plain language statement provided prior to interview. This information was obtained from peak bodies, psychiatric disability support service organisations and through discussion with the reference group who were consulted about this study. Although this information was provided, some participants still considered services such as CAT teams a part of the psychiatric disability support services. That they did not distinguish between acute and social rehabilitation services and the reasons for this becomes apparent in further discussions throughout this chapter. It is important to note here that because participants did not clearly define the differences between acute and disability support services, this factor did alter the focus of the research to include the broader mental health service system.

Participants were asked to describe their earliest experiences in contacting psychiatric disability support services with a view to explaining how they initially came in contact with these services and what the extent of those services were. For some, earliest experiences took them back several decades whilst for others, their experiences involved using psychiatric disability support services in the past weeks and months. Although
there was no specific requirement by participants to recall dates and times regarding their experiences, it was interesting to learn the differences regarding the supports that existed, or were non-existent some years ago compared to those available currently.

One participant commented that there was little in the way of organised community support services in the 1970’s and he had no experience of psychiatric disability support services immediately following his hospitalisation in 1972. In any case he did not have any need for psychiatric disability support services during his early experiences but described his network of supports during that time:

*I think it must have been either through word of mouth perhaps based on some article through the local press. I became aware that there was a person working with a group of people who had psychiatric disabilities. I became aware … well I rang up the person, that was the first move and I was then informed of one or two meetings (CC:266-270)*

In qualifying his involvement with the supports he had mentioned, he stated:

*Well I had no experience of the psychiatric disability support services in the 1970’s. I never felt any need for such animals. I had my own friendship groups. I was involved with the formation of a labour party branch when I came out of hospital in 1972. That was where I got … peer contact (CC: 277-282)*

Other participants interviewed agreed that not much had changed since the early introduction of psychiatric disability support services in terms of available information regarding community services and what they could access. Consumers, who were making
the transition from hospital stay to community, were not given consistent information about psychiatric disability support services and what was available to them on discharge from hospital. This was particularly so if consumers were experiencing their first admission to an acute hospital facility and were not aware that other support services existed. Some participants were not sure how they actually came to be in touch with psychiatric disability support services and speculated as to who might have contacted these services on their behalf as suggested:

*My psychiatrist I think must have contacted them and they came out and talked to me about what was going on (CF: 76-79)*

Another participant discussed the lack of information regarding alternative supports that should have been available to her once she was discharged from hospital.

*When you first come out of hospital after an illness you want to be able to access as much information as possible about your illness, first and foremost and then all the other options and therapies that are available. What you are given instead is just the medical model. And absolutely no alternatives. And whether there are or not, you don’t know. So there seems to be a sort of whitewashing and you just have to put up with what is in front of you I suppose. You are not listened to. I always wanted to have a counsellor and in the country that wasn’t available. So after having an acute psychosis etc you had nobody to talk to and when you wanted to talk to the psychiatrist they said it was just a bad dream, don’t worry about it... (CD: 610 – 613)*
This statement was supported by a participant who said that only following her own investigation and research into alternative support options did she realise that there were a number of alternatives for her to choose from. Even following her investigations however, she was not certain who should have been responsible for informing her of these options:

... and nothing is looked at and it was only now after my own research, I found that there are avenues, there are counsellors, and there are people who are interested in looking in that analysis, who look at alternative therapies even. Maybe that the medical model is still part of that, but it is not the only option ... And I think that you need to be aware that there are all those things right from the start. I don’t know who does that, psychiatric services or psychiatric disability support services people. I don’t know who (CD: 614-632)

When asked why she felt services were not able to provide her with satisfactory information about what options may be available to her following discharge, she commented that staff attitudes were responsible for the lack of advice. In particular she felt that it was easier for staff to not have to communicate with patients and this made their job easier.

Because it is easy. You just get shunted into this system. Like when you are in hospital and you are told to take your medication. It is just easier for them to have sedated people rather than have these people doing strange, eccentric and bizarre things ... I think it is just easier, that is why they do it (CD: 638-642)
Other participants stated that they were left to organise psychiatric disability support services for themselves, even though this may have presented a difficult task for some given their relative state of illness. Participants would simply be given contact names and numbers and advised to make the call themselves. In the words of one participant:

*I had to do a bit of searching around for myself.... They tended to give you a number and a name and just leave it at that and say ... you ring up and sort it out yourself. Which, when you have got depression, it is very, very hard (CH: 105 & 119-121)*

And:

... and just no follow-up no nothing, no ‘has she got anywhere to stay even’. It was just more a ‘see you later’. And of course, me being 19 and thinking – Oh – well - I have to. So I didn’t say: I haven’t got anywhere to stay. It was like OK, fine. See you. Because I wanted to be out of there anyway (CF: 43-47)

Similarly:

*I guess in the first stages it was mainly other people, like the first person that would have found out – a doctor or something has put me on to them and you would actually have to make the phone call and tell them why and what you need. That was the first stage. But now I think it is just a matter of basically asking and talking to a lot of different people and specifying exactly what you need help with. It*
is still really hard. I don’t think it is made easier. It is still really hard to access. A lot of people don’t take the initiative. A lot of workers don’t take the initiative to get phone numbers for you or whatever. They don’t think about it which I think is a really necessary thing. They think that you can do it yourself. Yes. I guess they think that she has got me. I am assuming she is not saying anything else. I am assuming she doesn’t need anything else, rather than - she is doing this at the moment, she is pregnant and she will need this, this, this, this of course; here are some phone numbers to give her. Rather than always waiting for you to ask. There needs to be a bit more of – maybe you need this or maybe you need that. Push it on them a bit more. Because a lot of consumers will not speak up and say what they really want (CF: 306-321)

Not all participants felt that they were not given sufficient information about psychiatric disability support services or assisted enough in obtaining information. According to these participants, the most consistent source of information regarding available services came from consumers case managers or workers. Those consumers who were fortunate enough to be ‘allocated’ case managers (CII) at an early stage of their illness, also received a considerable amount of information in some cases an introduction by the case manager to specific programs and services. Information provided ranged from suitable programs, opportunities for accessing these, and a range of other supports that participants stated they were not able to access for themselves. (CB,CD,CH).

Comments received on the effectiveness of case managers when linking with psychiatric disability support services all revealed that involvement by case managers provided a significant advantage for consumers and participants felt comfortable with them. In particular, reference was made on several occasions about case managers and the vital
part that they play in providing information about psychiatric disability support services following stay in hospital.

One participant stated:

_The case manager has a more sort of global understanding of what services are available and they would then refer from their clinical position to the P.D.S.S. and there would be a linking, maybe an introduction and it takes on from there and so there should really be collaboration between the clinical and the P.D.S.S. services and the case manager is really the key person in that because it just makes things possible_ (CI:72-80)

Another participant also commented on the benefits of case management when linking in with psychiatric disability support services for the first time:

_I also had the unusual situation that I had a case manager while I was still a patient at the...hospital...So I still had no contact with the public system and I actually got very good information from that case worker. That was one part of the public system that I had to say was that, the case worker that I had was very good. She was full of information of places to contact and people to know and see and was very helpful_ (CH:81-86)

Although case managers or workers were seen as instrumental in linking acute with psychiatric disability support service’s according to participants, there was often difficulty in accessing those people as one participant stated:
You basically had outreach from the Case Manager when they could get there. Now the Case Manager’s load was absolutely unreal. I, at times, was lucky to get an appointment once a month (CB: 75-77)

There was general agreement from participants however, that case managers and case workers were more effective in linking them in with psychiatric disability support services. They felt this was the case because of the information they believed case managers had about what was available in contrast to providers working within acute in-patient facilities.

One participant also made positive comments about information received from psychiatric disability support services workers themselves who attended acute facilities from time to time. Staff of the psychiatric disability support services would visit acute facilities to present information on available supports and programs that may be suitable for consumers.

They come out to our acute unit once a month and speak to our inpatients to let them know that they exist and that they are all welcome to come when they get out of hospital. It is one thing they do, outreach like that. The other ways, I am not quite sure what method they use to get themselves known. They have leaflets that are put around in our acute unit and so on (CE: 115-119)

While in a hospital facility one participant commented on the fact that there was no information for her family specifically as her parents were unaware of where or how to contact other carers for support:
I had no idea when I went into the acute ward that there was such a thing as a disability support sector or other services that you could access. You aren’t told anything like that. And in fact my parents weren’t even told what was actually happening with me in the acute ward and I suppose that is another issue for her to raise. But yes, she was quite concerned that she didn’t even know how long I was meant to be there and what was actually going on. Who do you talk to? Is there another carer to talk to. There was nothing told whatsoever (CD: 78-86)

From this participant’s reaction there appeared to be a lack of information about what was happening in the acute setting which was of equal concern to her carer.

**Consumer understanding of psychiatric disability support services, how they operate and what they provide.**

Participants were asked about their understanding of psychiatric disability support services and how they operate. For some participants, there was little distinction made between the receipt of initial acute assessment and treatment interventions such as the CAT teams (Crisis Assessment Teams) and those services that were offered by psychiatric disability support services even currently. For others though, there was a distinction between acute and psychiatric disability support services which they were able to explain in some detail.

As mentioned earlier, discussions regarding the early experiences that some participants had, had them inextricably linking psychiatric disability support services with crisis assessment and other assessment teams. Even though some participants still considered CAT teams a part of the psychiatric disability support services system, this question more
clearly identified what participants believed psychiatric disability support services offered in the form of programs and services following, rather than during an acute episode. The question intended to draw a distinction between acute services or those delivered in in-patient units and those that were delivered within the community and took on a social rehabilitation context.

Those participants who were able to articulate the differences between acute and psychiatric disability support services, explained that psychiatric disability support services provided an opportunity for them to ‘rejoin society’, following their acute episode. Services offered allowed them to learn new skills and to return to a relative state of ‘normal’ functioning. At the same time, as one participant stated, her involvement in disability support programs allowed her to maintain contact with clinicians such as her doctor whilst she was learning to cope with the ‘outside’ world:

*My understanding is that it is more about bringing people back into society. More so than just keeping them somewhere and keeping them stable and not helping them learn with living skills and things like that. More about teaching them again about how to cope with the outside world and all that sort of stuff and not in such a clinical way in a very normalising way – rather than in a clinical way. But also, keeping in contact with doctors and other people so that it is all very safe* (CF: 6 -12)

The need for consumers to ‘get their lives back on track’ was consistently stated by participants and reflected their understanding and experiences of the significant differences between hospital stay, or clinical services, and rehabilitation support services such as psychiatric disability support services within the community:
The P.D.S.S. is a non-Government organisation as distinct from the clinical services and so when people move into the community, back home or whatever they see the P.D.S.S. are there for them to help in their recovery, rehabilitation but also providing some sort of structure, things to do, people to meet and an opportunity to talk things through and set goals, get back to what they think they would like to be doing. To get their lives back on track I suppose (CI: 6-12)

Some participants were of the opinion that psychiatric disability support services could only be accessed following acute episode which resulted in them being admitted to hospital. That is, psychiatric disability support services were not used as a primary support service in the absence of any documented history of past acute psychiatric illness. When asked whether there was a dual role for acute services from providing acute in-patient care to disability support services, one participant commented:

No, it is usually people who have a psych. history and they are treated by the acute services...the community services, so often people would be having continuing care, maybe seeing a psychiatrist and availing of other services such as psychological services. So the two run in parallel but often there is cross-reference and overlap It is more psychosocial and really picking up the deficits that result from the illness. People loose their social skills and confidence, self esteem and really plummet and if they wanted to get back into some sort of meaningful activities, things that give them satisfaction, well they have to pick up those sort of
skills and confidence and be given some support to pick up jobs etc. (CI:18-27)

From this participants’ observations and experiences, an admission to an acute facility was a pre-requisite to accessing and using psychiatric disability support services.

Another participant also commented that she was not aware that she could contact psychiatric disability support services when she was not actually in crisis believing that this contact was only supposed to be a last resort:

*Well, it was sometime before I knew about emergency crisis teams and things like that and really understood what they did and what they were for. I thought beforehand that the only reason why you would call them was that you really were ... that that is it. That was the last final thing that you did. Where as I have now found out that you can actually ring them and talk to them when you are heading up to a crisis and not when you are necessarily just at the point of a crisis. I think that you should be aware of the various services that are available in your area. I have found out that there is a service that helps people into employment and I didn’t find out about that until much later on when I worked with the case manager (CH: 92-100)*

The need for general support from a psychiatric disability support service following acute illness is succinctly summed up by this participant:

*My understanding comes from the experience I have had in the country, which is the support service, which I suppose*
supports a person who has been diagnosed with a mental illness, to have a fulfilled life as they so wish (CD: 326-328)

Being able to socialise with people without having demands placed on them was also seen as an essential component of psychiatric disability support. The need for informal drop-in centres was mentioned throughout discussions with participants who agreed that these types of facilities were important for consumers to feel safe and not threatened and to continue their recovery from an acute episode at their own pace and in an environment that best meets her needs:

Yes. A psychiatric disability support service. And they can spend all day there and they don’t have to be involved in all the activities. If they want to sit around and drink coffee that is all right. And I think that drop-in facility is a really important facility. I used to like that when they did that at the Schizophrenic Fellowship which they stopped. I think that is an important facility to have somewhere to go and mix with people like you, and feel comfortable without having demands put on you (CE: 124-130)

Another participant specifically stated what psychiatric disability support services do for her, particularly how they are ‘there’ for her whenever she needs them:

They take me to my hospital appointments and they will be on call the whole time if I ever need to ring for anything, just to talk, when I go into labour ... All of those things. Because I don’t have many family members that are around and responsible for that. And just to keep an eye on how
they think I am. A lot of them know me from last time and they know how I was and how I was acting (CF: 114-119).

And:

[psychiatric disability support services] ... it basically was home based support where they would come out and make sure everything was all right and help me. And then they would have groups that you could go to. You could go in and just meet other mothers and talk too ... and just be there basically. Just have somewhere to go. You are very paranoid of going anywhere else, such as normal people’s houses. They just supported me in medication or whatever else I needed to do. They were supportive of that. In driving you places, taking you around (CF: 90-96)

Following her stay in the acute ward, this participant articulated her understanding of psychiatric disability support services and what they did for her:

... I had a case manager with psych services and as we were working on say, day-to-day projects, after you just get out of the acute ward... those baby steps. Getting through a day. Because it is so difficult after such a traumatic experience. I think I must have asked “is there a group that I can get together with that I don’t have, wont have to feel the stigma because I was too embarrassed to go down the street to see people I might have known. What am I going to say to them. I have been in hospital with schizophrenia. All these kind of things (CD: 88-93)
Having a case manager only presented part of an improved service system for some who stated that there needed to be more cooperation between acute and psychiatric disability support services. In one participant’s opinion, there was a lack of communication and what appeared to be tension between the service streams which prevented the timely linking with psychiatric disability support services following acute admission:

You pick up the fact that there is tension between the clinical services and the P.D.S.S. services...they have to work on overcoming those difference. I mean, really to work well and effectively to get them in place in a timely way it has to be good communication and co-operation. And it hasn’t really happened and I think that probably is part of the problem (CI: 63-68)

Differences between acute services and psychiatric disability support services.

When asked specifically about the differences between acute services and psychiatric disability support services, virtually all participants responded with comments about having no control over what was happening to them within the acute setting. By contrast, participation in psychiatric disability support programs and services provided consumers with the opportunity to at least make some decisions about their level of involvement and allowed them to contribute to some degree, to their own recovery, as stated:

... with psychiatric disability support services), they do ask you along the way “what would you like to have in the program. What activities would you like?”. And they would get us consumers involved and participate and bring up ideas, even run our own support things. However, with Psych. Services and what happens there - absolutely no involvement and not even asked (CD: 362-369)
And:

I find them quite distinct different parts of the service. I do. And I see the hospital stays as quite different and no where near as supportive as the outside services – the services once you get home ... are much better. I found that especially ...as far as the inpatient stays went that there was a shortage of nursing staff. The attitude towards you was usually pretty awful. It was sort of like you were a bit of a nuisance – the fact that you had taken an overdose. In fact I was told on my last occasion – “how dare I take an overdose because they were busy”. That is pretty awful. And whenever I seem to have any problems or feel suicidal they would just lock me a seclusion room and leave me

(CH: 188-196)

The following participant explained that there were many differences between acute services and psychiatric disability support services. Primarily, psychiatric disability support services were non clinical and treated individuals differently even though there was knowledge of a psychiatric illness. When in hospital, she was not able to have any normality returned to her life. All attention was focused on her psychiatric illness rather than any attempts made to re-focus on normal living activities. Psychiatric disability support services, however, were able to provide her with the environment and opportunity to feel ‘normal’, giving her support without her being ‘analysed’ as she stated:

A huge amount of difference. I am not sure how to explain it ... Just the fact that [psychiatric disability support services] are very unclinical. That it is very different to
going to hospital and being judged on a psychiatric level all the time rather than getting the situation normalised and going ... OK you do have this but we are not going to talk about that all day. We are going to make something or do something. That is what the difference is. And then just being able to sit down and talk to a support worker about anything and everything and not have it psychologically challenged. Knowing that they are not analysing you on a psychiatric or clinical level. Knowing that their job is ... OK, do you want to have a cup of coffee and we talk about it and we will find out what we can do about it rather than 'your mad and I think you should go back to your psychiatrist and get some pills' (CF: 238-249)

The issue of having some control over the choice of programs on offer and when and where consumers could attend these programs, established psychiatric disability support services as better alternatives to in-patient care according to participants. On the whole, participants had a greater freedom to exercise decision making and become involved depending upon their level of functioning at the time. Most participants agreed that a flexible approach to supporting consumers was preferred over the often prescriptive and rigid rules that they had experienced within acute facilities.

Access to psychiatric disability support services.

