

**SCHEDULING IN THE COMMUNITY**  
**Challenging Partnerships in Mental Health**



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## ABSTRACT

Studies have shown that the experience of involuntary admission to a psychiatric unit is a stressful event that may contribute to secondary morbidity in vulnerable individuals. The experience preceding involuntary admission, commonly known as a "schedule," i.e., the compulsory removal and transportation of a person deemed to be mentally ill or disordered from their environment to a psychiatric facility for further assessment, has had little attention.

The aim of this study was to identify the dominant factors of scheduling; the impact these factors have on the relationships between the main participants; and the current needs to develop a humane and consumer focused service. To this end, ten people who were scheduled; ten relatives of people who were scheduled; and ten clinicians involved in scheduling people participated in semi-structured interviews. These interviews evolved into a narrative style that better suited the topic under discussion and generated extensive amounts of data. A multifaceted method of analysis was used, predominantly of a thematic qualitative nature, to interpret the results.

The results show that the three groups experience the scheduling event in similar ways. Fear, anxiety, concern, betrayal, and lack of options predominate in all groups. The concepts of power, crime or illness, and information and education challenge assumptions about insight, competence, informed consent and working in partnership, and set the ground rules for effective therapeutic relationships. The need for comprehensive information and education programs; forums for discussion and evaluation of events; increased family involvement; ongoing trust relationships with mental health professionals; and increased resources were identified by those involved in this sensitive area.

In order to work in true partnership in mental health, particularly in the highly skilled area of acute interventions, we need to challenge our assumptions and beliefs and listen to the lived experiences of those we work with. Acute community mental health requires high levels of skill, knowledge and clinical acumen based on humanistic principles and ethical values as well as in medical knowledge. This thesis contributes to the knowledge and understanding required to develop partnerships and policies that can make this very human event more human.

## **DECLARATION OF ORIGINALITY**

This thesis describes the original work of the author, except as otherwise stated.

I hereby certify that this work has not been submitted for a higher degree at any other university or institution.

Patrizia Fiorillo

23<sup>rd</sup> February, 2001

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## Chapter I – Introduction

*It is true that there have been terrible abuses of people with mental illness, and that lawyers helped prosecute those abuses. But in our zeal to protect people's rights, we have created a climate in which mentally ill people sometimes keep their freedom but lose their mind, and in which the civil-liberties argument is sometimes used as an excuse for neglect.*

Anne Deveson (1998, p. 54)

While working as a nurse case-manager in a community mental health centre of a major Australian city, I was regularly allocated the files of people who had been assessed as requiring casemanagement. During this time I met two women whose involvement with the mental health system was instrumental in sparking my interest, from the community setting perspective, in the experience of being scheduled – the compulsory removal and transportation of a person deemed to be mentally ill or disordered for assessment at a psychiatric facility with a view to involuntary admission and treatment.

The term “casemanagement,” although considered politically incorrect due to the implication that people affected by severe mental illness are “cases” that need “management,” is used purposefully here as, in my view, it encompasses the elements of relationship, longitudinality, and active intervention (Harris & Bergman, 1988; Fiorillo, 1997). The more fashionable term of “care co-ordinator” denotes a more formal, detached, relationship. The term “primary clinician” is used in this study interchangeably with the term “casemanager” (see Appendix A, p. 190).

There are several studies on the effects of involuntary admission into a psychiatric hospital; they, however, focus on the experience of the person once admitted. This study focuses on the earlier event in the community, usually in people's homes or other non-hospital environments, when community mental health clinicians are called to assess people experiencing an acute phase of mental disorder.

Frequently, distressed relatives or police officers are the first to be present at an incident involving a person experiencing mental illness, and they frequently make the initial call to mental health services. The assessment by mental health clinicians that follows sometimes leads to a person being involuntarily taken into hospital for further assessment with a view to admission and treatment (a schedule).

This study explores the experience of involuntary removal of a person to a psychiatric facility from the perspective of the clinicians who initiated and/or enacted the schedules; family members who have been involved in their loved one's schedules; and the person who has been scheduled. Let me introduce the topic by presenting the two women's stories that created my interest in this topic.

### **Leonor<sup>1</sup>**

Leonor, was a 65-year-old woman from a non-English speaking background (NESB). Although in Australia for over twenty years, her English was poor and she was illiterate in her own language. She contacted mental health services because of depressive symptoms relating to the death of her husband, and her son's involuntary admission to a psychiatric unit that followed shortly afterwards.

Leonor's son, Luis, was a 32-year-old man who had been successfully self-employed for many years. Luis became acutely psychotic after the death of his father in a head-on motor vehicle collision. Due to his "personality change and strange behaviour," his wife left him shortly afterwards, taking with her their baby daughter. In two months Leonor lost her husband who took care of all their personal affairs; her son, who she described as "almost a stranger" due to mental illness; and her only grandchild.

Leonor came to the community mental health centre seeking help as she "was having some strange experiences" and was feeling isolated. After an initial assessment, she was offered short-term counselling, education about mental illness, and support to deal with Luis' newly diagnosed mental illness.

The sessions were held in her native language. During the initial session, she spoke of the day Luis was first scheduled. He was experiencing strange things, having visual hallucinations of his father flying through the sky, and had locked himself in the bathroom threatening suicide. He was attempting to remove the bathroom window so he could fly out and join his father. Leonor was frightened, as she was unable to pacify him and convince him to open the bathroom door. She pleaded with him, to no avail. In despair, she contacted her local doctor who reassured her he would get some help.