Participants gave different accounts of their experiences in accessing psychiatric disability support services. Whilst most participants were not presented with problems in accessing psychiatric disability support services, there were some unusual events that were experienced by two participants. One participant stated that she had difficulty in accessing services because she had to prove that she did in fact have a psychiatric disability. The reason given for this difficulty was the cost of services. The contention
was that psychiatric disability support services are not for just anyone who walks in off the street:

*I suppose I joined up and you had to fill out forms. I suppose you had to prove that you had a psych disability. I suppose because you are linked with psych. services you had to identify that you needed some support services* (CD: 109-111)

Another participant suggested that consumers may not wish to access psychiatric disability support services because of the ‘poor’ treatment that they had received within acute services which has had a lasting effect:

*What the problem with P.D.S.S. is ... is the that because consumers and how they have been treated in acute services don’t want to go to them. A lot of the time when they believe they need to go to them, can’t get into them. So what happens is that unwellness falls back on the staff of P.D.S.S.’s, which they are not actually funded to do. But they do it because the people don’t have any other step to fall back to other than the police or the CAT team* (CB: 408-413)

Most participants, however, were eager to leave psychiatric facilities and have access to psychiatric disability support services because they wanted to put the experiences of being in hospital behind them. As mentioned earlier, the need to feel part of a group who shared common experiences and who understood the complexities of psychiatric illness was an important factor in regaining a feeling of ‘normality’.
**Consumer expectations of services and what should be offered.**

Participants were also asked about what their expectations of psychiatric disability support services were and what they thought services should provide in order to best meet their needs. One participant described why he links in with services and what he expects to get out of his association:

> Well, I basically link in to enhance my skills and also for personal enjoyment which I couldn’t afford as in cheap meals, cheap movies, trips to wherever. That type of thing. Not really so much anything psych anymore. I have actually made my mind up about that. I sort of formulated a plan of what I do and what I don’t do (CB: 134-138)

Another participant stated:

> What do I think they should be all about. I think they should be primarily concerned with helping people to know what the hell they can do when they are in a dreadful fix. Offering what is recognisable as friendship as well as service. I should compliment things I said earlier by saying that I think that some of their staff who are in 1 to 1 are doing a pretty good job (CC: 428-432)

And:

> ... I think they should be providing knowledgeable friendship. They should be providing and honouring human beings and I don’t think that this can be easily come without having more highly experienced people doing it. I can’t see that the present system of
competitive bargaining and tearing down costs everywhere really helping anything to happen. Other people tell me that in the big organisations for instance staff are continually running around to meetings about this, that and the other (CC: 447-453)

He also stated that the success of psychiatric disability support programs depended on them being responsive to consumers in the way that they need them and want them to be: According to this participant, the provision of appropriate programs should not be dependent on how well or unwell a consumer is at the time. Consumers should be allowed to become involved with programs according to their capacity to participate:

O.K., it is very simple and it is very logical. What happens is that if you are there to support somebody, which is what P.D.S.S. is supposed to do. You go to that person, and it doesn’t matter what stage of wellness or unwellness they are at, you say “what do you want and how can I help you achieve it?” And you basically help them achieve anything that they want to achieve. Because it is going to make it easier on everyone all around and if that changes day by day then that focus is changed day by day and that is the only way I believe it can be made successful (CB: 673-680)

Another participant commented on the need to feel comfortable and supported in a safe environment with people who understand the issues surrounding mental illness as being paramount to her involvement:

Just from feeling encouraged. I have also done group therapy and I have found group therapy very useful. And I suppose this is a step on from that. It is a step that allows
you to just feel supported by having other people that are in your situation. Understanding your issues and talking to you about them. You can discuss your issues quite comfortably. It is a long process of getting used to being open about a mental illness and you can do that quite safely in those environments (CE: 185-191)

Similarly if psychiatric disability support services were taken away:

If that was taken away, I would be very insecure. Not that I would need them all the time or anything, but just knowing I can always go back there. Just like if you had family, knowing you could always go back there. Which I don’t have the security of that so this is my security blanket I guess (CF: 266-269)

And:

... I guess what I get out of them is that family. Not too much family like but just the knowledge that I can go there, somewhere safe to go, somewhere where I know I can go to. They will get me some sort of help in whatever is happening, whatever emergency that it is. It doesn’t feel very much like it is a life threatening emergency any more. It doesn’t feel like I am going to be totally trying to do it by myself. And that is what I get out of it (CF: 277-282)
According to this participant, several other consumers share her view about psychiatric disability support services providing support that they believed would otherwise be provided by families:

Yes, I know a lot of people definitely do. A lot of people have totally left, that have a mental illness, their families do ... just stigmatise and they are abandoned and they are pretty much by themselves. And they get used to being by themselves and get used to not being looked after properly or looked after in a nice way. So often you are rejected. I feel it takes me a while to think they do care about me and I will give them a ring. It is weird to think that someone is helping and looking after you, it still feels weird. And I think a lot of other people who use the services still feel weird and think they really do want to be nice to me (CF: 286-294)

The notion that there should be easier referral to hospital when things are not going well was stated by one participant. This statement becomes important in the context of earlier discussions where one participant believed their was significant tension between acute and psychiatric disability support services and the need for the service system to address this issue.

I expect to be able to contact somebody or talk to them when I start to feel that things are not going very well. I also believe that they should be able to easily have me referred to hospital, which is something that I have found is very difficult...There doesn’t seem to be a direct link with the services that you are used to using (CH: 143-148)
Impact of psychiatric disability support services on consumers lives.

Participants were asked what difference being in contact with psychiatric disability support services has made to their lives. Those participants who had regular contact were unequivocal in their praise for psychiatric disability support services and programs and how they have positively affected them:

I think I have been extremely fortunate because it has been a really good experience for me. Whether it is a combination of the people I met there. I never expected to. I came from a completely different background and for me then to have this much interaction with these people was quite unusual and I found that I loved it and I wanted to be involved in it more and more (CD: 219-223)

Consistently, participants were relating positive experiences about their involvement with psychiatric disability support services particularly in relation to the opportunity to meet other people and network.

Well it has been really important to me to meet other people who have got the same situation that I have got. The contact with other consumers is the most important thing. And I have become involved with the Consumer Movement and that has been the most useful thing to me ... more than the P.D.S.S.’s ... the PDSS has been the consumer movement. The Victorian Mental Illness Awareness Council and the Melbourne Consumer Consultants Group to which I belong and have belonged for years. They are both very helpful in my development (CE: 149-156)
Consumer perspective on the roles and attitudes of providers.

Hospital staff
Participants were asked about their experiences with providers. The initial intention was to specifically discuss those providers employed and working within psychiatric disability support services. However, many participants took the opportunity to volunteer information about their experiences related to the treatment they received in hospital and in some cases how their experiences affected their subsequent involvement with the psychiatric disability support services they were now using.

Participants responded with information about both providers and the physical environment of hospitals. In relating their stories, most commenced discussing the experiences they had had within hospitals and their subsequent involvement with psychiatric disability support services. The discussion about hospitals and the attitudes of staff was an emotive issue for some participants one who gave the following account of his experiences:

*Let’s face it, acute wards are gaols. Nobody really ever wants to go in them but they haven’t really got anywhere else to go* (CB: 640-641)

And:

*... I haven’t been to an acute unit yet that has been effective. And I was working with the state wide service so I got around to a lot of them and I know a lot of people that have been to the different services. I have been inside them, looked at them. They have got ‘fad’ ways of doing things. But it has got to do with the attitudes of staff. I can*
understand staff being very frightened because when a person is under a psychosis they can be absolutely, extremely dangerous. And a lot of them are not capable of handling that and they only have to get one good clock once and they are frightened for the rest of the year (CB: 654-662)

Similarly, other participants describe their stay in hospital and the treatment they received from staff. In many cases there was agreement by participants that there was lack of support from nursing and other staff.

Well I was constantly upset and distraught and found very little support from staff members. It was sort of like we were all there as a collection of patients with psychiatric illness but there seemed to be no individual counselling from the nursing staff and individual support given to you by staff. And ultimately when I was no longer under certification, because I had private benefits, they discharged me and referred me to a private psych hospital instead, so that they didn’t have to look after me any longer. So I sort of felt that I was kicked out of the system and forced into using my private benefits (CH: 43-50)

Participants were not sure whether the minimal time that staff spent with them was due to lack of skills or staffing resources. This participant said she was made to feel like a nuisance during her hospital stay.

I don’t know whether it was skills or whether it was just staff numbers. They didn’t have the facility to deal with
having me there. They indicated to me at that last visit that they only have a certain number of beds that were available for psychotic patients and as far as depression went or as far as any of the other mental illness went, they didn’t have the time or space available for them. They were just being basically nuisances for being there. And the faster they could get you out of that system and into something else ...

(CH: 215-221)

According to this participant there were other disparaging remarks made by hospital staff on her subsequent admissions which she felt highlighted the stigma that so many mental health consumers feel when their illnesses recur and they require hospitalisation. Staff at this hospital stated that she should be ashamed of herself for using an acute hospital bed when there were more serious cases that required more urgent admission. These attitudes were not consistent at all hospitals in which she had been a patient. In one particular hospital, she was received well and staff were immediately concerned with her safety and welfare. Other participants have also supported these comments about the differing judgmental attitudes of hospital staff:

Well they knew me from previous admissions. I had a number of other admissions and it was sort of like ... you know ‘oh not you again’ sort of thing. And very much ignored me and my needs and didn’t talk to me very much at all, except to tell me off for standing in the middle of the road. Instead of actually talking to me and telling me why ..., what is going on with you that is causing this problem I didn’t get any of that. Where as when I went to the (another hospital), as soon as I got there they said to me – do you feel unsafe, do you feel suicidal. So they immediately put
me in their intensive care area which is not actually locked but you are kept under 24 hour surveillance by a number of staff who looked out for me. ... there is three nursing staff there and they constantly keep their eye on me and you are not allowed off the unit itself. They are pretty good and they see you try and go out of the unit they come an get you and bring you back. I felt like I was a nuisance (CH: 257-273)

And these comments:

I think it is probably all of those things combined. And I think too people often form an opinion of you when you are sick and they see you again and they carry that opinion on and sort of treat you the same way. They don’t treat you as an individual and each episode may be a different problem or a different occurrence of a problem. I had no reason to be depressed. Or as I said the comment of how dare you take an overdose. We don’t believe that you have got anything to be depressed about. And I was quite badly man-handled there. I was actually dragged by two security guards to the unit from the casualty area to the psych unit and I had bruises up and down my arms (at X Hospital) the next couple of days I was very badly bruised (CH: 281-297)

This participant added that there was a recognisable change in hospital staff attitude for some providers within the hospital system during her stay, and these staff actually spent time with her and offered her support.
There was one doctor who was very good who came and talked to me while I was in intensive care and said what could he do for me. Is there any people that could be contacted. Was there anyone he could put me in contact with who could help me. Was there any requirement that I needed of him. Basically I think he sort of initiated the admission to (another hospital) and in contrast, the other hospital, when I got there was very good. I would like to just say that my parents are getting on in years and my father has Parkinson’s disease and they were required to drive down to Maroondah and then drive me to Melbourne. So there was no transport and he found that very difficult he gets very tired and Mum gets a bit night blind so it was very difficult for them to actually transport me. So I think that is a bit of a failing. That should have been – say ambulance transport. But because the way that the ambulance system is... (CH: 215-236)

One participant preferred to discuss the benefits of hospitals for both short term and long term stay. She stated that there was a need for consumers to access a range of accommodation following acute admission and discharge from hospital including the opportunity for supported transitional care.

I think there is clearly not enough hospital beds for people with mental illness. The area is under resourced and there is not enough beds. People who are ill can’t get into beds. The old institutions had some flaws but we didn’t have homeless people sleeping on the streets with mental illness like we have now and I think we have some people who
probably need that long term care. It should be not in a confined arrangement but in an arrangement that provides someone a supportive living environment. There is not enough step up and step-down facilities for people who come out of mental hospitals... We do have people staying in hospital because they can’t get accommodation for them. There is just insufficient accommodation out there at a rate they can afford. So some people need some sort of supported accommodation and some people will probably need a more intensive accommodation and I think that was one of the things that the old institutions provided which hasn’t been followed up in the move to the community (CE: 690-720)

This participant also stated that the institutions of old were able to provide consumers with activities that were relatively unavailable to consumers following their closure:

Another thing is that the old institutions used to have some sports things available to them. They used to have volleyball courts out at Royal Park when I was out there. You can’t do much in the way of your physical health in a psychiatric ward now. We are arguing to try and get exercise bikes and running machines, but we don’t have anything like that. There is nothing to do physically. We don’t even have a basketball ring. And if you try and bring it up, they say they are only there for an average of 9 days. But some of them are there for 5 weeks and it is a very boring environment and your physical health is neglected. When you say you have mainstreamed, people who are in
bed with appendicitis don’t need to keep physically fit. But people who have a psychiatric disability and are bored out of their minds and are taking medication which is going to make you fat, do need some facilities for physical exercise and they do need gyms or gym equipment and that is not being provided (CE: 690-720)

In providing her response to attitudes of staff within the hospitals in which she had been admitted, this participant had earlier stated that:

I suppose the staff (psychiatric disability support) had a nicer attitude than the hospital staff had and I don’t want to slam the hospital staff too much, there were quite some good ones there (CE: 30-32)

Psychiatric disability support services providers.
Participants’ experiences with psychiatric disability support service providers in terms of the support they received varied considerably. One participant felt that the attitudes of some staff working in the psychiatric disability support sector were those that were prevalent within institutions and these attitudes continue to create barriers between consumers and providers. For him, the attitudes are changing only very slowly:

Oh yes. Some of the attitudes are terrible. I do the firing squad for some of the people I know. It is mainly the old school and they are very slowly changing. But you have still got that barrier... we will say it is accountability and the legal side of it and that duty of care side of it rather than the human side of it (CB: 553-556)
And this:

*I see it as part of the ego not so much the attitude. It has got to do with “I know it all because I have done the training” but the fact is, it doesn’t equal the living through it* (CB: 587-589)

Another participant had a different view. He described the positive changes that were occurring within the community and psychiatric disability support services and the evolution of support services from institution to community during and following deinstitutionalisation practices:

*I am quite impressed really. They [staff] are a mixed lot, some are really dedicated and caring and all those things that are important ... some are just doing their job and really don’t engage with their clients a lot ... But I think by and large the visible changes that have happened in the last five years, a lot of the providers are unsure about. The system is evolving and [providers] struggle to find their new place within it. Now that there has been a move from hospital care to care supporting communities, this is quite a large change for nursing staff who have worked all their life in a psychiatric hospital, maybe 20 years ... what is required is to learn what has been offered in communities so that a niche can be made and just the confidence developed in what is being provided out there. It is really still an integrated system ... it really is a paradigm shifter and really does require good training and just getting to know other parts of services* (CI: 147-165)
This participant acknowledged the changes that have occurred over the past few years and made specific reference to the fact that even providers still needed to come to terms with these changes. The transition from institution to community has, in his opinion, been a significant event. Nursing staff, who were generally confined to operating within institutional boundaries now find themselves having to work within and with communities in order to deliver effective supporting care to consumers. The paradigm shift about which he speaks includes the changes to length of hospital stay with consumers now required to be supported earlier within the community than ever before. The ability by providers to understand all parts of the service system through appropriate training, was seen as a necessary ‘shifter’ to establishing integrated systems of care. Participant’s views on education and training were also canvassed and are discussed later in this chapter.

Additionally participants felt that the evolution from institution to community psychiatric disability support services may have been accepted and understood by some managers required to oversee its development and implementation, however, subordinate staff are still grappling with the concept as suggested:

   ... I think the managers, the people who drive the system understand it but the staff doesn’t necessarily understand the fullness of it (CI: 167-169)

Participants were also of the opinion that some psychiatric disability support services did not offer much to those who were relatively well, stating that providers seem to want consumers to be more ill than they are. These statements were supported by their belief that certain providers need to protect their own positions and are not particularly focusing on the care and support for consumers.
to me, they seem to have consumers there and they seem to require them to be more ill than they need to be. And this is an impression that I have got when I have been there to Annual General Meetings and things like that. They often have the consumer’s outdoors, not participating in a meeting, talking loudly and being disruptive so the meeting can’t be heard. It seems to me that this seems to be their role to be unwell and that disturbs me profoundly (CE: 47-53)

Another participant also felt that providers often made consumers feel incompetent by introducing them to new systems with which they were not familiar:

In my view, it is quite possible to make people feel more and more their own incompetence, to feel more and more insecure by introducing them to things saying it is easy, it is like this, when it is either beyond them or they don’t have the opportunities to get the practice. It is on the one hand, claiming to empower people, on the other hand it is to a degree subjugating people. (CC: 763-780)

Another participant agreed that the attitudes of psychiatric disability support service providers varied from service to service however, in her opinion the worst ‘type’ was reflected in providers adopting only a clinical view when supporting consumers where they were predominantly concerned with only providing and assessing medication needs.

... It is getting there. There are people in there that have the same attitude. There are so many people who have different attitudes. The worst type of attitude is that it is all
clinical and that it is all to do with pills and medication. I think that is the main attitude problem that you are only going to get better on this medication and that is all you need to do (CF:664-668)

The lack of commitment by providers generally who were not focusing on the needs of consumers was also stated by this participant:

They need more support from the people that are working there. They need to be way more encouraging and supportive, rather than Hey no! – your threatening to my job, your threatening to my time. I want to ring my daughter right now and you are interrupting me kind of attitude. I still see that very much happening. I think it happens in any work place. I think that if you are going to work in a place with the mentally ill, you need to be very committed. There is still a lot of childish stuff still goes on. You have got to sort of be the bigger with people with a mental illness. You can’t go down and argue. You cant get on that level. You need to be a bigger person and stay there and be very patient. A lot of people don’t have the patience. Just a lot more listening skills rather than telling what to do (CF: 630-640)

Another reason given for providers making available limited support options for some participants included lack of time consumers felt providers were committing to supporting them (consumers). In addition there was also the belief that providers did not want to put in the effort as this would create more work for them. Providers, according to some participants, were not prepared to acknowledge that support required a combination
of medication, counselling and activities and one participant believed that psychiatric disability support services providers lacked commitment in their role.

Because it is a lot of hard work to be there for a person, especially if they are coming off medication. It is going to take time. It is going to take a lot of time. ... Yes. I think it is a matter of not wanting to spend so much time and effort in your job. Some people just want to go there and say today I am going to make it an easy day and therefore they will. Which you can’t really do. You need to go and take on whatever happens that day (CF: 673-678)

And:

... And then you get the attitude of ... God ..., what more can we do for you? And it is like ‘a lot more’ (CF: 405-406)

Similarly:

there just seems to be too much of this sort of flippancy about the consumers. You have got mental health and so you wouldn’t understand. People can sit around and chat ... You will find nursing staff will spend hours in the office talking in the office talking about something ... some general thing that they would like to have a chat about, yet they say they are too busy to spend time with the patients. And to me, there is something wrong with the system when you have got them talking about the footy scores, when in
Case Managers/workers.
As discussed in the previous section, case managers and workers, according to participants, were predominantly the source of information and support for consumers both during their hospital stay and when they needed to access psychiatric disability support services. Participants were of the opinion that, if they were fortunate enough to be allocated a case manager/worker whilst they were still an in-patient, they had more support and assistance in accessing suitable psychiatric disability support service programs on discharge so that they could become actively involved with these as soon as possible.

Participants’ comments and opinions of the attitude of this group of providers were generally all positive with the exception that for most consumers, case managers workloads were unrealistic, which meant that they could not have contact with consumers as often as they should. (CB: p 1, 2 & 10).

Consumer involvement and participation in Services.
Participants were asked about their level of involvement with and participation in the development or design, and implementation of psychiatric disability support services and programs.

Although there were significant differences of opinion amongst participants regarding individuals desire to participate in developing or delivering services, all agreed that to participate at any level within the service system, must be a choice that is made by individuals and dependent on their ability to do so at the time.
I think that there is always something that each person could do on an individual basis, yes. It may not necessarily be in a major capacity but I think even if it came down to responsibility for carer of a facility or something like that that was fairly simple it could be fine (CH: 501-504)

All participants also stated that providers should take more responsibility in ensuring that consumers have opportunities available to them to participate in service development and delivery and that processes for consumers to express and interest in participation should continue to be developed.

Not all participants believed that their peers wished continued involvement with psychiatric disability support services once they have been introduced to them although still agreeing that consumers should be able to exercise a choice. One participant stated that in her experience, and for some other consumers whom she knows well, once a person has had a mental illness and recovered, they want to put that experience behind them and seek no further involvement as stated:

... I think there are lots of people, who once they have had a mental illness, they want to forget it, they want to put it away and return to a normal life and never think about it again. But some of them do have their mental illness revisit them. And I think then they tend to start thinking about what they were provided with and what might be done better (CE: 675-679)

Another participant supported this view but added that, in her opinion, there were two distinct groups of consumers in the context of involvement and participation with services and programs. She held the belief that some consumers were incapable of
contributing any more than they do because of their mental state at any given point in
time in addition to their level of education and capacity to learn. The other group
included those consumers who were more educated and willing to participate more with
program development and service delivery and who she stated should be used more by
services:

But you have two groups of people. You have got those that
want to go on and try and do something for the services
and help and you have got those that really ... they are not
capable of doing it. They need the support because of their
mental afflictions and they are often not capable of really
going any further as far as education goes. They just need
the simple support service. Just somewhere to go each day
with simple activities to keep them occupied. So I think you
have got fairly distinct groups. You have got those that are
relatively intelligent and educated that want to go on and
learn more and be involved more and participate a bit
more and maybe should be used a little bit more by the
services. And then you have got those who are really not
capable of going much further and their limitations are
attending the programs and they also may not want to be
involved in going any further. So you have got these two
ends of a spectrum. I suppose its like and education
program where you have got those who are not so good at
school and those who are better at school and you have got
to deal with both ends. You have got to see to the needs of
both lots of people (CH: 470-484)
For another participant, participation was a personal choice and depended on how far, within a service, a consumer wanted to go. That a consumer might choose to not participate may reflect their satisfaction with their own life situation at the time while others aspire to different heights:

*I think it is more about people and how far they want to go within themselves. They see themselves as all right and I feel all right with myself. Some people feel alright with themselves at this level ... at a higher level. Some people never feel alright about themselves and I think some people are satisfied personally with where they are. And it is probably the best they have felt in their life and they are doing as much as they feel they can and that's all they want to do. Some people don't. Some people know ... I am sure I can feel better than this. I am sure I can do more and have more and be more. It is about levels of what people are satisfied with* (CF: 476-484)

Most others whilst agreeing that consumers should have a choice in their level of involvement with service development were of the view that participation in service development was important for participants for a number of reasons. In particular, there was the belief that consumers were best placed to understand the concepts of mental illness through their own experiences and therefore they had a significant contribution to make to developing improved services that meet their own needs:

*I think it is very important and I think, from my point of view I would have to say that, unless you have actually suffered a mental illness, even though you might have the
best will in the world, you can’t really grasp the concept of what, in my case, having depression does to you (CH: 391-394)

According to all participants, having other consumers as members of a treatment team or a psychiatric disability support service, is comforting in that there exists a greater understanding of individual needs by consumer representatives that can be communicated to the rest of the team. Consumers are more able to empathise with other consumers and relate their understanding of what people in a similar position are going through. One participant went as far to say that there should be involvement by consumers on every project that involves mental health.

And there is nothing like hearing somebody else say, in exactly the same words as you, how they feel. And you know, you sort of immediately think ‘yes they do’. They understand exactly what I am feeling, they have used the same words, the same feelings, the same emotions. I think other people don’t necessarily understand that. They can give a certain amount of empathy, but I don’t think deep down they really know the real ins and outs. I think you do need a consumer involved in all projects that involve mental health (CH: 394-400)

Participants recognised and expressed the benefits of association with experienced professionals and the role that those professionals have in providing ongoing support to consumers. Most participants agree however, that in terms of partnerships with service providers in delivering services, there does need to be a balance between the knowledge and skills possessed by service providers working in the industry on the one hand, and the
experiences of having a mental illness that consumers bring to the service system on the other.

... I believe it is now a working together type thing. They help with the training, they help them with the licenses. They let them use the actual P.D.S.S. bus and they also help them gain funding through the local council to run their own place. And I know of two other places that have tried for that... You have got to have a really committed work force of consumers to do it. And as we know in any group, whether it is psychiatric or not, it is always left to a few and a few leave and change circumstances alter (CB: 532-539)

Participants stated that they also needed to feel comfortable in contributing to service delivery and attempt as far as possible to manage on their own. Whilst the majority agreed that there was a need for consumer only run programs, they also realised that there were significant benefits in having providers experienced in group work and management of programs who could step in at a time when consumers needed their assistance to resolve issues that they were not able to deal with themselves. (CB: p. 11)

One participant emphasised the need to have providers lend support to her as she facilitates a self help group. In particular she felt that support was most needed when there were difficult decisions to make related to ongoing participation of consumers within the group. While she also stressed that providers don’t need to be present all the time, having knowledge that there was support available provided added reassurance to individual consumers and the group:

The group I run is basically its own self support group ...

(when I became ill) and being the facilitator of the group,
left the group without a facilitator. So the group started to disintegrate. And what happened was, that the parent body, which had never really been very closely involved with the running of the group ... because they considered it to be a self help group and had left it at being very independent ..., had to step in and pick up the pieces and bring the group back together again. So I think you have to be careful that ....you can have self groups, but when you have people who are likely to have episodes of depression or suicide or anything like that, then there needs to be somebody else in an official capacity who can be there to back it up. I don’t think they need to be there all the time but I think there needs to be that reassurance to the group that, if there is a major problem going on or you have got a personality problem (we have had a number of people within the group that have been very destructive to the group) that they can then come in and act in an official capacity and say ‘you are not suitable for this group and you really shouldn’t be there’. Because I don’t think that is up to the individual to say that. I don’t think it is my role as a facilitator to say to somebody ‘look your behaviour is causing the group to fall apart and we don’t want you to attend anymore. Because that could be terribly damaging ... But I cant just make that decision and I feel that really needs to come from a professional and then the professional could offer them help that is more appropriate to their needs (CH: 414-435)

Another participant also commented on the benefits of consumer run programs with input from service providers on a needs basis:
I do think there is a place for service providers. I think that service providers have skills and these skills are needed. You need nursing skills, you need psychologist skills. And a lot of consumers have spoken about benefiting from these skills, particularly psychologists who are very thin on the ground in the public mental health sector. You need these people. You need psychiatrists and you do need medication because it does keep you well and so you need all of these professionals who can provide these things. Whether we should be employing them rather than the other way around, that might be the way we could do it (CE: 432-440)

Another participant stated that consumers needed direction at times but added that consumers and providers should work together to achieve better outcomes:

I don’t know about that consumers should run the whole thing. That is like saying that kids should run their whole kindergarten. That would be great. It would be really cute and really nice. And I am not being patronising to people with mental illness. But you need some direction some time, everybody does. It is a bit being like the people that are already up there – saying we can do this better than you. We know what we are doing. Let us do it all. Rather than saying, you guys know this and we know this, and we should work together. It is more about working together with the people that are already up there to make it better, rather than take over. ‘I’m not … we should all take over kind of person’ (CF: 616-624)
With the agreement that there were benefits in developing good working relationships with providers, some participants discussed their experiences in the partnerships that have developed with providers as a result of their increased involvement with program delivery over recent years.

For one participant, who wanted to pursue a career as a consumer consultant, getting to know staff better was important so that she could develop a good working relationship:

... I have decided that I really want a more active role in the whole [system] ... almost that I want to pursue a career in the industry. I suppose I would like to maintain some sort of relationships with the staff. Where you can talk about things, for instance, an upcoming job or conferences that might be pertinent (CD: 283-287)

This participant also commented that she felt her involvement was valued by providers:

Not only as a presenter that goes into schools. But we have feedback sessions where we sort of go “well this is working, this isn’t working, I think this should go. I suggest we do something like this and we try it. And my opinion is valued, I believe (CD: 390-393)

In contrast, one participant related what she felt was the ideal in terms of consumers running services and being responsible for programs in their entirety, including the selection and recruitment of suitable staff. In her opinion, when discussing with providers the selection of a position within a particular service, providers were reluctant to accept that recruitment of an individual with a mental illness might add value to service
delivery. Their attitude towards not having this included in the selection criteria was thought to reinforce and highlight the inadequacies of consumers held by some providers:

Yes it is very hard to imagine getting to that point. We recently ... had a position ... an entry level position. And the senior (person) who was promoting this position being formed, came up with a position description for it. And my colleague and I tried to argue that consumer experience should be mentioned on the selection criteria as an added benefit along with an extra language and that sort of thing, that they should throw in consumer experience as a strict term. ... we thought, you are not required to have a mental illness but it is useful if you have had one. And it brings something to the service that would not otherwise be there and it is something useful. It should be taken to be an asset that you have had consumer experience. We failed to get this across. That’s why I think it would be a long hard battle to ever get to the point where consumers were running the area mental health services and employing every one (CE: 473-495)

There were some participants who acknowledged the many changes that have occurred with respect to consumer participation in recent times. However, they also believed that on a number of occasions, there was a degree of tokenism involved in the actual participation in programs by consumers. The challenge was for providers to accept that consumers bring an important perspective to the continued improvement of psychiatric disability support services and other services within the mental health field. There was the belief that this tokenism was partly driven by psychiatric disability support services funding bodies who were placing demands upon service providers to at least include
consumers in areas of planning particularly if their contribution was dependent on this criteria, for example:

\[ \text{I don’t know if there are any left who are really open to it.} \]
\[ \text{It is a token thing and in my view they are using people to nominally satisfy government requirements, when in reality it does not happen} \ (CC: 352-354) \]

Another participant shared the view that although she may be involved with a psychiatric disability support service as a member of the board, she is at times not heard:

\[ \text{Yes, I just think there are lots of people that have lots of really good ideas and things to offer but often are not heard. I continually seem to get that from [name with-held]} \]
\[ \text{... I suppose through representatives like myself or whatever on the Board of Management. I have been told that you are still not even heard at that level} \ (CD: 442-447) \]

And from another participant who also felt that on occasions, although there was a consumer member on the board, other board members spoke in a language that the consumer could not possibly understand:

\[ \text{A lot of people still think it is (tokenism). I am not sure. I haven’t sat in on a Board of Management. I think in some cases, yes, it probably is. I have heard a lot of cases where the other people on the Board of Management are speaking a language that those consumers could not possibly understand and therefore they can’t even give an opinion} \ (CF: 510-514) \]
Another participant, whilst agreeing that tokenism exists within some programs, stated that her opinion as a group member is respected and she is well supported by other members.

*I think to a certain degree [my opinions are respected] but I think it depends on what area you are in. I think some places sort of do it for show. They put a consumer in place to sort of say, ‘we have got a consumer in this program’ doesn’t it look good. But I find that in the group that I am involved with that they respect my opinion and they are very much supportive and helpful towards that. And I found that during my recent problems that they were very good with the group* (CH: 441-446)

**Education and training.**

Most participants mentioned the need for appropriate education and training that needed to be developed in order for the prevailing attitudes within the mental health field to change. Educational programs and curriculums needed to recognise that the involvement of consumers through consultation in design of those curriculums and in the delivery of education and training programs was an important step forward in changing both provider and societal attitudes towards consumers.

The ability for providers to understand and empathise with consumers was seen as a significant criteria in education and training programs by almost all participants. To remedy this, participants throughout interviews reflected on the benefits of having consumers on treatment teams and working within psychiatric disability support services. Consumers brought their experience and knowledge as a result of having a mental illness, and were better able to empathise with consumers and support them in a non-clinical
way. The fact that this aspect of education and training seemed to be overlooked still and how this has affected consumers was succinctly stated by one participant:

... there seems to be something definitely lacking in their training. But I am not quite sure what it is that you do about it. Because as I said to you, they should actually experience this health. It is a concept that is very hard to grasp. But some how we need to change the attitude and stop ... and sort of people realise that it could just as easily happen to them. They could be just as easily a victim of depression or any other mental illness as anyone. And they need to see their patients and treat them as they would want to be treated themselves. And that is something that I have actually carried right throughout my own nursing as a general nurse, is that when I look after people I see them as either my Mum or my Dad or some body close to me. And I treat them how I would like to see them treated (CH: 575-585)

One participant commented on the ‘human aspect’ of the training that clinicians should receive in learning how to support consumers. For this participant, providers needed to be taught how to respond to and support consumers:

I believe because of the types of training that a lot of clinical people receive, the human aspect is taken out. And to get that human aspect back or to override their own personal feelings and a gut feeling of how they know to look after that person or what that person needs, it is not done (CB: 546-549)
Empowerment and the consumer movement.

The situation of merely being a consumer number on a board or any other program simply as a token gesture, received some attention from participants in the context of power struggles and the need for consumers to actually feel more empowered and in control of their own lives. Perhaps more than this though was the need for consumers to be respected and accepted as any other person would be.

For the participant, who felt that her views were valued and respected, (CH: 441-446), participation and involvement in the program as a facilitator gave her a feeling of being empowered. This was particularly so as her involvement included presentation and delivery of a paper in conjunction with service providers, at a prominent conference. She stated that being accepted as a person and ‘educator’, who was capable and competent in delivering services to other consumers, was the biggest compliment that she could receive.

*It does actually. I found that I felt a lot more involved when, (in conjunction with one of the convenors of the program) I was asked to give a paper at two conferences and we did the paper together. I found that that was the biggest compliment that I could receive. That they believed that I was capable of being a competent consumer and educator, the sort of person would come over and put the story and the picture over from the participants point of view rather than just from the carers point of view (CH: 451-457)*

Some participants felt that, to see other consumers sharing roles with professional service providers was empowering in itself because there is a basic understanding by providers that consumers can contribute positively and meaningfully:
... they just have the basic understanding. They are consumers and so they have the understanding of consumers. And that is empowering. To see people in those roles working professionally in the field who are consumers

(CE: 173-175)

One participant commented on what she was hearing at a particular conference where consumers are constantly saying that they want to be more empowered. For her, however, there are opportunities for consumers to be involved in their own supporting network and this is a way for them to be empowered if they chose to go down that path:

When I went to (a conference) I heard lots of consumers and lots of different people talking, and saying ‘but we are not as involved as much as we would like to, we are not as empowered as much as we would like to be’, all of these sort of things and then of course you would see some groups that have set up their own support network

(CD:594-598)

Some participants spoke of the consumer movement and its push to achieve a voice for consumers. Those participants recognised that there needed to be a group of people who as a single force, would assist in giving them a voice. For these participants there was also an opportunity to explain what they knew of the movement.

Well a consumer movement is, as I understand it, is a body of people who have had experience with mental health services, who have joined together to try and improve the service provision for themselves and other people like
them. And it is usually people who are in a bit better health, a bit more stable health but not necessarily. Our meeting of the ... group, sometimes our members had to go into hospital and come back. We have even had one of them rock up to the meeting while she was an inpatient and got some leave to attend our meeting. So you don’t have to be in startlingly great health, but you just need to have been either an experienced consumer or someone who has been a bit removed from it for a while. But I don’t think there is much link to physical health with the consumer movement (CE:381-391)

The same participant felt that the consumer movement offered independence once she was in less need of hospital or psychiatric disability support services following acute illness. She felt that at that time, she was able to focus on improving services with the support of other consumers who became pro-active in their endeavours to achieve better outcomes for all consumers.

I think people in the early days after they have been ill, the psychiatric disability services are the right place for them to be. When it is not long since you’ve been ill you need that balance of professional staff and consumer contact. But I think once you work on past, that if you do get to a stage where you reach a plateau, and you are not needing so much to return to hospital and that sort of thing, I think you are better off getting into the consumer movement and getting more independent (CE: 240-246)
Not all participants knew of a mental health consumer movement however. Those that did and were not consumer consultants themselves, inextricably linked the role of the consumer consultant with the consumer movement. One participant related her knowledge of consumer consultants in terms of what she had known they were doing in the field.

*I must say I don’t know an awful lot about it. I am aware of it through (psychiatric disability support services) in that they have got a consumer consultant and I know he goes to various hospitals and he sees that the various standards are being met and he listens to consumers complaints. But really unless I knew him I would have to say that I would know nothing about the consumer consultants and their role* (CH: 607-611)

Some participants who were aware of the mental health consumer movement and how it is constructed, stated that not all participants wished to participate and some simply preferred to live uncomplicated lives:

*No. Some don’t want to do that at all. Some don’t want to be in it at all really. Basically they want to stay home and they just want to live quiet lives and not really go .... It is about how far you really want to go. They might be at a spot in their life where they think that is where they want to be and you can’t push them* (CF: 469-472)
Summary.

The development and to some extent the evolution of programs delivered by psychiatric disability support services was evident to all participants interviewed. All participants now regarded psychiatric disability support services as common place within the mental health field, even though some did not make a clear distinction between acute services such as the crisis assessment and treatment teams and psychiatric disability support services. This appeared to be attributable to the often blurred recollections of events surrounding participants first encounter with acute services, usually CAT teams, in response to their psychiatric crisis. None the less, their subsequent experiences with psychiatric disability support services and their current association in terms of either active participation and involvement in service delivery or their need for other support and advocacy, has served to clarify the distinctions more adequately.

Participants knowledge of, and experiences with finding out about psychiatric disability support services and how they became to be involved with these services is explained quite differently by many. That they were able to share this information was as a result of having experienced varying degrees of difficulty in finding out about and accessing these services when they needed to.

Most participants agreed that there was not enough information that could enable them to effectively link into psychiatric disability support services either during their hospital stay or immediately following their stay. Even though information, did exist about various programs and services available to consumers within the community, the degree to which it was available or provided, differed enormously from one participant to the next. The degree to which participants received information about what was available to them in the form of community supports whilst an inpatient of a hospital, depended on the hospital and the attitudes of providers working within it as to whether this information was considered a necessary part of the successful transition from hospital to community.
Most participants felt that an important aspect of their effective recovery was to make a smooth transition from hospital stay to community. In order to achieve this, they required appropriate information about the programs and services that were available to them prior to them leaving acute care. In most cases however, there seemed few providers, apart from case managers and some medical staff, who took an interest in organising suitable information and viable options with which consumers could prepare themselves prior to leaving hospital. Participants related their frustration with the inability or unwillingness of providers within hospital settings, to recognise the importance of ‘life after hospitalisation’.

When information was provided, consumers were often expected to identify and seek out appropriate and suitable support services with little assistance from hospital staff. According to participants, their need for acute treatment emphasised that they needed as much support as possible for a number of issues not least of which was assistance with preparing supports in readiness for their eventual discharge.

That not all participants experienced a lack of support in terms of information and access to psychiatric disability support services, reflected the varying levels of commitment by different staff within acute hospitals as explained by participants. The support received by consumers from case managers and workers was positively regarded by those participants who stated that they were fortunate to be allocated such a person. That this particular resource was recognised by participants to be given ‘the advantage’ is perhaps highlighting an apparent need for consumers to be better regarded as individuals with individual needs and that these needs could be better served through regular contact and support from specific people working within the field.