Within a short time, a psychiatrist and a nurse arrived, accompanied by police officers. Leonor recounted how "they rushed through the door hardly acknowledging my presence."

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<sup>1</sup> All names are pseudonyms.

She wondered why the police were there. Luis had done nothing wrong. In the rush to get to Luis, both the psychiatrist and the nurse pushed past Leonor without either introducing themselves nor explaining their intentions. The police officers arrived and rushed through the house, proceeding to break down the bathroom door. Luis was half way out the window, leaning into the sharp drop outside. He was “grabbed and dragged down onto the floor, screaming to be let go,” and brought into the lounge-room.

The psychiatrist and the nurse briefly talked to Leonor, asking about what Luis was experiencing. Leonor told them, as best she could in her broken English, and Luis was taken away screaming and crying, pleading to the police officers to let him be. Leonor was too upset to say anything. She stood in the hallway, watching Luis taken down the stairs, distressed. She later described feeling numb, scared, stunned.

Leonor stayed behind. She looked around. The house was cold. She knew Luis was taken to a hospital nearby, but had no idea where. Silence had fallen all around her. She felt alone, ghosts floating inside her head. “Had this really happened? Was Luis really gone? And where to?” She recalled feeling desperately alone. If any explanations were given about what had happened or where Luis had been taken to, she did not remember them or had not understood them. No one returned to give her any news or information. There were no telephone calls to reassure her that Luis was all right. She felt like no one cared. She started to worry because Luis had gone into hospital without a change of clothes. “He can’t go to hospital without pyjamas!” she thought clutching to reality herself: “I have to keep moving, do something, talk to someone.”

The silence was too much. She packed a small bag with a few essentials: pyjama, toothbrush and toothpaste, hair comb: “Maybe he will need his after-shave; and his deodorant! What about packing some food? Hunger can be a problem in hospital where they do not feed you wholesome food.” The bag was ready. Leonor went out the front door looking for Luis. She knew there was a hospital close by, somewhere near the cemetery they visited daily. She took the bus — and a chance.

She walked around for what seemed a long time. It started to get dark. Leonor was scared and upset. Tears were streaming down her face. She was tired and cold. She had been past the cemetery, going in to make sure Luis was not at his father’s grave. Darkness kept falling. Where was the hospital?

Eventually Leonor came across a police station. She walked in, certain that an officer would help her locate Luis. Her concerns about Luis' well-being were growing: "It must be bedtime by now and he has nothing with him! How humiliating, shameful! The staff will think I am a thoughtless mother!" She entered the Police Station where police officers were leisurely chatting to one another. The sergeant on duty came towards her and stood at the counter, looking at her and smiling. He asked how he could help. He showed concern when he heard her story, helpfully arranging for a constable to escort her to the local hospital to try to locate Luis.

When they arrived at the hospital, the constable escorted Leonor to the Emergency Department (ED) (see Appendix B, p. 191). They inquired about Luis. The admissions' clerk checked the computer database, but there was no record of him. Leonor did not realise that psychiatric admissions were elsewhere. The psychiatric unit was quite separate, with an admission centre of its own. Her language difficulties and lack of knowledge of the psychiatric system were barriers to communication and access to relevant information.

Leonor was escorted home by the constable and advised to begin her search the following day. Being at home alone that night was frightening and distressing. She had never spent a night alone in her life. Where was Luis? Where could they possibly have taken him? She could not sleep. Disturbing dreams kept her awake, staring into the darkness.

Leonor returned to the hospital first thing the next morning and asked the gate attendant for directions to the main entrance. She mentioned Luis had come in accompanied by police and that they could not find him in the general hospital. The gate attendant pointed to the psychiatric wing at the back of the hospital. Leonor was running! Suddenly her weight was not a problem, and her high heel shoes felt like joggers! She arrived at the psychiatric unit where she found Luis, sedated and asleep on a mattress in an empty locked room, with nothing on but a hospital gown.

### **Lisa**

Lisa was a 42-year-old woman with a long history of involuntary psychiatric hospitalisations. She had recently moved into our area with her teenage twins. Within two weeks of arrival, she had an involuntary admission to hospital followed by another one week after discharge. When discharged the second time Lisa was referred to the local community mental health centre for casemanagement. The referral letter stated that Lisa was "non-compliant, aggressive, still unwell, and most probably impossible to engage due to personality traits."

Lisa was informed of my coming visit. I rang to arrange a suitable time. Lisa sounded anxious; her speech was pressured. She said I could call in whenever I wanted to. She would be home waiting. When I arrived the door opened and a small, stocky woman looking older than her stated age stood in front of me. Lisa was flustered about my visit and her unit had been spotlessly cleaned. At the hospital, she was told that someone from the health centre would be visiting and that if this time she “didn’t follow instructions” she would end up in hospital again.

Lisa called her two children into the lounge-room to introduce us and asked them to sit quietly on the sofa. She said: “Would you like to start with the kitchen or the bedrooms?” She directed me into the kitchen with a sweeping movement of her hand. The question surprised me. It did not make sense. I asked for clarification and Lisa stated she believed that I would be looking through the house to assess her activities of daily living and ability to cope on her own. Her ability to care for her children, she believed, was also under scrutiny. She assured me they were coping “okay,” and she was looking after them as best she could.