Some participants also described the difficulty that their relatives (carers) had in getting information about what was happening to consumers while they were patients in hospital. This frustration was compounded by the fact that carers were not given much support from staff even though they were obviously trying to support the consumer.
Some participants were able to provide little distinction between acute services and psychiatric disability support services and were therefore of the opinion that they were all interrelated in some way. This was particularly so when the circumstances surrounding their initial contact with mental health services involved such interventions by the crisis assessment teams, ambulance services, accident and emergency departments that provided medical interventions and admission to an acute hospital ward.

The general questions put to participants for discussion allowed them to differentiate between hospital services and those provided within the community by psychiatric disability support services. Most participants stated that they could make a distinction between the services following first admission and only when there was a need for consumers to investigate options for rehabilitation and on-going support once they had left hospital. Those participants who were initially unsure of what psychiatric disability support services were all about or what they actually provided, tended to acknowledge that some services were set up to help consumers achieve a more normal life following their acute episode and hospitalisation. Other participants who were aware of psychiatric disability support services and what they were established to do, also stated that those particular services gave them the opportunity to ‘rejoin society’. The notion of returning to some form of normality was supported by all participants in this group as being the primary function of services and programs run or supported by psychiatric disability support services.

Participants generally agreed that psychiatric disability support services were developed to support them following their acute illness. However, some were convinced that psychiatric disability support services could only be accessed if the individual had a documented history of an ongoing psychiatric illness. For them, there was little or no opportunity for those consumers who did not present with a history of major mental illness, to get support from these types of services. The point of this was that some
participants felt that far better outcomes could be achieved for consumers if they were able to access psychiatric disability support services before the onset of symptoms or illness occurred. In this context it was also felt that although psychiatric disability support services were in a position to support consumers with their disability, and this was distinct from acute services, there was little collaboration and understanding of the overlap that the two types of services share.

None the less, even though participants were not always entirely sure of the services they could receive through psychiatric disability support services, they were certain of their understanding of what should be available to them as people who live with an ongoing disability. They were also sure of what they wanted to achieve through their association with psychiatric disability support services and to what extent these services were able to best meet their needs.

Some participants were of the opinion that psychiatric disability support services provided them with the families that they did not have and that for the most part, these services were there for them if and when they needed to use them. There was a general view shared by almost all participants that the informality of services created an environment of acceptance for every person and this made them feel much more comfortable about themselves and their illness.

There was also a consensus among participants that because of the nature of mental illnesses, consumers often found it difficult to socialise and reunite with friends. The continued need for informal social gatherings of consumers such as drop in centres, where they could support one another gave consumers an opportunity to make choices about their level of participation. Additional opportunities for participation and involvement with psychiatric disability support services came in the form of consumers being involved with development, design or delivery of services. This could occur either as representatives or facilitators of support groups, representation on committees to
actually being employed as consumer consultants. Whatever the level of participation, participants were all of the view that they should be allowed to contribute at a level with which they felt comfortable and one where they had exercised a choice.

Participants were asked to comment on the roles and attitudes of providers. Consistent with the view of some participants regarding the difficulty to make distinctions between acute and disability support services, participants found it necessary to comment on the attitudes of hospital staff as well as those providers working within the psychiatric disability support service sector. For these participants, there was a relationship between their experiences in hospital and the way that they perceived psychiatric disability support services. From the point of view of capturing the concept of their understanding of mental health services overall, discussions about the treatment they received in hospital placed in context the way that some consumers viewed psychiatric disability support services. Most participants commented negatively about their stay in hospital mainly from the point of view that staff did not provide the support that consumers expected. There was also the opinion that staff attitudes reflected that patients were just nuisances and participants described some hospital staff as lacking genuine knowledge and regard for them and their complicated issues as they recover from their mental illness.

One participant stated that he still believes hospital wards to be gaols and that he had not been to an acute unit yet that was effective. Participants commented that they believed the poor treatment they received was as a combination of lack of skills, inadequate training and inadequate staffing numbers.

Of significant note was participants’ belief that the attitudes of providers within psychiatric disability support services was to some degree an extension of the attitudes that prevailed within the large hospitals and one they had experienced over time. Although only one participant specifically stated that he was displeased with psychiatric
disability support service providers, the remainder had mixed experiences with providers in different services. Importantly, some participants acknowledged the evolution of psychiatric disability support services and the fact that it was also difficult for providers who were once a part of the institutional settings to now radically change the way that they view consumers and provide services. In one particular participants’ experiences, although change was occurring slowly, there was a need for a review of education and training and a complete paradigm shift by providers for a complete and successful transition from the concept of institutional care to community services. It should also be noted that consumers involved in the reference group and who were actively involved in service delivery as consumer consultants, were also of the opinion that psychiatric disability support services risked the potential of becoming institutions in their own way, with the only difference being that there were no physical barriers present.

Participants generally felt that they ought be able to participate in the development and delivery of services if they so chose. According to participants, the extent to which they should be included in service delivery at any level was dependent on a number of factors including level of functioning, personal choice and what they felt they could contribute. The fundamental criteria that assisted consumers to be involved was seen to be the mechanisms or processes that should be established to allow the inclusion of consumers in service and program delivery. There was not always a clear process available or advertised to consumers and this needed to be rectified if more consumers are to be given the opportunity for greater involvement. One participant drew distinctions between those consumers who preferred to simply accept services as they are delivered believing that for these people there was no desire to be any more involved with programs and services than they had to be, for their own purposes. The second group she described as consumers who were aspiring to become as involved as possible and who wanted to go on and learn about how best they could contribute to creating better outcomes for consumers. Her understanding of the choices that should be available to consumers within the mental health service system, perhaps parallels what is already occurring in
our society where individuals have a choice about their goals and make these choices in the context of their limitations and means.

All participants saw the need for some consumer only run programs but added that it was appropriate for providers to support them in times of crisis and for some direction. They agreed that consumers and providers should be working together in partnership where consumers are valued as equal members of a team. Some participants stressed this relationship and felt valued as a result, although there was also the opinion that there still needed to be the realisation by providers that consumers are capable and could become members of a treating team or support team. This was an obvious barrier that still exists for some participants however. Participants related these barriers to the attitudes of providers who they believed did not wish to accept that consumers could bring their own experiences and knowledge of mental illness and subsequent disability. Some participants also referred to their participation as token gestures suggesting that their involvement may only have occurred as a necessary function of funding allocations and government rhetoric.

Although not wishing to sound derogatory one participant provided the analogy that allowing consumers total control over programs would be like allowing children to run their own kindergarten. Although this is a rather simplistic view, it does highlight the vulnerability that some participants feel, should they be expected to take on such roles as a matter of course. This participant further qualified her statement by adding that she felt everyone needed some direction at some time.

Education and training was discussed by participants in the context of changing the prevailing attitudes of providers that they believed still existed. An important ingredient that some participants felt was missing from essential education and training course that are supposed to prepare and equip providers with the necessary skills to support consumers was the notion of empathy that many felt through their experiences, was
conspicuously absent. Participants felt that this skill needed to exist inherently and were not clear on how educators go about instilling this in providers. They reiterated that to have experienced a mental illness was by far the best education but also realised that there needed to be a way where providers, in the absence of a lived experience, could achieve a better understanding of consumer needs.

It important to point out that the concept of having empathy for what consumers are experiencing is not new and has been included in psychiatric nursing texts for several decades.

*Empathy is the capacity for participating in or vicariously experiencing another’s feelings, violations or ideas (Rowe 1984, p. 61)*

None the less how educators relate this essential component and associate it within the process of recovery and support for consumers appears to elude them. One participant summed up his experiences and spoke of the ‘human aspect’ that for him was missing in the relationship he had with providers.

The concept of providing unconditional support to consumers is not new and has been a part of the curriculum for psychiatric and other nursing students for some time. The connection with providers inability to achieve this appears to be a result of the organisational cultures prevalent within the large mental health institutions and documented in the many reports into the treatment of persons with a mental illness. (Human Rights and Equal Opportunity Commission 1993).

The issues surrounding consumer participation and involvement in service development and delivery were synonymous with their struggle to achieve acceptance and to be valued. All participants felt that they would like to be accepted by providers in a way that
empowers them to take control and responsibility for their own lives. As discussed by participants there were degrees in terms of the ways that this could occur, particularly as consumers agreed that support and guidance by professionals who possessed appropriate knowledge and skills, was desirable. However, to be accepted at a level where the involvement by consumers is seen by providers as an asset to the services and programs was according to one participant the ‘biggest complement’ she could receive.

There was considerable support from participants regarding the need for them to be involved with their own consumer movement. Whilst not all participants understood fully what the mental health consumer movements activities were, there was a general consensus that there needed to be a group of proactive consumers who could give consumers a voice and represent all consumers with the objective of improving service provision. In relation to this, consumer consultants were linked to these activities as most participants recognised that the role has been developing in recent years and most participants have had some sort of association with those in the consumer consultants role.

In chapter 9 the experiences of carers is discussed and analysed. In particular the relationship that carers have with consumers and their association with services as they attempt to provide support for consumers is explored.
Chapter 9: Experiences and Opinions of Carers.

Introduction.

Prior to interviews carers were provided with information explaining this study psychiatric disability support services and in material distributed to delegates at a mental health conference.

Whilst carers were given the same opportunity as consumers to volunteer their time for in-depth interviews only five carers stepped forward. They were all enthusiastic about the opportunity to share their experiences about their involvement with the mental health service system. All also stated that they were primarily interested in contributing to any positive changes that their participation may produce in particular better outcomes in the relationships that they have with consumers. Other factors that contributed to their willingness to participate included a desire to achieve more support in their role as primary carers. Most carers indicated that providers needed to gain a greater understanding on their involvement with consumers and the difficulties they faced in their caring role from day to day.

Brief encounters with carers who did not participate in in-depth interviews.

Attempts at active recruitment in the form of canvassing carers did not provide a suitable response as those who were approached did not wish to participate to any degree. Whilst in-depth interviews were not able to be conducted, the often brief discussions with this group did yield important information that was substantiated by almost all carers contacted and also those later interviewed. Those responses are briefly outlined below and contribute significantly to a better understanding of the frustration that these carers stated they experienced. They felt that not much has changed in the time that they have been involved with someone who has a mental illness or psychiatric disability and they explained that their efforts to do so went relatively unnoticed by providers in any case.
This group therefore all responded with similar reasons for not wishing to participate and these have been briefly outlined below. They included such issues as:

1. Feeling despondent about repeated attempts to gain more information about the consumer. Carers who indicated that they had had difficulty in obtaining information about their carer role and options for support also stated that they had only managed to secure information through a lot of individual research of options that might be available to them. The early stages of their involvement with consumers proved to be the most difficult as many explained that they were left to manage unaided under extremely trying circumstances. This was particularly so in carers endeavours to gain a better understanding of what was actually happening to the consumer as a result of the consumers illness, and how to best manage the situation in the absence of any substantial support.

2. Not being informed about the consumers progress due to confidentiality and legislative requirements. Once carers had moved through the initial crisis in assisting consumers to manage their symptoms, with some support form the crisis teams, they experienced ongoing difficulty in accessing further information from providers. In particular, providers often stated that they were not able to divulge confidential information about consumers, even to significant carers, unless they received express permission from the consumer. As communication between carers and consumers was often diminished, according to carers, their role became even more difficult as the consumers psychiatric illness and subsequent need for psychiatric disability support services increased. Carers felt that they were not included in discussions about treatment options, discharge planning or given vital information about what consumers were planning for their future in light of their subsequent disability.

3. Carers felt that the frustration they had explained earlier, coupled with their belief that there is an unacceptable lack of resources for consumers particularly transitional and
longer term accommodation, made them sceptical of this research that claimed their may be benefits in recording their responses. They felt that they occupied a position of powerlessness when crisis developed, and they have difficulty accessing treatment and support services despite their repeated attempts to do so.

4. This group of carers also felt that to become too involved with this research may compromise their already fragile relationship with consumers. They did say that when the consumer is well enough, in their opinion, to manage their symptoms such as being compliant with medication and attending scheduled medical or rehabilitation appointments, most consumers wanted to be more independent. This meant that they should take a step back and not be caught up in additional involvement with providers or people conducting research lest they strain the relationship and make it difficult for future involvement in crisis situations. Discussions with individuals in this group about confidentiality revolved around their need to pass on what they considered to be vital information about the consumer and which would assist treatment teams in supporting consumers. Their preferences for providers to treat this information sensitively was on many occasions not adhered to, also affecting their relationship with consumers.

Whilst some carers who did not wish to be interviewed did provide some feedback about their personal experiences during the brief telephone encounter, and these were noted as above, it was not possible to gain an in-depth understanding of their grievances in a similar way in which those carers interviewed were able to. Rather, this data proved useful in further probing carers who attended the in-depth interviews and provided considerable avenues of exploration during these sessions.

**A definition of carers and the caring role.**

It is recognised that a variety of positions that provide care and support to people who have a physical or mental illness exists. There have also been varying explanations and
position descriptions developed to outline what carers actually do. It is necessary here to provide some clarification on the activities of carers of people with a mental illness to place their role into perspective.

The Macquarie dictionary provides a succinct definition of the term care, however, it does not clearly translate into the functional aspects of the carers role as it is practically known. Indeed the term carer cannot be found. None the less providing a dictionary definition of the term care will assist in understanding the literal meaning and how it can be expanded to form the word carer.

*Care. N …do all that is required for child, invalid, feel regard for, be concerned* (p. 116)

The Carers Association of Australia provides a relatively uncomplicated description of who carers are and what they do and although their statement includes caring for people with a mental illness or psychiatric disability it is not specific to that group:

*Carers are usually family members who provide support to children or adults who have a disability, mental illness, chronic condition or who are frail aged. Carers can be parents, partners, brothers, sisters, friends or children. Some carers are eligible for government benefits while others are employed or have a private income.*


In the United Kingdom, a national charity called the Princess Royal Trust has been established to provide training and support for carers, as well as raising funds for development work. The trust provides a definition of who a carer is but also expands this to explain the carers’ lot:
A carer is someone who, without payment, provides help and support to a friend, neighbour or relative who could not manage otherwise because of frailty, illness or disability. Most carers would still not recognise themselves under the term 'carer'. They are just people trying to cope as best they can while helping to look after, for example, an elderly relative who has developed Alzheimer’s, a partner with Multiple Sclerosis or a young child born with cerebral palsy. They may even be juggling paid work with their unpaid caring responsibilities at home.

(http://www.carers.org/new/html/default.asp)

The DPS Guide to care at home circulated in Victoria, is a publication that provides information to carers about the various services and products that are available to them within the community. The guide uses plain language to explain what is available. The publication explains carers in the following way:

If you are a person that is the helper you may consider yourself a husband, wife, brother, sister, son, daughter, neighbour, nephew, cousin, niece, friend, lover, partner, relative or employee. All of the organisations that you approach will consider you under the one banner of carer. A primary carer is the person who has taken up the task of doing most of the helping. If you assist a carer or do some chores then you may be referred to as a secondary carer or simple carer. (DPS, p. 9)
For the purposes of this research, carers have been determined to be those people who have identified themselves as the primary supports and advocates for people with a mental illness and or psychiatric disability. They are neither paid employees or volunteers but rather those people who have been caught up in the system as a result of their relationship with a significant other person who has a mental illness or psychiatric disability.

**In-depth carer interviews.**

Carers who did wish to be interviewed, voluntarily gave an account of both the issues that those who did not want to be interviewed raised as well as their additional positive experiences and perceptions of the acute and disability support services with which they are involved. It is possible therefore that responses from this group may be more likely to give a more acceptable account of those service systems discussed.

It is significant to note, however, that all carers, that is, those who responded briefly by telephone with reasons for not participating, and those who were prepared to be interviewed, all took the opportunity to describe the events leading up to their necessary involvement they had with consumers. Some of these responses were detailed and were generally about the shock and disbelief they had experienced when they discovered that their adult children had a mental illness and would require ongoing medication, rehabilitation and support. The in-depth interviews conducted with some carers commenced with them describing how they first came to be aware of symptoms and the behaviour that consumers displayed. Their own perceived lack of understanding of the behaviours associated with mental illness and subsequent psychiatric disability, created a stressful and difficult time for them as they began to cope with what was happening to the consumer and they were keen to share this aspect of their experiences fully.
The purpose of this chapter is to provide a discussion of the issues that carers wished to raise about their experiences with psychiatric disability support services in relation to the following themes.

1. Carer’s experiences in their current role as carer and support for the consumer and their relationship with consumers.
2. The perceived relationship between carers and consumers.
3. Carer’s views on acquiring information, contact and introduction to services.
4. Carer’s understanding of psychiatric disability support services and how they operate.
5. The roles and attitudes of providers.
6. Carer participation and involvement in services.

**Carers experiences in their current role as carers supporting consumers.**

**How carers became carers.**

All participants interviewed were keen to discuss their experiences. They were asked about their role and what being a carer for someone who has experienced or is experiencing a psychiatric disability meant to them. Although there were a number of different responses to what actually constituted the role of a carer, all participants individually interviewed stated that being a carer was not a choice they had. The role was thrust upon them as they were faced with having to deal with someone close to them who was experiencing a mental illness.

... *us carers in the mental health, we are never asked to become a carer – it is thrust upon us by whoever it is being sick or the government I suppose and I don’t want to be political about it. The system that should have been broken down, the old system of institutions and stuff like that. And I do think they should do a bit more and might come out a*
bit later. But I must say it was thrust upon us, the wife and I (Carer V: 8-14)

Another participant responded similarly:

I didn’t want to become a carer, it was thrust upon me and I still don’t like being a carer. I would rather have my son back the way he was before he got ill. I haven’t put me hand up as I say, I had it thrust upon me (Carer Y: 66-69)

Although these two participants made clear statements about the lack of choice they had in choosing to become carers, other participants including those within the groups also felt that becoming a carer was a role that they had to accept because of their responsibility as a parent.

Additional responses about what it meant to be a carer reflected the need for carers to be able to be with the consumer 24 hours a day when they are in a crisis or acute phase of their illness. Participants felt they needed to be there for the consumer when they were in crisis and to assist them through this period often without the assistance of health professionals. One carer described how he does spend all of his time with the consumer during a crisis and this is what it means to him to be a carer:

But as for being a carer – what does it mean to be a carer. Well we care for our son. He becomes sick with a mental illness and we don’t fully look after him now but while he was in a crisis we were with him 24 hours a day and 7 days a week for 5 years of it (Carer V: 16-19)
Another participant summed up her role and what being a carer meant to her, describing the many roles that she has:

*With my limited amount of experience, what I am trialing at the moment is we have to be the person that assesses and evaluates and you have to try and be the parent, doctor and sometimes the psychologist in trying to understand what is going on with the patient – being the family member for me* (Carer W: 5-8)

And similarly:

*I am basically trying to pick up the pieces and help them with everything that has happened. (They) need constant support ... needs me. I have tried to pull out of it but I am his major support person* (Carer X: 13-16)

Similarly, another participant described being on the front line because she felt that, without her support during a critical time, there are not the health professionals available all the time:

*To be on the frontline. The cavalry doesn’t arrive to be honest. The cavalry being people (who) are the professionals* (Carer U: 3-4)

Other participants also described their support for consumers as being on the front line or providing the initial support until other professional help is either found or available. In general, all participants believed that they had a responsibility to be there when the
consumer needed them and many stated that they at times needed to provide continual support over 24 hours.