I reassured her that my presence was to assist her in any way I could in keeping her out of hospital, not to make judgements about her living and parenting skills. She broke down in tears and told me how she felt that her life had been out of control for many years. A single mother living at home with her parents, Lisa believed she was prevented from living an independent life and taking responsibility for her own family. Her parents were strict Catholics and Lisa stated she had been consistently “shamed and humiliated” about her unwed pregnancy. When the twins were babies, she fought to prevent her parents from adopting them out.

When Lisa moved to her current address, she thought she had for the first time the opportunity to be a mother – and the head of the household. She felt stressed, however, by her unfamiliar environment, and was “terrified” of becoming involved with psychiatric services again. Although the hospital staff stated that her last relapse was a consequence of non-adherence to treatment and lack of insight into her illness, she explained that it was actually due to her son throwing her tablets down the toilet in a fit of anger. She had not known how to get a replacement without alerting mental health services in the area, which she did not want to do “at all costs.”

Lisa’s first schedule happened quite suddenly. Police attended to her call for help because her son was being violent towards her and his twin sister. Upon arrival, her son allegedly convinced them that Lisa was the one who was violent. After all, she did have a very long

history of mental illness with long involuntary admissions. The police took Lisa in the back of a paddy wagon to a local hospital where she was assessed and transferred to the local psychiatric unit. She was discharged a few days later without follow-up and had been home only a few days when another argument erupted between herself and her son. This time her son called the hospital. He told them she was becoming increasingly unwell and was aggressive, and the hospital staff called the local crisis team to assess the need for re-admission.

A psychiatrist and two mental health clinicians arrived at Lisa's house. They listened to her son's story and they whispered among themselves. Then one of the health workers "got on the walkie-talkie" and next thing the police were at her door. Lisa thought she was not given a chance to explain what was happening, and was dragged away screaming and protesting, again in the back of a paddy wagon. When she arrived at the hospital she was restrained, sedated, and placed on a mattress in an empty room, on her own.

While recounting this story, Lisa became tearful and agitated. Her speech rate, volume and pitch increased. She had outbursts of weeping and shouting, and expressed feelings of hatred towards one of the health workers whom she perceived as "disrespectful and patronising." She expressed anger, sadness and hurt. Anger at the mental health staff whom she felt had ignored her pleas, behaving as though she "didn't count as a mature human being." Sadness for her fate, and "the fact that my children witnessed my humiliation." Hurt because the whole event was very public, with neighbours hanging out of windows to "look at the spectacle." Lisa thought she would never be able to face her neighbours again. Moreover, she was terrified that involvement with the mental health service would mean that she would never be responsible for her own life, and would not be free of control from others.

### **Impact of a schedule**

These two scenarios made me realise the major impact of schedules on the emotional well-being of people who face loss of freedom, control, and self-determination – whether their own or that of a loved one. The impact of a schedule does not begin with transport to a psychiatric unit for assessment, or with the involuntary admission that follows. Life experiences affect people's behaviours and thinking patterns in many ways. A long time may have passed between the development of the initial symptoms and the time when the effects of the illness bring people into contact with the mental health and/or legal systems (Loebel, Lieberman, Alvir, Mayerhoff & Szymanski, 1992). These symptoms have a cumulative effect on those

around the person experiencing the illness, usually family members, but also friends, neighbours and acquaintances.

Over the last three decades, there has been a major shift in the mental health field toward de-institutionalisation and increased community care of people affected by mental illness. This shift has been associated with a change in care location, with over 90% of people with chronic mental illness now living outside the hospital (*National Mental Health Strategy, 1993*), and a change in the concepts of treatment and rehabilitation. The efficacy of community-based care has been shown by research around the world (Stein & Test, 1980; Sullivan, 1992; Diamond, 1995).

The principle of care in the least restrictive environment has been widely recognised as essential to the provision of community care recognising the right of individuals to respect, privacy and information (*Mental Health Rights Manual, 1995*). This principle is set out in New South Wales (NSW) within the *NSW Mental Health Act 1990* (NSWMHA, 1990) to be considered when assessing a person experiencing a mental illness as to their need for care and control, and the use of coercion to provide necessary treatment.

Literature examining the attitudes toward, and the effects of, involuntary admission to a psychiatric hospital on people who experience mental illness and their families abounds (Kane et al., 1983; Toews, el-Guebaly, Leckie & Harper, 1986; Conlon, Merksey, Zilli & Frommhold, 1990; McFarland, Faulkner, Bloom, Hallaux & Bray, 1990; McGorry et al., 1991; Parrish, 1993; Lucksted & Coursey, 1995; Kanter, 1996). However, information about the events *prior* to the hospitalisation and their effects on those involved is lacking (Ponderotto, 1987; Parrish, 1993; Joseph-Kinzelman, Taynor, Rubin, Ossa & Risner, 1994).

By the time people experiencing mental illness come into contact with mental health services they may have lost contact with their family, lost their jobs, housing, and friends, and found themselves in trouble with the law. The scheduling event, whether initiated by mental health professionals, general practitioners, or police, brings to an end a history of distressing events. This often happens through forced transportation, usually by police officers, to a psychiatric ward or emergency department where they will be further assessed for admission.

Expressions of anger and frustration by consumers to clinicians about the process of scheduling are common. They include concerns about the behaviour of some clinicians during and after a schedule, and the lack of support shown to relatives and friends. Families and friends often complain that some clinicians are "cold and insensitive" at the time of crisis, and

neglect to inform them on how to access the psychiatric unit or hospital for visits, news and information.

There is plenty of anecdotal evidence, in my experience as a clinician, a colleague and a participant in scheduling, that mental health clinicians both in the community and hospital settings are aware of the feelings experienced following such an event. These are the same as those reported in the literature on involuntary admission and include loss of trust in the psychiatric system; loss of trust in people generally; overwhelming feelings of anger; and anger toward staff members involved in the schedule. Feelings of powerlessness; nightmares about loss of freedom and rights; sudden crying spells; startled responses; poor self-esteem; lack of trust in own judgements; and feelings of shame are also reported (McGorry et al., 1991; Parrish, 1993; Joseph-Kinzelman et al., 1994; Lucksted & Coursey, 1995).

Mental health clinicians reported that families described feelings of anger; lack of trust; breakdown of family relationships; and powerlessness. Families also described intense grief; a sense of loss for the loved one; and an overwhelming sense of guilt for being part of the scheduling process. Being unable to plead or intercede for the person experiencing the mental illness was also mentioned (Stein & Test, 1980; McFarland et al., 1990; Parrish, 1993; Joseph-Kinzelman et al., 1994).

Literature investigating the scheduling event, the compulsory removal of a person deemed to be mentally ill from their environment to be further assessed for admission into a psychiatric facility, could not be found. Only two articles, Ponderotto (1987) and Joseph-Kinzelman, et al. (1994) addressed this issue, albeit not as the focus of their papers.

### **Mental Health Promotion - The Project**

This research study was developed as a mental health promotion project (Fiorillo, 1998). Mental health promotion is defined as: "Enabling people, communities, and populations to increase control over and improve and/or maintain their subjective well-being, optimal development and use of mental abilities (cognitive, affective, and relational) and the achievement of goals consistent with social justice" (Scanlon, Williams & Raphael, 1997, p.7).

The aim of this mental health promotion project was to assess the impact of schedules on those most closely involved: the people who were scheduled, relatives of people who were scheduled and community mental health staff and determine whether the process and emotional outcome of the event could be improved. Its specific objectives were to describe



the experience of those involved and investigate whether information about rights, the *NSWMHA, 1990* and the need for involuntary admission were given. Areas of good practice, areas for improvement in the scheduling process and whether there is a place for community education, family involvement, and debriefing were explored.

In order to achieve these objectives, ten people who were scheduled, ten relatives of people who were scheduled and ten clinicians who were involved in scheduling people participated in a semi-structured interview. The interview schedule sought information of a descriptive nature about the event they were involved in, what their feelings were at the time, and how it impacted on future involvement with mental health services.

The results of this research shed some light on a very complex topic. Solutions may not be possible, but acknowledgement of the need for high levels of skill amongst mental health clinicians, additional community resources, sensitive information campaigns, and ongoing support to those who are scheduled and their relatives are essential. There is no doubt that such intervention needs to be conducted ethically and therapeutically, with the best interest of the person who experiences mental illness, and their families and friends, in mind. The event must be seen as a learning opportunity for all, to improve the practices and outcomes of mental health services, to provide support to relatives, and to enable the recovery and well-being of people who experience acute mental disorders.

Some methodological issues became apparent as the interviews progressed and these are described in detail in the methodology chapter (p. 33). Extensive data were gathered, which depth and intensity challenged classification into comprehensive themes. Therefore, the reader may feel like there is some repetition and find some themes running through several chapters. The scheduling event, however, evolves through the chapters and a comprehensive understanding of the experience for those involved is achieved. The participants were candid in their accounts, and some of the stories will engender feelings of sadness and pain. Some readers may find the information confronting.

### **Assumptions**

This work started with the assumption that mental health clinicians involved in scheduling people needed to be more sensitive to the needs and experiences of those on whom their practice has the greatest impact. It also assumed that information about the legal aspects of psychiatry, collaboration between service providers and consumers, and discussion about the

unfolding of the events was not happening. This has been confirmed largely by the data collected from the three groups.

This work did not assume, as initially proposed by some colleagues, that mental health clinicians practice in any way that is intentionally or inadvertently damaging to those they work with. Rather, this work acknowledges that the scheduling event is complex and demanding, and subject to many uncontrollable variables. For exactly these reasons, it deserves special attention from managers, service providers and consumers in developing policies and processes that support team discussions of the ethical aspects of the event and consumer participation in service planning.

Ethical issues are fraught with difficulties, and several contradictions became apparent between the therapeutic and defensive values in the practices described. There remains no doubt that this event requires high levels of clinical skills and judgement if we are to focus on positive therapeutic outcomes. Both hospital and community mental health services need to reflect on their practices and allocation of resources to ensure a schedule does not happen. unless involuntary hospitalisation is, beyond any doubt, the least restrictive option.

### **Chapters' overview**

This work is divided into four parts. Part I includes the "Introduction," "Background Literature" and "Methodology and Demographics."

Chapter I – Introduction. This chapter provides a definition of casemanagement and current trends involving this concept and includes the stories of the two women whose experiences were instrumental in sparking my curiosity about the topic. The Health Promotion framework and project on which the study was based is described, alongside a brief overview of the de-institutionalisation process and the principle of care in the least restrictive environment. My position and assumptions in relation to the data gathered are clarified.

Chapter II – Background Literature. This chapter begins with an examination of the current legislation and the rights of people who experience a mental illness or disorder. It then provides a description of the scheduling event and information about recent investigations on the topic of involuntary admission. Coercion in treatment and hospitalisation; clinical decision-making; consumers' attitudes and perceptions towards involuntary hospitalisation; family perceptions; the dangerousness criteria; ethical and moral issues and Post Traumatic Stress Disorder (PTSD) as secondary-morbidity are discussed.