The personal impact of being a carer.

That carers spent much of their time supporting consumers particularly during acute episodes or a crisis, also meant that they had little time for themselves and their own pursuits as well as for other family members. One participant articulated the significant impact her role as a carer had on her life:

*I didn’t choose to be a carer. I’d like not to be a carer. It really impacts on my whole life. I have got no life. I tried to go away ... (for a) holiday and ‘my daughter had an episode. So partway through the holiday I was having these calls about what was going on... I had to come back. I can never virtually go anywhere without them contacting me or me having to ring to see if everything is alright or what is happening* (Carer X: 28-34)

While all other participants were asked to respond to the impact that caring for someone with a psychiatric disability had had on their lives, most responded similarly to the previous carer but also reinforced that they did not have a choice. All other participants without exception indicated that their lives had changed dramatically as a direct result of their caring role. The ways that impacted on participants as a result of their role also included a financial burden that they felt they were required to bear. This financial burden was often created and directly related to the activities of a consumer when they were unwell.

A number of participants stated that their health had been compromised as a result of their caring role. Whilst the physical demands of spending a great deal of time with
consumers was commented on, providing services for consumers such as transport, organising activities and constantly being vigilant about the possibility of relapse also placed significant stress on carers.

On most occasions the stress carers experienced related particularly to the times when the consumer was suffering another relapse of symptoms, however the often unpredictable behaviour of consumers also contributed. Whilst participants stated that the stress eased somewhat following acute episode and when both their lives and that of consumers approached a sense of normality, there was an ongoing need for carers to seek treatment themselves often to the extent of requiring antidepressants. (Carer V: 690-697)

One carer stated that at times she felt suicidal because of the situation with the consumer and that all issues including lack of support and recognition from providers contributed to her state. (Carer X: p. 15). The extent to which participants received support and the perceived recognition they received in their role is discussed further in a later section of this chapter.

**Parents as significant care givers.**

All participants, except for one were currently caring for adult children. Although they were all conscious of the fact that they were currently supporting consumers who were young adults, some explained that they had a responsibility as parents, to provide support and to care for their ‘children’ whom they felt needed their help. One carer stated that there is a conflict with being both a carer and a parent because the relationship he had with his son as a parent was less effective than his son’s other friends.

*Trying to be a better parent and carer we knew was our responsibility. Unfortunately there is a conflict with being a parent and a carer because he has good friends who have supported him and they get on much better with him than I*
do with him. I think I put in a lot more with his life than they did but I am very grateful that they exist anyway. But it is always more difficult for dad to say “look son if you are patient your medication will help you, if you keep taking it ... the medication will maintain It” (Carer T: 139-146)

Another carer also commented on the difficulties of having both the role of a carer and parent of an adult consumer:

Of course by being the parent you have the problem that he is a 25-year-old person, he is not a child – it is very difficult to say you must take these tablets when they think there is nothing wrong with them. A little bit of support to the carers would have been all right (Carer W: 118-122)

Carers perceived relationship with consumers.

The relationship that carers had with consumers, varied depending on a number of factors. During the initial stages of a consumer’s acute illness, for most participants the relationship deteriorated rapidly with the resultant need for hospitalisation and treatment. Even during and following recovery for some participants the relationship did not recover to the pre-illness state. Others agreed that supporting their child through the initial phase of an illness was the most difficult period, but that the situation tended to improve.

One carer commented on the good relationship she had with her son prior to his mental illness and how this relationship changed significantly following his acute episode. It was particularly difficult for her as she stated that as her relationship with her son was deteriorating, she felt she was not getting the support she wanted from providers who she believed failed to assist her son in better understanding what was happening to him:
[My son and I] have always been very close. He came to me when he had a problem. When he first became ill and went into hospital he absolutely hated me and he hated me forever more. He wouldn’t talk to me there and it was extremely hurtful because we weren’t getting any help from the doctors to help him understand what was going on and why we had to do certain things and that is where the communication barrier fell down. The doctors and nurses weren’t helping and they weren’t helping us because there was this antagonism but I kept going to the hospital and keeping my distance and ensuring he was O.K. And again I lacked confidence in his care (Carer W: 365-373)

Other participants within the group commented on the issue of acceptance by consumers as they attempt to support them throughout their recovery:

Some consumers don’t think carers are any good at all, they don’t want a bar of them. They probably don’t want them to know anything, others appreciate the support they get from carers ... (Carer Z:422-424)

And also:

What happens when a person has a relapse they quite often develop an intense hatred for the person that’s caring for them. ... they don’t want them involved... I’ve heard that many times (Carer Z: 429-432)
Following on from an initial crisis, participants believed that they were there to ‘pick up the pieces’ and to assist consumers to return to a normal life. They believed that it was necessary for carers to understand how the consumer might react to them organising treatment during a critical period of their illness, such as when the consumer is experiencing severe psychiatric symptomatology.

Not all participants believed this was a lasting attitude for consumers. One carer stated that he believed this attitude only prevailed during the very acute phase of the consumers illness and that the consumer understood why the carer had been involved in organising the CAT team or hospitalisation. The consumers behaviour reflected his serious illness at the time. Following the acute episode he believed that the consumer became more understanding of his actions:

... I think deep down they recognise that though in a lot of cases the consumers are abusing the carers or parents; “you’ve put me into this rotten joint and you know, I hate you” and all of that but that is while they are sick but when they are on their good side they appreciate what you do for them I think but it mightn’t come across as that in those terms but I think they do ... (Carer Y:85-90)

Another participant commented that when the consumer was not in an acute phase of an illness she was accepted as a carer well. However, she would often be abused when the consumer was unwell and required acute treatment. She also stated that this was because she was the first one in the’ firing line’ so to that extent the symptoms of the consumers illness would be vented on her as a carer:
They accept it extremely well when they are well. When they are unwell, I am the worst in the world. I get called everything. I am the first one in the firing line of being abused, verbally. That is hard too. I mean you know that they are not well but you can only listen to. You know it is hard ... I am a fairly calm person, I let it go over my head and I just ignore it. The last time I think I just had to walk away. I had to get out of it (Carer X: 112-121)

In addition, and supporting what other participants had stated earlier, this participant also believed that the consumer in most cases, did not realise what they may have said or done and in her experience, the consumer became remorseful at his actions and conduct following an acute episode:

I don’t really think they, a lot of the time, even realise how much or what they have done. [My son] is always very sorry when he does anything to upset me (Carer X: 126-130)

Carers views on acquiring information, contact and introduction to services.

When participants were questioned about how they found out about psychiatric disability support services and how they came to be in contact with these services, most responded that there was a lack of useful information available to them. They described being given information in the form of pamphlets with little follow up support or explanation about accessing these services and which services may be the most appropriate for their situation:

Well the interesting part about all of that was that when [consumer] was unwell in hospital we were told there were
all sorts of services available. We were told this by the mobile team. They handed us leaflets and at the time we were under so much stress the last thing we wanted was a whole lot of paper work thrown at us. We had no idea what was going on. The doctors couldn’t tell us anything so they meant absolutely nothing to me. I stuck them all in a folder and thought one day I will look at them. We didn’t really get any help from any of the doctors because we couldn’t communicate with them for a start, they had no idea where we could go to… (Carer w: 90-98)

This participant also stated that even when she was in a position to make contact with those services she felt abandoned because providers did not contact her. This reinforced the notion for her that consumers would struggle on their own without the essential care and support provided by her as a carer.

But what I find with a lot of those services is you ring them and you hit a brick wall. It doesn’t go any further. No one ever calls you back or follow up. So you are really on your own so I really believe if it wasn’t for my husband and I looking after our son God only knows where he would be now. I feel really distressed about kids that don’t have parents or family to look after them (Carer W: 102-106)

Another participant voiced her frustration with the service system as she too felt that responses to her request for assistance were not received on a number of occasions. In addition, she felt that when the consumer contacted services herself because she needed support, providers assessed that the situation did not require immediate intervention stating that the consumer did not sound bad enough for them to come. This showed a lack
of understanding by providers but also, in the opinion of this carer, that services were too busy to respond unless the situation was critical. (Carer X: p. 5)

*I try and say that if [my daughter] rings it is a cry for help. It is a crisis. I cant understand why. I suppose I do because they are so busy, that’s what they keep telling me. We have all these people ringing and we cant… Surely if you have got computers and things now, you could look up and say oh … if she rings it means that she needs help* (Carer X: 190-194)

Most participants agreed that often their contact with providers proved to be frustrating because they were unable to convey successfully that their child needed help. All agreed that the technology that providers now have available to them keep accurate and up to date records of consumers was not being adequately used. They felt that providers should be aware of the needs of consumers in relation to the triggers particularly also as many consumers and carers are well known to the system.

**Confidentiality and the rights of carers – a two way street.**

Participants discussed their additional frustration with providers who they stated were reluctant to share information about the progress of consumers. Most participants cited the reasons as issues surrounding confidentiality where providers had stated to them that they were not in a position to disclose information about the consumer. Providers qualified their reluctance to provide information about consumers by advising carers that to do so would be unacceptable to consumers who were protected by privacy laws. In addition providers had stated to carers that any breach of confidence would undermine the relationship that they had established with consumers. Participants stated that this was in no way a reciprocal arrangement as they were prepared to provide information to
providers in an endeavour to ensure that consumers received appropriate support and treatment for their symptoms. (Carer Z: p. 11).

Participants were prepared to discuss their concerns and issues with providers in an endeavour to assist consumers to recover and to assist in developing the relationship between the consumer and provider. However, their requests for some information not to be passed on to the consumer, lest it cause increased friction and compromise their already fragile relationship with consumers, often went unheeded.

One participant remarked that the issue of providers disclosing information despite an agreement that she had with them that it would not, was her main problem with the service system:

My main problem was that because my daughter is who she is, she gets her files. She FOI’s (freedom of information) her last file. My main problem was that anything that I say to the nurses or the doctors they put in the file and [my daughter] gets it back and I get it thrown at me. I have a big problem with that! Because I say to them there is a lot that I want to tell you about what [my daughter] is doing but are you going to write it down. I don’t think it is actually fair that they should give [my daughter] stuff that I say because I have rights too. But they don’t seem to listen. She got the whole file that just had everything that I had said the last episode. ‘Your mum said you are doing this or that’. So what that does is that that makes you really reluctant to speak, to say... I got desperate last time I just had to do it anyway otherwise ... (Carer X: 280-290)
When this participant had further discussed the issue with providers, requesting that sensitive information not be passed on to consumers, providers agreed to comply. However, as this carer pointed out, their was a distinct lack of communication between providers which meant that her request had little impact:

*Well you might get one that says alright but the next one forgets. Or it is not in the communications. It is not passed on. Like we came to an agreement ... It is sort of like you are hitting your head on a brick wall* (Carer X: 304-309)

Some participants stated that they were actually putting themselves at risk by sharing information about the consumer with the service provider. Although they realised this, they felt that they were in a position to be able to provide the treating team with information that may be vital in the correct treatment of the consumer.

*What I’ve done in the past is encouraged other carers to do ... if confidentiality is required and the person they are caring about particularly in a relapse stage, they don’t want anyone to know what’s going on, the carers have relative information, you know really important information as to the things that that person is doing, and sometimes it is a matter of being dangerous, they need to get that across to the treating team* (Carer Z: 443-448)

Participants also realised that there were occasions when it was difficult to discuss issues with all parties present.

*In real practice it is sometimes impossible to have everything out on the table. If you are going to go home*
and live with somebody, you know and they’ve got their hands around your throat because you told the doctor something that he wasn’t to know and they are not stable
(Carer Z: 473-476)

Although participants acknowledged that consumers were entitled to privacy and confidentiality as a basic right, the situations with which they are faced in caring for consumers made it necessary for them to have access to information that would assist them in caring and providing support for consumers as well as gain a better understanding of what consumers might be going through.

One carer stated that he believed there had been a breakthrough for carers in relation to being able to receive more information from providers about the consumers current mental state and that he felt the law had made this a right for him as a carer. It also changed the relationship he had with certain providers:

*I think ARAFEMI had a wonderful breakthrough back in the 80’s when they got the law changed which said that health services were able to give information to next of kin whereas before that it must have been quite difficult. So once that acceptance that there was a right for carers to have information, that seemingly changed the relationship with the psychiatrists and psychiatric nurses* (Carer T: 571-577)

One participant within the group stated that he believed that carers also have rights as the primary care giver to know and understand the condition of the consumer:
If they’re going to be the primary carer, they have rights to know … to have information about the condition or current mental state of the person they’re caring for you know… I think this confidentiality rule has got to be looked at…
(Carer Z:494-498)

And:

I mean carers have rights and needs as well. I mean if the doctor knows that there’s a real sort of hatred towards one of their carers or they maybe unsafe or they might ………go off their medication, that person’s safety can be really jeopardised (Carer Z: 480-483)

Carers understanding of psychiatric disability support services and how they operate.

When participants were asked about their understanding of psychiatric disability support services and how they operated, responses generally included their knowledge of all services from in-patient facilities to CAT teams and case managers. No one carer responded with a succinct explanation about psychiatric disability support services and what they offered. For participants there seemed to be little distinction between acute services and those offered to support people with a psychiatric disability. One carer stated that some providers try to do their best for consumers and this seemed to sum up for him the extent of services delivered, that is, those providers who cared and those who did not.

In my experience I have dealt with the public system as far as my son is concerned, however my wife is a sufferer as well. Probably going back to post natal depression why we didn’t recognise it. She saw a private psychiatrist. But as
we focus on the consumer and my awareness. There are people there who try to do their best to help sufferers of mental illness. It is the question of the interface and how they find the service and how they deal with the service (Carer T: 5-10)

Participants were also of the opinion that the relationship they had with providers was important. They would generally not be able to manage on their own and needed the support of professionals. For one carer, there was a need at times to lobby the CAT team to get the support and assistance that he required, but he stated that he felt it would be almost impossible for him as a carer to support and care for a consumer on his own:

It is almost impossible to do it on your own. We have on a couple of occasions had to lobby the CAT Team a bit hard to get them to make contact and I remember on one occasion they did come and went out the front and they drove away again... Now that was fine at the time but I remember my wife saying at the time we really weren’t crying wolf. When they finally came and said yes he does need support and needs to go into (hospital) .... He went voluntarily and that wasn’t a problem (Carer T: 259-266)

Other participants agreed and stated that the partnership with providers was essential in achieving better outcomes for the consumer, particularly as carers became more aware of the different ways in which psychiatric symptomatology manifested itself and they (carers) needed to learn strategies in dealing with these changes.
Support for Carers.

One carer stated however, that there was not sufficient support for carers themselves from providers because providers were more focused on care and support for the consumer and tended not to realise that the carer also needed support. Whilst participants stated that they certainly had no problems with consumers receiving the best possible support and this was as it should be, they also agreed that there was a real need for carers to receive professional support in their caring role. Among the reasons stated was the belief by participants that providers were satisfied with the support that consumers, who were fortunate enough to have carers, were receiving from carers. It was thought that service providers were turning their attention to and providing more support for consumers who did not have carers.

One carer shared her opinion on where services are concentrated. She determined that providers considered that a carer who was willing and able to provide support for the consumer required less interventions and support from other services and therefore she as a carer received less support and attention:

This could be totally wrong – I sometimes think that if people have nobody, they probably get more support from the system than if they do because I think because of the shortage of staff ‘oh they have got a caring parent we don’t have to put in so much support’ so I think it goes against you in a way (Carer X: 66-69)

One carer gave a number of possible reasons for the obvious lack of attention that carers received from providers including the belief that some carers may present as too demanding.
It is a big ask for them to be concerned for the carer but I think it is probably easier for them to look after the consumer. You could imagine some of the carers might be difficult. Maybe they see us as difficult, not helping. I am sure they would have liked us to have established more discipline in our family situation with our then 30-year-old son. I have said to them we have this crisis and you are the CAT Team, and their answer would be for us to get in touch with ARAFEMI. I think also they are dealing with many consumers who are completely alone, don’t have any support at all. So at the end of the day they know there is a roof in place and meals are there, transport, telephone and money, that we do have those services available for him

(Carer: 357-366)

Consumer run services.

Participants were asked about the benefits of consumer only run programs and services. Specifically they were asked whether consumers should be responsible for their own care and treatment, managing their own symptoms, and whether there should be services run for consumers, by consumers in their entirety. In the opinion of consumers their involvement at this level (as discussed in chapter 8), apart from empowering consumers, it creates opportunities for them to achieve changes to the way that programs and services are delivered. Most participants agreed and some expressed the desire to see their son or daughter more actively involved in service development.

One participant stated:

*Excellent and good luck to them. Through ... the carers group we in fact, are in touch with local consumers as well.*
We know a number of them and we meet them regularly and many of those are quite active in the services. I wish my son was like that but he is not. He doesn’t want a bar of it (Carer T: 458-462)

One carer responded quite differently. He was of the opinion that during a crisis, consumers were not able to take responsibility for themselves and as they moved through their illness towards recovery, there was still a lack of insight into their condition. For him, when recovery did occur there appeared to be no acceptance by his son that he ever had an illness, which further strained the relationship:

In crisis time they need to be probably locked up or whatever the case may be so they don’t do harm to themselves ...right. As they go along I think they get that opinion that there is nothing wrong with me, I have been unduly forced into taking this medication. I have been forced to stay in there (a psychiatric facility) I have been forced to sign the community treatment order and I have been forced to do this and I have been forced to do that ... I believe they are not well at the time when all this is said (Carer V: 504-510)

This participants experience led him to believe that there was no place for consumer only run services as consumers were not capable, during most of their period of illness, to make decisions or organise services.

The role and attitudes of providers.

The relationship that carers have with providers has been briefly discussed in the previous section. As stated, all participants agreed that it was important to have
confidence in providers who were involved at various stages of the consumers illness and rehabilitation. Participants responses to specific questions about the attitudes of providers differed significantly from one carer to the other and within the group. One carer stated:

Oh well it’s like everything. You’ll get good ones and bad ones. And I think you are lucky if you get a caring case manager and a caring psychiatrist and generally a carer type, a caring type and then you’ve got the ones that are just, oh I don’t know I suppose in for the money (Carer Y: 466-469)

And:

I do think that the service providers or clinicians are getting more into understanding carers ... they want to know more about the carers and their roles too ... and I think it’s slowly changing ... There is a big change there ... I think they are getting into that. They’re realising the carer is such a vital person because I had the CAT Team ... And they would say, look we can take you to the flat and try and explain to (the consumer) ... you know. they haven’t got carers and they are stuck in a room and you know they’re case managers have got to go there more and more ... if they had the carers they’d know what’s happening ... and the carers are starting to understand their problems. Like partnerships ... if it’s not a two-way partnership, it’s not going to work (Carer Y: 513-527)
Whilst some participants were satisfied that providers were providing adequate support, other participants agreed but also stated that it was necessary for them to actively pursue providers in order to achieve the outcomes they required.