Chapter III – Methodology and Demographics. This chapter provides a description of the methods of data collection and analysis used in the study. From the beginning, the study evolved in its methodology thus enhancing the value of the data gathered. This study was initially developed as a semi-structured questionnaire and moved through to becoming a semi-structured qualitative interview. The focus is on the lived experience of those involved, and this led to its analysis developing into a qualitative thematic narrative with limited quantitative data. Included are the demographic characteristics of the informants (Table 2) and an overview of the people involved in each story (Table 3).

Part II includes the thematic analysis of the narratives with a focus on the broadest and most prominent concepts. These are “Power”; “Crime or Illness?” and “Information and Education.” A discussion of each concept is included with the results.

Chapter IV – Power. This chapter presents the first and most basic concept on which the whole practice of scheduling is based. Power is experienced differently by the three groups interviewed, and its use in this context challenges social values such as benevolent paternalism, autonomy and self-determination.

Chapter V – Crime or Illness? This chapter describes the conflict between mental illness and deviant behaviour on which stigma, intolerance and stereotypes are based. This conflict is evident in the common use of police officers and paddy wagons in enacting schedules and in ensuring safe transportation to hospital.

Chapter VI – Information and Education. This chapter discusses the lack of knowledge and information people in general have of mental health legislation. This ignorance affects the experience and hinders the opportunity for prevention and early intervention. The current notions of informed consent, competence and insight in psychiatry are challenged as antithetical to working in partnership.

Part III looks specifically at the development of and challenges in therapeutic and supportive relationships during the scheduling event, and its impact on mental illness:

Chapter VII – Relationships. A brief discussion about the current knowledge of the value of therapeutic relationships in mental health work builds on some themes. “Desirable circumstances” looks at what each group see as needed for a positive outcome. “Feelings at the time” opens a window on the feelings experienced by the three groups at the time of the schedule. “Effect on relationships” points out how the event can strengthen or damage existing or developing relationships and future contact with mental health services. Finally,

“Trust and families” examines the impact of this experience of relatives’ level of trust in the mental health system and its clinicians.

Part IV provides a description and analysis of suggestions given by the informants on how to improve the scheduling event and the conclusions drawn from the study. It includes: “Can scheduling be improved?” and the conclusion.

Chapter VIII – Can scheduling be improved? This chapter begins with an exploration of what the informants thought was done well at the time, and what was the worst part of the event. It proceeds with a description of factors such as family involvement, debriefing and staff training and skills identified as necessary to improve the outcome of a schedule.

Chapter IX – Conclusion. A summary of the findings draws attention to areas requiring improvement to provide treatment options and interventions that are humane and based on strong ethical tenets.

To provide the reader with a context for the events described, narratives of the schedules are provided in Appendix C (p. 192). Fifteen stories are recounted in their entirety, as told by the participants, but with some editorial licence to enhance clarity. The further 15 stories are told with more brevity. I add a note of caution here, though. When people are under stress, they do not always “hear” what they were told or remember what happened. Memories are fragile and these stories are narratives of the past and need to be treated as such (Skultans, 2000; Campbell, 1994). It is noteworthy that this is the case with *all* the stories, and each one is validated in its content by another. While there may be doubts about each and everyone’s memory we cannot deny the reality of the events.

This study has enabled changes in my clinical practice through increased knowledge and awareness of the issues involved and their impact on individuals (Fiorillo, 2001). Hearing the stories challenged my assumptions about insight, competence and working in partnership. Moreover, it has grounded my perception of people experiencing an acute episode of mental illness as “people” rather than “illness.”

To facilitate the reader becoming familiar with each participant, the stories are introduced in the text with a number, and the page where this can be found in Appendix C (p. 192). Additionally, cross-referencing will be made throughout the text to guide the reader to topics presented or reinforced in other parts of the study.

## Chapter II – Background Literature

*It is unfortunately true that by and large those areas which broadly relate to community issues and the problems of the relation of medicine and health to the community and even areas which relate to disability as distinct from mortality have tended not to have been highly regarded by research effort in Australia.*

Prof. Ian Webster, Quoted in *Human Rights & Mental Illness*  
(1993, p.821)

Concern regarding treatment of persons against their will has been expressed over time in many ways and in many places. Essential to advancing this debate is an understanding of the current influences in mental health care, its definition, the evolving thoughts on access to treatment and delivery of service, and the relevant legislation. The definition of mental illness and the criteria for involuntary admission, including patients' rights, as defined within the *NSWMHA, 1990* are provided here. Additionally, a definition of "schedule" is given, followed by an overview of relevant topics. Coercion, decision-making, perceptions and opinions, effects, dangerousness criteria, ethical and moral issues and secondary morbidity are the most studied topics in the literature.

On a national level, it is estimated that 28% of the Australian population will meet the criteria for a mental disorder in any given year (Andrews & Teesson, 1994). In NSW alone, a report by the state government revealed that 150,000 people were being treated for a mental disorder (*Leading the Way, NSW Dept. of Health, 1993*).

More recently, a national study to estimate the 1-month and 1-year prevalence of mental disorders in the Australian adult population<sup>2</sup> found that 17.7 % of the sample (n. 10,600) had one or more common mental disorders. These included anxiety, depression and substance abuse and were associated with considerable disability in activities of daily living (Henderson, Andrews and Hall, 2000). Additionally, a study of the "*Low Prevalence (Psychotic) Disorders*" was conducted as part of the *National Survey of Mental Health and Wellbeing (1999)*, and gathered information through a census of 3,800 Australians aged 18-64 years of age with psychotic disorders. This national study of people living with psychotic illness found that between 4 and 7 persons per 1,000 adults in urban areas seek contact with all kinds of mental health services due to symptoms of psychosis. For a high proportion of these people, the course of the illness is continuous and unremitting (Jablensky et. al., 1999).

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<sup>2</sup> This survey did not include ATSI people, NESB, and non-private households such as prisons and nursing homes in their sample.

Contemporary practice in mental health work involved a shift from long-term hospitalisation to provision of treatment services in the less restrictive community environment (*National Mental Health Strategy*, 1993). The principle of "least restrictive care" is outlined in the *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care* adopted by the United Nations General Assembly in 1991 and endorsed by the Australian Health Ministers in 1992. Principle 3 states that "every person with a mental illness has the right to live and work, as far as possible, in the community" (*Human Rights and Mental Illness*, 1993). This involves hospitalising a person only when a less restrictive option to care is not available (*Mental Health Rights Manual*, 1995).

Mental health services in Australia are required to provide the least restrictive and least intrusive treatment and support possible in the environment and manner most helpful to, and most respectful to, the consumer. Least restrictive is defined as "imposing the least personal restriction of rights and choice in balance with the need for treatment" (*National Standards for Mental Health Services*, 1996, p.26).

The developments resulting from this evolution in thinking has produced a growth of community services, in particular 24-hour crisis services, to provide acute care to people affected by mental illness in their own community. However, the nature of current practice and resources is such that at times people must be admitted into a psychiatric facility for care, treatment, and / or containment. Such an admission may also have to be on an involuntary basis.

### **The NSW Mental Health Act 1990 (NSWMHA, 1990)**

A schedule is the process of compulsorily conveying a person to a gazetted facility, for assessment by a prescribed person. The grounds for scheduling people experiencing mental illness are contained within the *NSWMHA, 1990*. This legislation specifies that a person must be suffering from a mental illness or disorder and that owing to that illness or irrational behaviour:

*There are reasonable grounds for believing that care, treatment or control of the person is necessary: (a) for the person's own protection from serious harm, or (b) for the protection of others from serious harm. In considering whether a person is a mentally ill person, the continuing condition of the person, including any likely deterioration in the person's condition and the likely effects of any such deterioration, are to be taken into account.*

(*NSW Mental Health Act, 1990, Section 9, p.6*)

### Rights of persons affected by mental illness

In NSW, mental illness is the only non-infectious illness governed by an Act of Parliament and bound by legal-judicial measures. The legal rights of persons affected by mental illness are described within the *NSWMHA, 1990* as the same as those of the general community. Exceptions include times when it is necessary to be coercive in providing care, treatment and control of an individual, or in protecting the community from an individual's behaviour; and the added rights of a detained person to be treated in the least restrictive environment. This last point means that if a less restrictive alternative to hospitalisation becomes available the "patient" must be discharged to it *even if* the involuntary treatment order is still active (my emphasis).

### The schedule

The national survey of people living with a psychotic illness (Jablensky, et al., 1999) draws data from a sample of 586 men and 394 women (total n. 980) who had contact with health services and met the criteria for psychosis in a period of one month. They found that 52% had at least one hospital admission in the year prior to the interview, and 46% of the total were admitted involuntarily at least once.

State laws attempt to protect people from unwarranted detention in institutions, as well as protecting the community from possible risks caused by people experiencing mental illness. In NSW, where this study was conducted, the law states that involuntary admission is necessary when a person is mentally ill, a danger to themselves or others or to their reputation due to their symptoms and/or behaviours, and *not consenting* to hospitalisation and treatment (*Mental Health Rights Manual, 1995, p.5, my emphasis*). The legal document used is called a Schedule II form (Section 21 of the *NSWMHA, 1990*). Community mental health professionals, general practitioners (GPs) or police officers primarily initiate the schedule (see p. 1 for definition) after the person experiencing mental illness comes to their attention through their behaviour and/or speech becoming disturbed or disruptive. Coulter (1973) noted the early negotiation of what constitutes mental disorder occurring between family and other community members, leading to the need to seek specialist assistance. These specialists provide the initial labelling and subsequent interventions such as scheduling.

Scheduling involves a number of specific practices, many of which may be viewed and experienced as distressing. These include mental health professionals and/or police officers making unannounced visits at the homes of people whom they seek to hospitalise. They may also use mobile phones and paging systems and "talk over" the person, among themselves and

with relatives or neighbours. Police officers arrive, and frequently restrain and “drag” the person into a police van (paddy wagon). The person may arrive in police custody at a hospital that is either unfamiliar to them or has negative connotations from previous experiences; once there, they may be subjected to further restraining and enforced sedation. For people living on their own, the process may also involve forcible entry into their premises by police (including breaking down of doors or windows). Schedules involving the police are enacted when the police and ambulance services are able to co-ordinate a mutually convenient time (such activities often have a lower priority than many other emergency service duties). This may occur after dark when the police workload may have decreased, or it is known that the person will be home.