*I suppose they vary. I think mostly they think that I am over protective mother. I don’t know. The case manager that [my daughter] has now is actually quite good. I am saying something positive. But we had to really almost demand that she have the case management. [My daughter] quite likes her so that is good so hopefully she will ring her. But I rang her when I was worried about her and nothing happened but maybe she was too busy* (Carer X, pp. 259-264)

In that context, participants were reinforcing their belief that without them as advocates for the consumer, there was a significantly reduced potential for consumers to get the support and care they needed.

For one carer, there was little satisfaction from the time of initial assessment to actually getting support for the consumer. The delay in achieving positive outcomes meant for her that the consumer takes longer to recover and to get well:

*... as time goes by, one of the things which would have been really important to me would have been not only to have a good assessment done by the doctors but get them into rehabilitation as soon as possible because I think the longer it goes on, he has been out of work now for 2 years, the longer it takes for them to get well* ... (Carer W: 124-128)
This carer also stated that the difficulty she had with the ‘mobile team’ forced her to write a letter of complaint seeking action. For her and the consumer, this resulted in the support from the mobile assessment team and a case manager whom she stated was very good:

_We do have a case manager that works with the mobile team and the only reason that we have the mobile team is because we went through so much trauma at the hospital that I wrote a letter of complaint to the mobile team people and they knew I would take it further if nothing was done so because of that I really believe that I have a really good case manager and a mobile team to look after him. Other than that I don’t believe that would have happened. Unfortunately, when you are going through so much stress the last thing you need is pushing people to do your job, which is what we had to do. We felt we were fighting the doctors, the staff, the system and trying to deal with the illness as well which we had no understanding_ (Carer W: 132-142)

Another carer stated that she has little support from providers whom she believed thought she was an over protective parent. This was particularly obvious for her when the consumer was in hospital and in her opinion not ready to leave.

_They don’t really listen to the carer either because they think that you are over the top and over protective. I know when she is ready to come out. I would be the first one to say I would be happy to take her out. Because I know her_
obviously. I can tell. But they don’t really listen to that
(Carer X: 589-593)

Carer participation and involvement in services.

Participants stated that their level of participation and involvement with services was minimal with the exception that most were involved with carer support groups where they received support from other carers. Most but not all participants became involved with carer support groups on their own volition. As discussed earlier, participants stated that they needed to do their own research to find supports for both the consumer and themselves as this information was not routinely made available. That they were not given the same support as the consumer in terms of their caring role, meant that they felt isolated and alone, particularly during difficult times occurring during the consumers illness. When this issue was discussed amongst the group, there was agreement that the establishment of a full time carer support provider who would be available to provide advice and support for carers. One carer remarked as follows:

One thing that occurred to me is that perhaps each area mental health service could have a ... you know, full time carer support worker. You know in a sort of a parallel role of a case management ... so issues of confidentiality and all the difficulties in the conflictive role in case management. The case manager ... should be able to do a lot of things that we are talking about but they are overworked and so you really need some sort of separate intentional role which supports and resources carers in the community and I think to me it’s logical. You know because that would address a lot of the problems we have because then there would be a voice within the service itself and also (be) in
When this role was discussed in relation to the role of the consumer consultant, participants stated that this for them is seen as a completely separate role. Whilst they acknowledged and accepted there was a need for consumer consultants as many participants were aware of consumer consultants and their activities, they also stated that the responsibility of a carer support role could not be loaded onto consumer consultants. One participant stated:

... in fact you know the consumer consultant role is very important and it is also under-resourced. And I guess you couldn’t load that onto it, couldn’t load the carer responsibility onto that. No I would say it would be more sort of like the case manager, going visiting and seeing what’s going on and supporting ... giving information and a bit of education and maybe being there ... at the time of a first episode and so forth (Carer Z: 343-348)

Other participants stated that it would be beneficial to have a care support worker dedicated to providing opportunities to carers for both debriefing following a crisis and for ongoing support.

I think that would be great. I used to look and think who can I ring. Who can I talk to about this. I don’t know if I am doing the right thing. I don’t know what I should do. You just fee totally alone. You have got all this stuff happening to you and you have got nobody to talk to too ... (Carer X: 349-352)
And:

*I really wished that a carer support person was in touch with me or I had a number that I could ring them when I just wanted to talk or was worried that maybe something was happening. Just somebody I could ring just to discuss it. When something is starting to happen you think who can I ring. Who can I talk to* (Carer X: 475-479)

**Summary.**

The recruitment of carer participants for in-depth interview proved to be difficult. Despite efforts to recruit participants through much the same approach as consumers, including the circulation of fliers and direct canvassing, few carers agreed to be interviewed. Brief encounters with carers on the telephone generally during the first and only contact, elicited useful information that explained carers frustration and dissatisfaction with the mental health system. Whilst these carers were not prepared to be interviewed face to face at length they did not object to me making reference to the information they provided.

The main reason given by those carers not wishing to participate in interviews was that they felt that no changes would result from their contribution and the process would be a waste of time. Other responses from this group of carers is summarised as follows:

1. Carers felt despondent about repeated attempts to gain more information about the consumer. Their efforts to provide better support for the consumers were frustrated because they felt that the rights of carers were not regarded to the same degree demanded by consumers;
2. Not being informed about the consumers progress due to confidentiality and legislative requirements;
3. Carers felt that their frustration, coupled with their belief that there is an unacceptable lack of resources for consumers particularly transitional and longer term
accommodation, made them sceptical of this research that claimed there may be benefits in recording their responses;

4. This group of carers also felt that to become too involved with this research may compromise their already fragile relationship with consumers

Those carers who did participate in in-depth interviews described their roles as one that had, by default, been forced upon them and many used the term ‘thrust’ to describe this. None of the participants who were parents would willingly choose to be a carer for someone who has a mental illness. Participants perceived there to be no choices for them and they explained their multitude of responsibilities and the difficulties they faced as both carers and parents. It is interesting that all participants with the exception of one were parents and carers for adult children. This fact alone created difficult situations for carers who stated that there were inherent difficulties in being forced as parents to accept the overall responsibility for maintaining the health and welfare of their children well into adult life.

A further complication was perceived to be the need that carers, as parents had to spend a considerable amount of time, sometimes twenty four hours per day, with their adult children, particularly through the acute phase of an illness. Participants felt that they made a difference to consumers lives by being there for them as often professionals were not available to assist with support.

There was consensus amongst participants that, had it not been for their involvement in supporting consumers, there would be nobody to ‘pick up the pieces’. They described themselves as being on the front line providing the initial support and care in the absence of professional help which they often found difficult to attain.

The impact that the caring role had on carers personal lives also featured significantly in discussions with all participants. Most regarded their caring role as a full time occupation
that distracted them from their own personal pursuits. Few participants found the opportunity to venture far from home. When they did have the opportunity to have a break, the constant thoughts of the consumer and in some cases constant contact by consumers meant that they often needed to return to once again assist in sorting out problems. Relationships with spouses and other family members were adversely affected as a result of the time commitment by many carers. This was particularly so when the other spouse did not wish to be involved in providing support for consumers because the issues with which they were faced at the time were overwhelming.

Participants also spoke of the effect that their caring role had on their own health with many needing to seek treatment for physical and stress related disorders. Some participants stated that they themselves had been placed on anti-depressants and had cause to access general practitioners and psychiatrists. The concern that consumers may relapse and carers would be placed in a position requiring them to intervene, was a predominant factor contributing to their state of health. One participant remarked that she had at times felt suicidal because she was not able to get the support she needed for the consumer and her attempts at dealing with a crisis created a situation where she felt at her wits end.

Participants described their role as a difficult one. During the initial stages of a psychiatric crisis when they felt they needed to organise acute assessment and other necessary services in order to protect the consumer, their perceived role often created significant tensions between them and the consumer. Participants were keen to point out that although they continually learnt more about psychiatric illness and disability during the consolidation period of their caring role, they were also of the opinion that the deteriorating relationships they had with consumers occurred as a direct result of the consumers illness or disability. Relationships that carers had with consumers prior to the consumer developing a mental illness were mostly referred to as normal and for these
participants, there was a definite period when they had determined that these relationships changed for the worse and in some cases continued to deteriorate.

Most however, stated that they believed consumers understood that carers had their interests at heart. Once the acute episode had resolved, there was an opportunity for carers to assist in ‘picking up the pieces’ referred to earlier, and to resume relatively ‘normal lives’. For these participants, consumer’s behaviour and conduct reflected the symptomatology of the illness. Carers continued to support consumers with the premise that the consumer would recover. This was despite reflecting that they often suffered a great deal of abuse from consumers during an acute episode and in the weeks following, during recovery and rehabilitation. Some participants in fact believed that consumers were not responsible for their actions during an acute episode and that they did not realise what they were saying at the time. One carer stated that the consumer was apologetic once they had sufficiently recovered from their acute episode and it was this acknowledgment that reassured the carer to continue with support.

The absence of useful and appropriate information dominated discussions when participants were asked about how they acquired information and what assistance they had in accessing services. Although they were given some information in the form of pamphlets and leaflets, most described the lack of suitable advice and options with respect to additional support for consumers. Other participants stated that although some contact details may have been provided during the initial stages of the consumers illness, they were in no position, at that time, to comprehend what those services had to offer and why.

When carers did contact service providers wishing to speak with someone, providers did not return calls leaving carers to wonder what would become of consumers who did not have carers to advocate on their behalf. This was a dominant feature of the interviews held with consumers. Participants also experienced occasions when consumers
themselves attempted to contact providers to obtain immediate support as they felt in themselves that their condition was worsening. Some participants were frustrated to learn that providers did not intervene or provide support to consumers early enough and that hospitalisation could have been avoided had providers responded appropriately with support when consumers needed them to.

The reluctance of those providers to share information with carers about the progress of consumers to better help them provide support was of major concern for some participants. Providers cited confidentiality and privacy laws with which they were required to work. Participants stated that providers explained their inability to pass on information to carers about consumers because they were required to protect the consumers rights in addition to preserving their relationship with consumers. Carers’ willingness to provide information to providers about consumers however, often placed them in a compromising situation for a number of reasons. On a number of occasions, consumers would be told what had been discussed with carers and this placed considerable stress on their relationship with the consumer. Some participants believed that as a result those providers had placed them at personal risk of verbal abuse from consumers particularly when the consumer was not well.

Participants did point out that they in no way wished to compromise the rights of consumers. Their comments though, indicated that at times a carers rights were not observed in the same way as consumers ought to be. One participant stated that providers have an obligation to ensure the protection of carers through recognising that at times carers can be placed in situations that posed a considerable risk to their physical and emotional health.

Participants generally did not make any distinctions between those offered by acute in-patient services, CAT teams and rehabilitation. Rather, they gave an account of the many issues they faced in supporting consumers and the different services they were required to
access at different times particularly discussing the involvement or lack of involvement by providers when they felt consumers needed them.

All participants stated that it was important for them to have a good relationship with providers as they acknowledged that their task of caring for consumers was a difficult one and one they could not carry on their own. There was consensus that providers often neglected to provide the necessary support for carers and providers focused all their attention on supporting the consumer. Whilst participants unequivocally agreed that consumers benefited from as much support from providers as possible, they also stated that carers should receive support in their role as carers. The option of a carer support person to whom carers could have access when necessary was proposed by several participants. This position would be responsible for providing continual support for carers in their role as well as initiating debriefing for carers who required this. Participants believed that the lack of support they received from providers was proportional to the amount of assistance and support they were able to provide for the consumer. It was felt that when carers were providing significant support, providers generally turned their attention to consumers who did not have a carer.

There was a mixed response from participants about the benefits of consumer only run services. Whilst many participants acknowledged that consumers did recover sufficiently to have more involvement with the development and running of services and programs, some felt that consumers, for the most part, were not capable of operating at this level. Their experiences in caring for consumers whom they knew well, indicated that most did not wish to be more involved with service development.

There was also significant differences of opinion about the prevailing attitudes of providers in terms of how providers viewed carers and the support that carers stated they should receive. Some participants believed that although support by providers was lacking, some providers are beginning to understand and appreciate the role of carers.
Whilst participants stated that providers believed their role was often vital to achieving better outcomes for consumers, there were not the resources to provide additional support for carers.

The fact that carers felt they needed to actively pursue support from providers suggested to them that not enough is being done to confirm the recognition by some providers, that carers are a vital and necessary part of the treating team. Participants were of the opinion that without the support and assistance they offered to consumers almost on a daily basis, consumers would be significantly disadvantaged. For carers to continue to provide support to consumers in the way that they do, meant that in turn, they required much more assistance and support from providers and that strategies to ensure this occurs should be developed and implemented.
Chapter 10: Findings and Implications of the Research.

Introduction.

The purpose of this chapter is to provide a discussion of the findings derived through in-depth interviews with consumers and carers and relate this to the major themes that have emerged from those interviews and the literature on empowerment and the mental health consumer movement.

The aim of this research was to gain an understanding from consumers and carers about their experiences with psychiatric disability support services and how these services have impacted upon their lives. That is, the research initially set out to focus on those people who were seeking support for the management of their psychiatric disability following diagnosis and treatment of their illness. Whilst providers have articulated the differences associated with acute care as distinct from psychiatric disability support services (Vicserv), participant consumers and carers interviewed generally were not able to or interested in identifying these differences although some acknowledged that they did exist. The exception here was consumer consultants who were keen to make distinctions. This information emerged as a result of the in-depth interviews conducted during the course of the study and supports the use of qualitative methodology for this research.

As the study progressed it became apparent that for the most part, consumers and to some degree carers, did not place great emphasis on the need to separate out acute services from psychiatric disability support services. It was more important for them to discuss their overall experiences with the mental health system. In particular areas identified included: choice in treatment options, attitudes of providers working in hospital and community services, responses of providers in relation to crisis situations (for both consumers and carers), information and access to services in response to needs and acquiring the right types of services for their situation at a time when they needed them.
As the research initially set out to focus on participants involved specifically with psychiatric disability support services, options to deal with this change of focus to explore consumer experiences with the broader mental health system, were considered. One option that could have been employed would have been to develop exclusion criteria. That is, to select only those participants who could clearly identify the differences between acute services and psychiatric disability support services. However, it was thought more preferable to recognise and accept that consumers and carers adopted a broader view of the service system and the differences between acute and psychiatric disability support services was relatively unimportant to them. It is important to note at this point however, that the researcher acknowledges the differences between acute and psychiatric disability support services, but no attempts were made to stress this to participants other than the information that appeared on the statement containing background information to the study. The discussion that followed therefore often included references to both mental health services delivered within acute in-patient units and those that were experienced through association with psychiatric disability support services.

The scope of the theoretical chapters was intentionally widened to take account of a broad cross-section of developments within the mental health field. Firstly there was a need to include what was occurring in the mental health field outside of Victoria so that developments could be compared and contrasted and discussed in the context of national and international trends. Additionally the background material offered in chapter one provides considerable insight into the history, progress and development of mental health services within Victoria, particularly in relation to the progress of services from institution to community. This information was then related back to the opinions of consumers and carers who have shared their experiences through the process of in-depth interviews. Although there is evidence that other states within Australia are focusing on a more community oriented service system with increased involvement by consumers, the research conducted in Victoria by consumers or at least with their involvement suggests that, Victoria leads the way with respect to more consumer activity.
The primary objective is to present the views of consumers and carers in relation to their knowledge and experience of mental health services. Importance was placed on consumers level of participation and involvement, how this has occurred or been achieved, and whether their involvement has made any sustainable contribution to the way services affect them. In this context, the discussion revolves around the opportunity and capacity consumers have to take control of their own lives through strategies that seek to empower them. Several factors that have influenced this capacity have been explored. Primarily these represent the significant changes that are required in the relationship between consumers and providers if reforms that purport to support consumers are successful. These will be discussed more fully and specifically, the following areas will be addressed:

What consumers and carers believe are the effects of institutional care and deinstitutionalisation and how they have responded to the changes that have occurred;
The difference between acute services and psychiatric disability support services. In particular, the relative importance consumers place on differentiating between services.
A discussion of the prevailing attitudes of providers. In particular the experiences that consumers and carers are having with providers operating within institutional settings and those who are providing community and psychosocial rehabilitation services, specifically psychiatric disability support services;
Participants experiences of the support they have received particularly in the areas of acquiring information, contacting and accessing psychiatric disability support services.
How the role of carers, in particular their relationship with consumers and service providers supports consumers and providers during the consumers recovery from acute episode to support for their disability;
The role of consumer consultants and their contribution to accelerating the progress of the mental health consumer movement. This includes the potential consumer consultants see for further development of the mental health service system and the effect they have had on policy development thus far;

The empirical findings will then be related to the theoretical framework of the thesis and include a discussion of the following:

- The evolution of the mental health system and the progress of rehabilitation and support for consumers and carers;
- A discussion on the differences between mental illness and psychiatric disability;
- A discourse on the principles and practices of empowering strategies;
- The origins of the consumer movement and how consumers became mobilised;
- An exploration of the different terms used to describe consumer participation through consumer practices of self-determination and self help.

The development of mental health services in Victoria: An historical perspective.

The way in which care and treatment has been provided to people with a mental illness has evolved significantly over the past two hundred years since those early days when convicts first arrived from England to the shores of Australia. According to Dax (1989), the evolution of care and treatment of people with a mental illness has been taking place for the past two centuries. A significant aspect of the evolution involved strategies and decisions often by the governments of the day to provide more of a community perspective in the delivery of basic care and treatment. It is clear also however, that the evolution has not taken place without a struggle.

It can be argued that the rights of consumers, during the early years of Australian settlement, right through until recent times, were not given the same attention as they are today. Certainly there has been ongoing debate about how and where people who have
been diagnosed with a severe mental illness are treated and cared for, but decisions were almost exclusively made by bureaucrats for and on behalf of patients and supposedly in the interests of the community. The decisions to separate people with a mental illness from mainstream society were probably based on a few ill-conceived notions and assumptions and an ignorance towards the understanding of their needs. To some degree these continue to be present today. They included such reasons as: nothing further could be done for them and people with a mental illness would always require custodial care; some behaviours exhibited as a result of psychiatric symptoms were frightening to normal people and needed to be hidden from public view; people with mental illness were dangerous and the community needed to be protected. These notions are also responsible for the prevailing attitudes that have seen the further development of initiatives stifled, greater consumer participation being an example.

The development of new treatments including the introduction of psychotropic drugs and changes to the various acts that govern the protection and treatment of people with a mental illness and psychiatric disability, have partly contributed to shifts in direction away from an era where institutional, custodial care was virtually the only option available. What is clear is that there is now more tangible evidence to suggest that the interests and indeed the human rights of people who have a mental illness are receiving more overt consideration than was previously the case, and this trend could be better served through collaboration between consumers and providers.