### **Current research**

Research in Australia in the area of mental health is “neither highly funded nor highly regarded.” This fact has been noted by the *National Inquiry Into the Human Rights of People with Mental Illness* (1993, p.821). Literature relating to the scheduling event itself could not be found. Only Joseph-Kinzelman, et al. (1994) and Ponderotto (1987), addressed this specific issue (see p. 16).

One result of this lack of funding is that there is a paucity of data in many areas related to mental health. This paucity of information may reflect the difficulties inherent in studying the effects of mental illness on those affected by it, be it the person themselves or those close to them. Furthermore, general acceptance of the bio-medical explanation of mental illness may cause difficulties in accepting that the behaviours of people experiencing severe mental illness may at times be the result of choice and psychosocial learning, rather than symptomatic of an illness (Sullivan, 1992, p.205). Interventionist measures such as the schedule are therefore seen as necessary when hospitalisation is the only option to safeguard the well-being of both the individual and the community.

Although the process of involuntary admission has received little attention in either the Australian or the international literature, some related areas have been extensively addressed. Table 1 provides an overview of the available research. The majority of this work has been conducted in the United States.



**Table 1.**  
**Overview of Literature on Involuntary Admission to Hospital**

Topic	Authors
Coercion in treatment and hospitalisation	Hiday, 1992; Lucksted, & Coursey, 1995; Diamond, 1995; Lidz, et al, 1995; Nicholson, Ekestam, & Norwood, 1996; Kaltiala-Heino, Laippala & Salokangas, 1997.
Clinical decision-making for involuntary admission	Miller, & Fiddleman, 1983; Ponderotto, 1987; Dworkin, 1988; Bagby, Thompson, Dickens & Nohara, 1991; Aviram, 1993; Anderson & Eppard, 1995; Hendryx, & Rohland, 1997.
Patients capacity for decision-making	McKinnon, Cournos, & Stanley, 1989; Wong, Clare, Gunn & Holland, 1999; Hoyer, 2000.
Attitudes and perceptions towards involuntary hospitalisation	Spence, Goldney, & Costain, 1988; Conlon, et al, 1990; Joseph-Kinzelman, et al, 1994.
Change of perception about detention following treatment and discharge	Srinivasan, Soundararajan, & Hulin, 1980; Snowdon, 1981; Kane, et al., 1983; Toews, et al., 1986.
Changes over time in patients' reactions to being committed	Kane, et al, 1983; Toews, et al, 1986

Perceptions and effects of the use of coercion

Hiday (1992, p. 360) reviewed empirical research on civil commitment addressing coercion. She begins the review with a definition of coercion from a subjective perspective, stating that "coercion is any action the individual says it is." Objective definitions are much harder to achieve and Hiday provides an account of the various definitions found in different studies focusing on "different points in the continuum of pressure that may be used to obtain treatment for the mentally ill" (Hiday, 1992, p. 361).

Hiday (1992) also reports on the difficulty of defining the use of "threats" as constituting either coercion or, alternatively, the provision of information about the possible consequences of refusing the proposed treatment. Overall, she found that the results of available studies were inconclusive, with findings showing predominantly positive and some negative experiences of coercion. Hiday (1992) recommends further research on the possible outcomes of the use of coercion controlling for confounders such as psychotic symptoms and life events.

Luckstead and Coursey (1995) surveyed 105 persons affected by mental illness and examined their experiences of pressure and force in three different areas: medication, outpatient therapy or rehabilitation, and hospitalisation. 57% (n. 50) of the 88 responses reported having felt pressured or forced into hospital admission at some time during the course of their illness. 58% (n. 51) of the total sample reported having experienced some pressure in at least one of the three areas surveyed. The most common effects of the perceived coercion identified were anger and fear. For some, the experience left them less willing to enter the hospital when they needed to, while others said it made them more willing. Over 30% said pressure or force is always appropriate if it is in the person's best interest, although a minority of approximately 15 % said that force should never be used. Approximately a quarter of the respondents felt that treatment refusal should never be permitted, while the remainder three quarters felt it should always be allowed except in psychiatric emergencies.

#### Decision-making about hospitalisation

Ponderotto (1987, p. 542) identified hospitalisation issues and processes (both voluntary and involuntary) as a gap in the knowledge and education of counsellors working in a variety of settings. He states that "many counsellors are first exposed to issues of client hospitalisation when they are confronted with the issue in vivo." Little seems to have changed in the intervening years.

The first issue confronting mental health clinicians is whether to hospitalise people experiencing mental illness at all. Hospitalisation carries lifelong stigma, interrupts people's lives, results in loss of self-control, and affects self-esteem, self-efficacy and self-concept (Ponderotto, 1987). Therefore, the decision about whether to hospitalise a person cannot be made lightly. However, the person's physical well being and safety must always be a primary consideration (Everstine & Everstine, 1983).

Ponderotto (1987) argued that the counsellor (or clinician) must make a decision as to whether hospitalisation is the most appropriate way of dealing with an acute crisis. This decision must consider the ethical responsibility to be knowledgeable about diverse concerns regarding hospitalisation and should include:

- 1 a clear understanding of when hospitalisation is warranted, and
- 2 familiarity with inpatient procedures so that their clients and families can be adequately prepared.

(Ponderotto, 1987, p. 542)

Assessment for involuntary admission is challenging for mental health clinicians as legislative requirements stipulate that treatment should occur in the least restrictive environment.