There is little doubt that the extremely poor reputation of the mental health institutional care system in Victoria and in many countries around the world, has been thoroughly exposed. In Victoria, there is now undeniable evidence obtained through the many national inquiries and investigations into mental health services and systems conducted over the past three decades (Commonwealth Dept of Human Services 1993, Commonwealth Dept of Human Services 1994, Commonwealth Dept of Human Services 1996, WHO 1998, and others) that there was indeed a need to improve treatment and
services for people who have a mental illness. In most cases, it was not just a matter of refinement to achieve improved outcomes within particular services, but rather, systems wide radical reforms that demanded that basic human rights for people who have a mental illness be recognised and respected. A major guiding principle in the treatment of mental illness is that consumers have a right to receive that treatment in the least restrictive environment (Mental Health Act, 1986).

It can be argued that the National and State inquiries that exposed extremely poor practices within the large mental institutions acted as a catalyst for the reforms that had to occur. The subsequent reports often returned findings of alleged physical and psychological maltreatment of patients by staff, the appalling conditions in which they were forced to live and the poor attitudes of staff to changing this situation. (Commonwealth Dept of Human Services 1993). This associated with the inability of mentally ill patients (consumers) to speak out about the reported violations, perpetuated the declining state of our mental health system and further disenfranchised consumers from the community. The practices within some institutions, until the time that they were publicly exposed, went unnoticed by the community and it is perhaps this separation and isolation from community activity and scrutiny that has served to create and perpetuate the myths surrounding mental illness and the people who are affected by it. That consumers and carers have become increasingly disillusioned with some aspects of the service system as a result is not surprising.

The reports have demanded the attention of governments and the community and governments have, in different ways, reacted to protect their own integrity by leading systems reforms. History also suggests that mental health issues have not really been able to influence voters sufficiently at the ballot boxes yet governments and political parties in opposition have seized upon unfavourable reports to gain political leverage over their opponents. Participants note that unfortunately government strategies often result in the promise of additional funding and other resources but these generally fall short of that
required to make a real difference in services offered. All participants agreed that there were still too few services to meet the needs of consumers and carers and this has become especially obvious with community services that often fail to provide support when it is most needed.

The effects of institutional care and deinstitutionalisation on both consumers and carers and its implications.

A situation that has occurred within Australia and one that can be linked to a trend that has affected most Western countries, is the introduction and in some cases the completion of deinstitutionalisation policies adopted over the past three decades. The response to the National and State inquiries by governments can be held partially attributable to the phenomenon occurring within Australia, although it appears that some move to deinstitutionalise patients had been occurring for some time. The outcome of the inquiries served to perhaps speed up the process. The more likely reason is the increasing recognition that long term institutional care is no longer the only option available for people with a mental illness. Again, this recognition has emerged and is a reflection of the changes to various acts dealing with mental illness, and the continued evolution of psychiatric disability supports services that, according to National and State policies, are becoming more common place and consistent with the rights of individuals to receive treatment and care in the least restrictive environment. The other major influence is the consumer movement that is gathering force and will be discussed below.

All participants related the significant impact that deinstitutionalisation has had on stakeholders. However, there were varied opinions about the specific effects deinstitutionalisation policies were having on consumers as distinct from carers. The speed with which deinstitutionalisation occurred within Victoria was dramatic. As stated, this could have occurred as a result of the inquiries that prompted governments to action. Evidence suggests however, that although deinstitutionalisation policies have been developed and commenced in the 60’s, the effect of these policies was particularly felt in
the past decade and a half. The majority of the large stand alone psychiatric hospitals within Victoria were decommissioned in just over a decade commencing with the decommissioning of the Willsmere Hospital in Kew in 1989. A number of smaller facilities accommodating people with acute symptoms for shorter periods of time and generally annexed to general hospitals were established in their place. Apart from the fiscal benefits realised through the closure of the large psychiatric hospitals, there was a consensus that this strategy, which had become to be known as mainstreaming of services, would assist in reducing isolation and in reducing the stigma attached to mental illness so often associated with long term institutionalisation. It would also facilitate greater access by consumers to more appropriate services aligned to their needs as well as allow them to access a range of other services located within the general hospital setting.

Not withstanding the obvious benefits that a move to smaller more focused services were to achieve, all participants asserted that the smaller services that were focused on providing acute inpatient care were now much more difficult rather than easier to access. To this end, the impact of these reforms is felt by both consumers and carers. To have a consumer admitted to an inpatient unit often required either carer or consumer making several approaches to providers often with little satisfaction. Participants believed that providers were often insensitive to cries for help by both consumers and carers. In addition, the lack of resources, and the reluctance of providers to spend time exploring strategies to assist consumers and carers to better manage their symptoms also contributed to delays in treatment. This meant that consumers symptoms had the propensity to worsen resulting in subsequently longer hospital admissions and shorter periods of remission.

The other issue revolves around the perceived level of commitment and involvement invested by the providers in a range of settings both hospital and community. Receiving adequate acknowledgment and support was according to a number of participants dependent upon having the ‘right’ provider assigned to their case. There was a significant
degree of support for case managers whom participants felt took a greater interest in consumers at every stage of their recovery. Consumers recognised that there is now more opportunity for them to become and remain more independent. However, it was important for them to also have a professional support them through difficult times such as a relapse of an acute episode as well as throughout their rehabilitation while guiding the consumer towards relevant programs and services. Those consumers who were allocated a case manager were considered more fortunate by other consumers than those who were not. It would seem that to provide a case manager or a mentor of some kind to all consumers, if consumers so chose, would not be such a difficult task and would certainly have the effect of ensuring consumers pursue realistic treatment and support options.

Similarly, carers were of the opinion that they would also benefit greatly from having a type of professional carer support worker similar to the case manager, who primarily assisted carers in their role. The need for such a worker was emphasised on a number of occasions and several issues were raised that supported this strategy. Firstly, there was consensus amongst carers that they were not offered the necessary support required for them to adequately carry out the carer role from first encounter with mental illness to subsequent support of the consumers disability. This was particularly apparent during the initial period of first diagnosis and treatment of consumers where carers were often distressed about symptoms and the ‘different’ behaviours exhibited by consumers that they were not adequately equipped to deal with. A carer support worker would provide information on strategies that would enable them to acquire information quickly and easily when required. There were occasions where carers felt at a loss as to who to call in a crisis and even when they were able to consult a provider, they were faced with unnecessary delays receiving help. Another major concern for carers was that they felt that providers placed undue emphasis on the need to maintain confidentiality when they were attempting to discuss their concerns about consumers and the consumers’ illness or disability. Whilst they understood that consumers may be sensitive to providers
disclosing certain information, they also emphasised that their rights as carers were compromised as a result of inadequate information. To them, the right to access vital information about the progress of a consumers recovery was essential if they were to adequately provide options that could support consumers. Further to this, without the necessary information, carers felt that at times they were being placed at risk from consumers. The role of a carer support worker would facilitate communication between carers and consumers and avoid the stress of seeking other avenues to access information during difficult periods. The type of role discussed can be compared with the developing role of consumer consultants. There is significant opportunity for a more collaborative relationship to be established between consumer consultants and ‘carer consultants’ that in turn would benefit the treatment and support option offered by providers.

This is particularly pertinent as most carer participants contended that they were thrust into the role and as many were parents, they felt they had a responsibility to offer their support in the best way that they could even though they were not sure of what support to provide and how to provide it. Having the support of a professional support worker specifically dealing with carer issues would allow them to maximise their potential as carers whilst maintaining their relationship with consumers as parents.

Finally, carers feel they now have a greater responsibility to ensure that accommodation is available when consumers are discharged from hospital, because there is not the accommodation options open to consumers and providers do not do enough to source options. Their contention is that they need to be always ready to accept consumers as there is little consideration given to them by providers about where consumers should live following discharge. In many cases, carers are not consulted at all. Consumers often arrived at home unexpectedly and without giving notice to carers. Participants state that this places great strain on their relationship with consumers. They had not had the opportunity to alter their plans to accommodate the arrival home of consumers. In some cases the carers home was not the consumers pre-hospital residence however, their
accommodation had been lost during their hospital stay. Although this issue goes to providers taking the necessary steps to including the circumstances of carers in discharge planning strategies, the assistance of a carer support worker would have contributed to carers more involvement into the process.

Other reforms that continued to focus on the development of community services included the formation of crisis assessment teams and additional resources for the development of psychiatric disability support services. This was to have occurred in parallel with psychiatric hospital decommissioning, although investigation by consumers, representative organisations and peak bodies as well as reports undertaken by the Commonwealth government have all suggested that the funding realised through the closure of large hospitals had failed to follow consumers into the community. There is still concern raised by participants that the service system continues to struggle from insufficient funding. There was a consistent reference made to the often lack of response by providers in both attending to care needs whilst consumers were hospitalised and in what they described as inadequate response to calls for support of consumers and carers within the community which were directly linked with the perceived inadequate resources available.

**Differences between mental illness and psychiatric disability.**

The literature places some importance on recognising the difference between mental illnesses and psychiatric disability. Services such as Vicserv in particular stress the importance of support for a person with a psychiatric disability that should be aimed at improving such areas of consumers lives as resocialisation following hospitalisation, access to financial support, employment opportunities, and reintegration into societal norms. Continuation of clinical interventions and treatment modalities following acute episode and during rehabilitation does not allow consumers the opportunity to move out of a sick role. In fact it could be said that the reverse is true. Additionally, clinical interventions tend to focus on the treatment of symptoms rather than on restoring a
persons capacity to deal with activities of daily living, a loss that is often a consequence of mental illness.

The developing psychiatric disability support services sector is recognition that there are distinctions made between mental illness and psychiatric disability. Psychiatric disability support services are delivered in an environment that assists consumers to regain control over their own lives. An environment free of invasive clinical interventions encourages consumers to adopt a ‘well’ role and only seek more intensive treatment and support when they feel it necessary. The association with other consumers within a supportive and encouraging environment significantly enhances self esteem and allows consumers to regain confidence in their own abilities as they recover or become more knowledgeable about their mental illness and disability.

The difference between acute and psychiatric disability support services was discussed in the context of gaining a general understanding from consumers about these different service systems. Some consumers were able to provide little distinction between them, however, in most cases the differences were relatively unimportant to most participants. What is important is that a smooth transition is achieved between acute and community services and there is little doubt that effective information and communication plays a significant role.

Consumers agreed that even though they may have been relatively uninformed about psychiatric disability support services and what they propose to offer, they understood that these programs assisted them to achieve a more ‘normal life’ following an acute episode. There was also a consensus amongst consumers that psychiatric disability support services were only able to provide support services to those people who had a previous diagnosis of a severe mental illness. This seemed odd to some who expected that as community based services there should be the opportunity for people to access these services well before a crisis occurs. This again raises questions about the current
level of collaboration that exists between providers of acute services and providers of psychiatric disability support services. Psychiatric disability support services are operating as discrete components of the mental health service system, separate from acute services so as to engender the sense that psychiatric disability is quite different from mental illness. Therefore it can be easily construed that acute service are synonymous with mental illness. The distinctions are clearly articulated however they must share a close relationship to effect a process of optimal recovery for consumers as they find themselves in varying stages of illness and rehabilitation.

Whilst the service system is attempting to distinguish between mental illness and psychiatric disability both consumers and carers do not find the distinction important. Rather, what is important for them is that there are services that are available and accessible and participants want the service system to be more responsive to their needs.

The prevailing attitudes of providers and the implications this has on opportunities to achieve consumer empowerment.

Empowerment is inextricably linked to mental health reforms in which deinstitutionalisation featured as a central component. The process of deinstitutionalisation has lead to consumers and carers being forced to accept more responsibility to manage mental illness as opposed to this being left almost entirely up to providers within institutions. Is this what consumers actually want or is it a response to an inadequate situation in the community? If one or one’s relatives are not being cared for by the providers, one must begin to address these issues oneself through a consumer group or a consumer consultant. The important consideration is that the power imbalance that formally existed in the relationship between consumer and provider according to participants is restored to a more equitable one. For almost all participants interviewed, there was a perception that a shift in power has occurred and has subsequently allowed consumers to experience more control over their own lives. For most it had been
achieved through voluntary participation in programs and services and was partly due to reforms that have begun to change practices within the mental health system.

That it has taken the introduction of serious measures such as Royal Commissions, national and state inquiries and the closure of hospitals that were once thought to bring asylum to people with a mental illness is not to be lauded. However, these measures have resulted in the reforms that have enabled the transition from institution to community and have brought consumers closer to achieving greater autonomy and control over their own lives. The changes, in fact, although slow, have positioned consumers to become more involved with the mental health service system in ways that just a few decades ago had not been considered and where long term institutional care was accepted policy rather than a necessary treatment option. In particular, there is now an increased recognition that consumers do and should have a capacity to question the types and ways in which care and treatment is delivered no matter what the environment. Long term institutional care provided little opportunity for this to occur.

The right to make decisions about one’s own care and treatment options and indeed where and when to seek that treatment is fundamental to the principles of empowerment and the doctrine supported by the World Health Organisation. The power that is conferred by one party by means of either downward delegation or authorising a person, (Barnes 1988), is no more or less a power than that which has been achieved through ones ability to exercise the power that each of us inherently possess (Foucault 1954). They are states of empowerment that both acknowledge a persons capacity to take control and to place them in a position where their contribution can be valued. Barnes assertion is that to confer some power on one party means that the other party must relinquish some power also. Literally taken, this is perhaps correct. However, according to consumers, it is important for providers to acknowledge that the relinquishment of some power and authority that they held particularly within institutions, is paramount to developing a productive relationship. It is one that respects the contribution that consumers can make
now that both stand equally outside of the hospital walls that formally decided who was and who was not powerful. Participants assert that both the desire and the need to assume a more proactive role is a combination of deinstitutionalisation and the ability for providers to accept that a paradigm shift has occurred where some consumers have become more comfortable about assuming a more assertive stance. It is a product of a change in environment and an indication that consumers are ready willing and able to involve themselves given the opportunity. In essence, it is conceivable to assume that the power that has been taken by consumers was neither given nor lent to them.

The discussion about the relative balance of power between consumer and provider does not end here. Just as power can be conferred through delegation/authorisation and through one exerting one’s own ability to exercise power, there must also be another choice that is available to consumers. The acceptance or non acceptance of power should not be construed as powerlessness. Is it true that “only empowerment can invest people with the sense of self efficacy, which enables them to act in productive ways” ? For some consumers their choice was not to actively pursue changes but rather to avoid certain issues as a strategy to protect themselves. Sometimes productive action can best be achieved in a safe environment with clear boundaries and guidelines with the majority of control or power given to another.

Bray and Preston-Shoot (1993) suggest that there are four key components for empowerment including a conceptual framework, a personal will, an organisational commitment and a developed practice base. The question must be asked of how many of these components are possible in a state of mental illness in any case. Some participants explained that the emergence of the consumer consultant role has allowed other consumers to withdraw to some degree as they are aware that another group exists who it is hoped would assume a pro-active stance on their behalf. That consumer consultants neither accept or aspire to advocacy in this way warrants further discussion.
Information is a powerful tool however, and those who don’t have it want it or need it and those who do have it don’t always want to share it. This dynamic needs no further explanation, however, in the context of access to information about mental health services, the degree to which information is withheld from consumers and carers is largely related to the pre-existing attitudes of providers. There is a belief amongst participants that providers are still in a relative position of power and determine from time to time and from consumer to consumer what sort of information would benefit them if at all. Their attitudes are still very much a legacy of the days of custodial care whether they are working within an institution or within the community. Some consumers did state that once in the system, the information highway was easier to get on and stay on.

The notion that staff should change their behaviour to effect an empowered state in consumers may merely be another tool of group dynamics, to actually effect control of the group. One either directs in a structured and disciplined way or in a flexible, spontaneous way but the provider, it appears is still in control directing the outcome. The outcome in this case may be different to self help groups, support groups and community houses, but who has directed this. As an example, consumers feel disillusionment with the mental health system citing issues of forced admission and treatment. This then poses the question of will other groups such as police and children and carers soon cite examples of abuse due to the non-treatment inherent in a community based, consumer based mental health system.

**The broader implications of changes to power balances.**

Community power is limited because resources lie in institutions and once community groups become too big or too powerful, they then risk becoming institutions themselves. The concept of elite power suggests that if communities are governed by groups who vie for and hold an amount of power there is little difference between institutional based power, community based power, consumer consultant power and consumer power – the
few will continue to dictate to the many. This issue was of particular importance to members of the reference group who articulated their concerns regarding the transfer of this elitist power from that which was formally contained within institutions to the evolving community service sector wherein psychiatric disability support services are delivered. A priority of the mental health consumer movement is to ensure that services become more responsive to individual needs of consumers yet at the same time continue to encourage and foster the doctrine of self determination.

For the majority of carers, the reforms offered little comfort. To a significant degree they felt that they were actually being dis-empowered particularly now that long term institutional care or alternative supportive accommodation is either not available or inadequate. Carers are now placed in a position where they feel they must provide that support to consumers because there is a lack of other options. They continually reinforced the fact that the caring role was “thrust upon them” and they were inadequately prepared to deal with the almost constant attention they felt needed to be given to consumers. Their role in effect is compromising all other aspects of their lives including having no time for themselves and others, being unable to take holidays for fear that the consumer would experience a relapse of symptoms and the limited time available to them to pursue employment opportunities. In addition carers suffered emotional and physical symptoms of stress themselves which they directly attributed to their role and for which they sought medical intervention. It was interesting to note that amongst their comments about lack of choice, carers also felt that the policies of the recent past had also left consumers without choice. The concept of the development of alternative medium term transitional accommodation for consumers recovering from an acute episode was frequently raised as an option and something that carers suggested would assist them to maintain a caring role for longer.

Consumers agreed and also stated that the ‘system’ has been ‘abusive’ to carers whom were placed in a position where they were forced to accept more responsibility. These
were complimentary remarks that could at first be interpreted to mean a healthy relationship existed between consumers and carers. However, participants identified several barriers that were thought to potentially inhibit a more collaborative partnership with each other, the mental health system broadly and with providers specifically. These will be discussed further in the section that follows.

Firstly almost all participants agreed for varying reasons, that the transition from long term institutional care in favour of the development of a more community orientated support services system, needed to occur. They stated that they welcomed the opportunity for consumers to receive better services that this transition promised to offer, and as was also their right. According to most participants this quality should have been directly related to and achieved as a result of deinstitutionalisation. All participants offered views that represented both ends of the care and treatment spectrum for them during their hospital stays. Their experiences ranged from an absolute disgust of the system to comments that suggested that overall the care and treatment they received was quite adequate. In the context of these varying opinions the discussions that revolved around the attitudes of providers and in some cases the changes that needed to occur to improve relationships between consumers, carers and providers was appropriately relevant.

The consumer movement.

Empowerment is a concept that involves individuals having control over their own lives. A state of true empowerment is achieved and exists when an individual is able to make choices or at a minimum, have the opportunity to make choices. The choice to participate or not to participate must be up to the individual and includes that individuals capacity to do so. (Foucault 1954). From the point of view of a person with a mental illness or psychiatric disability, their capacity to exercise choice and control is often limited by factors that are in many instances, beyond their control. One such limiting factor, that of being disenfranchised and marginalised as a group, is to some degree being overcome because consumers have become increasingly aware that as a group, they are able to
effect change in the way services are delivered. The choice to participate has become possible for many and because consumers have a willingness to act, they also have the opportunity to pool their resources to effect change.

The mental health consumer movement continues to gather momentum both here in Australia and overseas. The movement generally is about changing the balance of power from providers to consumers by taking account of a number of issues of concern for consumers and carers. It is about looking at the changes that are occurring particularly from institution to community based services and making sure that the same structure, injustices and power imbalance is not repeated. For consumers, there has also been the desire to change the partnership of care from provider and carer to consumer and advocate.

The basic doctrine of consumerism within the human service system is that individuals who have a direct experience with a particular life condition such as aging, disability or mental illness, are more knowledgeable about their own needs and interests than are their professional counterparts. There was a general consensus amongst participants that the consumer movement serves to strengthen the relationship between consumer and provider whereby consumers feel more comfortable about asking questions, questioning treatment strategies and indeed forming a partnership with providers so that they can be actively involved in selecting treatment options. According to consumers the question is not whether they know better than providers but whether providers are prepared to accept that consumers can offer valid options with respect to their own treatment and support. Consumers are suggesting that they can contribute in a way that will benefit both themselves and providers and are not suggesting that they know everything, even though they have experienced first hand the effects of mental illness.

There has been a number of ways by which mental health consumer movements have been identified. The terminology used to describe these movements differs but in general
terms they are all lead by the principles of self determination. The exception here is that the terms self help and advocacy seem to be used interchangeably frequently throughout the literature however, they seem to be very different. Self help is particularly consumer driven has a flatter power structure, is a fluid group, more democratic and less hierarchical. Advocacy on the other hand represents a vertical power structure, has implications of paid employment and appears at times to be working for the advocacy group rather than the consumer. They could therefore be construed as a quasi provider under a different name.

The role of consumer consultants and their contribution to accelerating the progress of the mental health consumer movement.

The introduction of the consumer consultant role has marked a significant event in the history of the consumer movement and signalled the potential for further development of the relationship between consumer and provider and to a degree between consumer and carer. The role was not conceived by accident. Rather, it was developed in response to the need to facilitate effective communication between consumers and staff of an acute in-patient unit who were involved in a research project that sought to improve outcomes for in-patients. A group of consumers were to act as a resource for the projects activities and subsequently formed the Melbourne Consumer Consultants Group. This is perhaps one of the first steps towards the development of an appropriate strategy that would bring providers closer to understanding consumer issues and indeed allow consumers the opportunity to facilitate this process.

The formation of the group in 1994 is arguably a Victorian milestone in the history of the mental health system. It is one that will, in future, be recognised as the birth of professional mental health consumer activity in Australia and involvement with the mental health system, and the catalyst for the introduction of training and education curriculums within the mental health field.
As the literature suggests, those who have lead the development of consumer movements, often a single person with drive, energy and commitment, have been given the auspicious title of consumer champion. There is no doubt that the title should also apply to those consumers, in consumer consultants who have taken up the challenge to lead reforms on behalf of other consumers. They can be considered champions because they are leading the way through their involvement with services at a number of levels within the mental health service system. Their participation is empowering on a personal level but perhaps more importantly they are an example to other consumers of what can be achieved.

By their own admission consumer consultants want to empower other people, not advocate for them, not speak on behalf of other consumers and not replace one authoritarian role with another. They have taken the opportunity to be involved with the delivery of mental health services and as consumers in their own right, they can also share their experiences on the benefits and barriers to involvement and participation in the mental health service system.

Of significant importance is the contribution that consumer consultants can make to developing training strategies for other consumers and providers. Their expertise, developed within Victoria over the past seven years, will provide an invaluable resource and should be included in basic graduate and undergraduate curriculums. Perhaps as a pre-requisite to this however, the introduction of a formal education and training program for consumer consultants would further enhance their ability to represent the service system. Governments have already acknowledged and recognised their contribution to the development of policy (Melbourne Consumer Consultants Group 1997) and several consumer consultants are already providing their own literature on numerous issues related to their own experiences with the mental health system. (Pinches 1996, Clarke 2000).
Most participants had knowledge of consumer consultants and understood what their role was. Some consumers interviewed, aspired to take on a similar role themselves because the role offered gainful employment as a pre-requisite, but also because they felt that the role offered them an opportunity to ‘get involved’ at a level that could effect some meaningful change. Others were pleased that there existed a group of consumer consultants who understood what other consumers were going through and who could represent them. Even though consumer consultants stated that they did not assume the role to achieve greater power and status than their peers and they saw their role as more facilitative, this was not the expectation that other consumers had. Their expectation was one of having a more powerful group of consumers represent them and if necessary advocate for them. It is understandable that this perception has been adopted by those consumers who are still finding difficulty in dealing with a community oriented mental health system and whose history often included a substantial length of time living in an institution.

The reference group for this study included three consumer consultants who were approached to provide advice and feedback on the course, content and conduct of the research. Their significant experience could be identified from the outset through discourse on a range of topics, and their contribution extended much further than providing support for the researcher. Whilst it was explained earlier that not all consumers wished to participate in developing mental health services further, consumer consultants had accepted the role so that they could continue to advance mental health reforms in a way that benefited all consumers. Their primary objective is to continually stimulate interest in and understanding of what consumers are constantly going through. Their role has at times been difficult for them, particularly as some of the negative attitudes with respect to mental illness and psychiatric disability prevail where participation is still construed as tokenism. As one consumer consultant aptly stated:

*My role is never to be silenced*
In a sense, this role has emerged as an important reform mechanism in its own right. As the role is consolidated and evolves further it is hoped that more consumers will be engaged in consumer provider consultative and collaborative relationships. In turn the status of people with a mental illness and psychiatric disability will continue to be elevated.

**Changing Attitudes and reflections of the past.**

The issues raised by consumer respondents whilst discussing their experiences with the hospital system and the subsequent support they expected to receive once living in the community varied considerably. Although consumers often gave similar accounts of their difficulties in obtaining help and assistance when they needed it, and there was a sense that a significant gap still exists between them. Participants who are carers were generally parents caring for their adult children. Most assumed the caring role by necessity and all are still grappling with the responsibility they face.

The transition from patient or client to consumer has added a relatively new dimension to the relationship between consumer and provider where decisions about care, treatment and support becomes more collaborative rather than prescriptive. The title consumer itself reflects a relationship that is based on service and implies that if a customer is not satisfied with the service then the onus of making reparation lies with the provider. This recognition has slowly afforded consumers more responsibility and choice and is merely the first step in allowing consumers to demonstrate their ability and capacity to make a real contribution to improving service delivery. It also supports the belief held by consumers that their participation will improve outcomes for people both as patients within an acute hospital setting and for those receiving support for their psychiatric disability within the community.
Despite these reforms the stigma associated with mental illness continues to be present today. In any case, the inquiries and the subsequent reports have raised questions about what people are doing to improve care, treatment and support for what has been often recognised as one of societies most marginalised and disadvantaged groups. The inquiries have had the effect of setting a course for reforms that mandates the introduction of continual improvement. In addition, there has been a continual focus on establishing and maintaining accountability for the quality of services that are provided.

The inclusion of carers and consumers in particular must be more than a token gesture from the service sector as the perceived tokenism by consumers only serves to create greater barriers to participation.
Summary.

In brief the major findings of this research are as follows:

Until recently, people with severe mental illness, who were facing a lifetime of psychiatric disability and those who found themselves in a caring role did not have as many options available to them as they do today. People who were diagnosed with mental illness were often confined to live out their lives within the large institutions of the past.

There have been several mental health reforms affecting consumers and carers that has radically changed the circumstances for consumers including: deinstitutionalisation, changes to the Victorian Mental health Act, development of smaller more targeted inpatient facilities, mainstreaming and integration of acute hospital services, further development of community services in particular psychiatric disability support services, support for the recognition of equal human rights for consumers and the processes that have already been developed to facilitate increased opportunity for consumer participation in service delivery. These reforms have all occurred over a relatively short period of time – the past two to three decades, in Victoria at least. For some consumers, those who are more active in terms of participation in programs and services already, the reforms have been welcomed and long overdue. For others, they have been less significant although all respondents agree that changes to the way services are delivered has had to occur if consumers were to become more empowered to take control over their own lives.

The divergence regarding the benefits of deinstitutionalisation came from carers who, whilst supporting other reforms in general, claimed that there was now not the accommodation available to meet the needs of consumers and that services unfairly relied to heavily upon them to fill the gap. Their contention is that not only are they expected to accept consumers upon discharge at the discretion of service providers, but that they are
not consulted adequately, are given inadequate support in their role and do not have their own needs met.

The need for providers to be more accountable for the services they deliver has become more evident to respondents. Even though this has probably occurred as a result of exposing the poor conduct and practice of some providers following the well publicised inquiries and investigations that have taken place, the benefits are clear.

Overall, the attitudes of service providers towards mental illness and psychiatric disability was improving according to most respondents. The nature of services particularly those delivered from within the community is now not one where the provider assumes all control of the people under his guidance. Programs have been established where consumers and carers take responsibility and direct activities and only require the support of providers when necessary. For some consumers, particularly consumer consultants, this arrangement is still far from the ideal where they see a service system that is entirely run by consumers. Most other respondents however, conveyed the merit in having access to a professional who could provide support to them when they needed it. In any case respondents did acknowledge that there is more collaboration between consumers and providers and the development of the consumer consultant role has assisted to strengthen this collaboration.

There is still some resistance by providers in accepting consumers as being able to contribute to program delivery, service development and evaluation. However, more consumers are participating at various levels both on a voluntary basis and as paid employees of mental health services. As these roles develop providers will derive a greater understanding and appreciation of the knowledge and experience that consumers can bring to improving the service system.
Consumer consultants represent an important step forward in bringing mental health issues to the fore and in ensuring that the reforms continue to benefit all consumers. Whilst preferring not to be referred to as advocates, consumer consultants do, either directly as members of a treatment team or indirectly as protagonists of the mental health consumer movement, impact considerably on mental health policy. Although a relatively new role, they lead the way for other consumers to become actively involved with and participate in mental health services. Evidence suggests that this role has been developed to bridge the gap between consumer and provider and is accomplishing that task. According to carers, a similar role developed to support and speak out for carers would have similar benefits. The role could act to promote the relationship between carers and providers in much the same way as is the case with consumer consultants. An added benefit of the role could be to assist in facilitating the improvement of problematic relationships between carers and consumers, an issue of concern raised by many carers over the course of this research.

The initial focus of this research was on the experiences of consumers and carers involved with psychiatric disability support services. Almost all respondents however, preferred to relate their experiences with the mental health system in general and some shared considerable chronological information about their first association with mental health services. It was not important for them to distinguish between mental illness and psychiatric disability or between acute services and psychiatric disability support services. Rather, their focus was on the service system as a whole, with important issues such as accessibility, responsiveness, and being provided with the appropriate services for their needs when they needed them. The general consensus was that one service should not be isolated from the other. In many cases, better communication between services would have prevented the difficulties that some respondents experienced in relation to getting the right treatment and support for their current circumstances. Consumer consultants on the other hand felt there was significant importance in recognising and purporting the differences between mental illness and psychiatric
disability. They stated that to continue to provide clinical treatment in an environment where one only requires support for a disability, only serves to perpetuate the sick role and inhibits recovery or opportunities for consumers to regain some ‘normality’ in their lives.

**Limitations of the Research.**

The researcher undertook to utilise a qualitative methodology in order to explore in detail the experiences of consumers and carers. Major themes were presented for discussion as it would not have been possible to account for every issue raised by respondents. That respondents chose to share the complexity of their lives is reflective of the need for more inquiry into areas that are of concern and importance to them. Several issues raised that did not fit into the context of this research could be further explored in subsequent research proposals.

The difficulty in recruiting respondents for interview reflects the current status of the mental health system despite the often positive responses from consumers about reforms. Carers were more sceptical about the purpose of the research and most who declined to participate stated that they believed nothing would change as a result. There is a clear indication that more investigation into the issues concerning carers should be undertaken.

As this research utilised qualitative methodology to achieve an in-depth understanding of the experiences of consumers and carers, it is not possible to generalise the results of this study. The research was conducted with consumers and carers using mental health and psychiatric disability support services within Victoria. It is therefore not possible to assume conclusively that the same results would have been obtained had consumers and carers in other States of Australia been interviewed, where programs and services may have been delivered differently.
Implications for mental health service delivery.

Changes to the way mental health and psychiatric disability support services are delivered are apparent particularly in the development of more extensive community programs. The data that discusses the experiences of participants in addition to strategies located in the discourse on empowerment suggest that there is increasing recognition that participation by consumers and carers in the development and delivery of services particularly psychiatric disability support services, improves outcomes for consumers. Collaborative relationships between consumers and providers assist in facilitating consumer participation and this has been demonstrated in Victoria through the Understanding and Involvement series of projects conducted by Epstein and Wadsworth (1994, 1996).

The growing mental health consumer movement has been instrumental in identifying and pursuing improvements to mental health services particularly in relation to the progress of consumer run services. Increased consumer participation would therefore further enhance services delivered to people with a mental illness and psychiatric disability.

Efforts to foster collaboration and participation should focus on the desire to development and deliver services that are rewarding and beneficial for all stakeholders. In this context providers need to develop their understanding of the contribution that consumers can make. The development of frameworks that guide providers to this better understanding should have both a conceptual and practical basis and should be included in curriculums and training that seek to enhance service development and delivery underpinned by active consumer participation.

This research provides another step in determining the evolution of the mental health service system within Victoria, Australia. It has been conducted at a time when consumers and carers were experiencing the effects of a number of reforms that had been introduced over the past decade. It is hoped that this research will stimulate further
research into ways that will shed light on improving the lives of mental health consumers and their carers.

Conclusions.

The research overall suggests that the significant reforms that have taken place over the past few decades have contributed to the empowerment of mental health consumers. Opportunities now exist for consumers to participate in service design, delivery and evaluation and the principles on which their inclusion is based are firmly grounded in the charter of rights and responsibilities developed by the World Health Organisation. This charter has been endorsed by the national goals and strategies for mental health within Australia, and in Victoria they are reinforced through the development of frameworks for service delivery. The variation in responses from consumer participants however, suggests that the extent to which consumer participation is realised in reality remains highly variable and is highly influenced by the attitudes of service providers.

Whilst policy documents propose that similar recognition is given to carers through these strategies, interviews conducted with carers suggest that the reforms have impacted adversely on their lives in many ways and have to some degree actually disempowered them. Carers agree that the changes brought about by recent reforms have served the interests of consumers and contributed to opportunities for them to live more productive lives. Carers have welcomed these changes. However, they feel that they have been left to struggle with the day to day demands of caring for someone with a mental illness without having regard for their own personal health and circumstances and with limited opportunities for genuine participation. As carers, thrust into the caring role, their lives have become compromised.

This research suggests that the impact of mental health reforms has led to increased opportunities for consumer participation in services, however similar opportunities for carers have not been realised. Throughout this thesis, the importance of the relationships
between consumers, carers and providers of services have been discussed. There is recognition that future efforts should focus on collaborations and partnerships that seek to strengthen the relationships between consumer, carers and providers. The differences in responses provided by consumer and carer participants throughout this thesis, supports the notion that suggests that greater emphasis needs to be placed on developing collaborative relationships between them. These relationships should enhance services and the development of structures designed to facilitate participation by both consumers and carers. Services need to take account of the inherent differences between the issues of consumers and carers as participation in service delivery becomes more prevalent. This research has discussed the experiences of both consumers and carers in an effort to expose the issues with which both groups are faced. Responses also suggest that there may be an inherent difficulty in empowering both groups at once, in that the empowerment of one group may by definition lead to the disempowerment of the other. If government policy is to transform its rhetoric into reality this issue must be carefully examined with a view to the development of strategies to increase the empowerment of both consumers and carers.

The implications of this research suggest that this recognition extends beyond mental health and psychiatric disability support services to the disability sector as a whole.
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## Appendices.

### Appendix 1: General questions for consumers as reviewed by the reference group.

1. Please describe your understanding of psychiatric disability support services and how they operate?

2. Please describe your earliest experience in contacting psychiatric disability support services. Eg. following acute

3. Can you describe for me how you found out about these services?

4. How often are you in contact with these services and for what reasons?

5. Please discuss when you are most likely to seek and use psychiatric disability support services?

6. Please describe how your current experiences with psychiatric disability support services compares to your earliest experiences?

7. Do you access these services for yourself or do you access these for others eg.; family, friends etc.

8. Explain the differences has contact with psychiatric disability support services made to your life?

9. Discuss what you want to get out of involvement with psychiatric disability support services? Compare your earliest contact with your involvement now!

10. How do you find the necessary supports through the stages of recovery from acute illness to needing support for a disability?

11. What supports are available to you and what are you using at present?

12. Have you ever been consulted in regard to your satisfaction with the services you have or have not received? If so in what way?

13. How would you like to be consulted about your satisfaction with the services you are receiving?

14. Have you had involvement in the development of a particular part of a psychiatric disability support service?

15. How important is it for all consumers and carers to be involved with psychiatric disability support services. Please discuss why?

16. If you had an opportunity, how would you like to become involved in development of psychiatric disability
support services such as planning the services or design and evaluation?

17. Please discuss how you would like to participate?

18. Is there a process that you know of where you can get involved in psychiatric disability support services program design, delivery or evaluation?

19. Discuss the process would you like to see developed so that you can be involved if you wish?

20. Do you have any additional comments you would like to make about psychiatric disability support services?

Appendix 2: Example question guide for carers group.

1. Please describe your role as a carer?

2. Please discuss what you think consumers expect of you as their carer?

3. Can you explain how do you feel about the mental health system generally?

4. What is your understanding of psychiatric disability support services and how they operate?

5. Were you satisfied with the assistance you were given by the psychiatric disability support service. Explain.

6. Have psychiatric disability support services made a difference in any way?

7. What do you wish your involvement to be with psychiatric disability support services? (eg. Continual involvement, on as needs basis etc.)

8. Is there a process that you know of where you can get involved in psychiatric disability support services program design, delivery or evaluation or just have a say? Please explain.

9. Have you ever been consulted in regard to your satisfaction with the services you have received? If so in what way?

10. How would you like to be consulted about your satisfaction with the services or support you are receiving?

11. Have you been asked to assist in the management of the person for whom you care?
12. How do you think you can make a difference to the person for whom you care by being involved?

13. What is your understanding of being empowered?

14. Do you feel that you are empowered with regard to assisting the person for whom you care? Please discuss your experiences.

15. Many carers contacted for interview have declined to participate. Would you like to comment on that?

16. Please comment on the attitudes of health professionals. If negative response, what should be done to improve the attitudes?

17. What is your opinion on allowing consumers to choose whether they receive services or not even if it puts them at risk?

18. What is your understanding of the consumer movement?

19. What do you know of consumer consultants and their role?

20. What becomes of consumers who have no carer?

21. In your opinion what do you think consumers most want?
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