Anderson and Eppard (1995), in a phenomenological study of decision-making processes prior to involuntary admission, interviewed 24 clinicians who made assessments in a community-based urban psychiatric emergency agency. They identified nine elements of decision-making as part of the initial risk assessment:

- 1 the assessment was based on facts;
- 2 the assessment was individualised, except in highly complex situations;
- 3 the state mandated criteria that the person must be mentally ill, especially if the person is a danger to self or others were considered;
- 4 alternatives to hospitalisation were investigated;
- 5 decisions were made in collaboration or consultation with other team members;
- 6 intuitive reasoning and gut feelings were used;
- 7 connecting<sup>3</sup> with the person made the assessment easier as it was based on previous knowledge of that person;
- 8 caution was used to minimise the effects of such a decision, and
- 9 the clinician's own inability to control all contingencies in trying to prevent the consequences of stigma or self-harm from the decision to hospitalise were recognised.

(Anderson & Eppard, 1995, pp. 727-728)

Bagby et al., (1991) conducted a study of 495 psychiatrists in Ontario to assess the importance of several factors in decision-making about hospitalisation. They were asked to make decisions about commitment based on three hypothetical case vignettes. The person's legal requirements for committal, the possibility of successful clinical treatment, availability of alternative resources, and presence of psychotic symptoms were factors assessed.

The psychiatrists' decisions on whether to commit were made primarily on legally mandated factors such as dangerousness to self or others, inability to care for self, and evidence of psychosis. Availability of other community resources and the person's potential for response to treatment played only a small part. It was noted, however, that some decision errors did occur, with more false negatives than false positives<sup>4</sup> being identified. The authors stated that this outcome appeared to indicate that this sample of clinicians unintentionally erred towards preserving the rights of the individuals over the protection of society.

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<sup>3</sup> Connection in this context involves the development of a therapeutic trust relationship between the person and the health professional that is conducive to good communication, care planning and achievement of common goals.

<sup>4</sup> False positive: erroneously identified as dangerous. False negative: erroneously identified as not dangerous.

### Perceptions and opinions about commitment

There is some evidence that involuntary admission is not necessarily a traumatic, negative experience in subsequent treatment episodes (Isohanni & Nieminen, 1990) and that once patients receive treatment and leave hospital their perception about detention often changes to a belief that it had been appropriate. Toews et al. (1986) examined the influence of time on patients' reactions to involuntary commitment. This Canadian study was based on Allen and Barton's (1976, cited in Toews et al., 1986) smaller study which found some differences in patients' opinions about commitment at the time of admission and discharge but no change at three, six, and twelve months. The larger study by Toews et al. (1986) found that committal was generally viewed neutrally by most patients at any stage.

Toews et al (1986) sought patients' opinions regarding reactions to committal, knowledge and use of appeal mechanisms, attitudes toward the hospital, attitudes toward current issues regarding committal, and perceived effects of the committal and asked questions designed to elicit indications of the patient's self-image. The results showed little significant change of opinion over time. The largest differences were about claimed knowledge (or lack thereof) of the fact that they were committed, and in the knowledge and exercise of their rights (Toews et al., 1986, p.414). This lead the authors to conclude that patients need to be notified in writing of their rights and recommending that such information giving is recorded in case the patient denies they were given it.

Conlon et al. (1990) examined the characteristics and attitudes toward committal of 28 patients hospitalised for the first time in an Ontario provincial psychiatric hospital. Semi-structured interviews were used asking patients to describe what they liked and did not like about the committal. Areas of inquiry included whether a satisfactory explanation of committal was given; the benefit of having someone represent their interests; whether they felt the committal was necessary; whether the committal had led to treatment; whether the outcome was helpful; and whether the outcome was harmful. All responses were around 50%<sup>5</sup> except for the harmful outcome, which had a response of 18%. Overall, 63% had an unchanged attitude towards psychiatry, with 18% feeling more positive and 18% more negative. Some of the findings indicated that involuntary admission was positive in that it led to treatment. The resulting confinement was seen negatively. As the respondents were all first admissions, perception that committal was good could be based on lack of previous

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<sup>5</sup> Where no numbers are given, no numbers were provided in this and subsequent articles.

experience, the higher chance of a positive outcome from treatment, and because the illness had not yet seriously affected personal relationships.

Aviram (1993) examined ways of maintaining a balance between the medical and legalistic models to avoid unnecessary commitments and enhance community mental health services. He quoted research that suggested a relationship between the commitment process and the services and resources available and recommended examining the systems and structures existing within organisations that influence the way scheduling occurs.

Aviram's (1993) study investigated organisations that had established screening services to balance civil liberties with the need for treatment. The aim of such services was to provide access to crisis teams and other effective community services, and encourage voluntary hospitalisation. The structure and processes of the screening service were analysed to assess how these services operated and performed their functions and how they affected hospital admissions and commitment decisions. The study included the way screening service staff interacted with other mental health and related services. It was expected that the new system would show a reduction in the number of inappropriate commitments, a decrease in the number of hospitalisations to state hospitals, and an increase of referrals to community mental health services.

The results were not what they expected. They found that there was a degree of conflict between staff and psychiatrists about the need for hospitalisation and that where there was no service affiliation with a psychiatric unit at a general hospital voluntary admission was more difficult. Consequently, the service had higher rates of involuntary admissions to state hospitals; and the rates of admissions from the screening centre to the administratively related admitting unit were much higher. They also found that screeners actually encouraged hospitalisations. Five factors were involved in increase, namely: pressure from the community, lack of alternatives and community resources, staff concerns with liability, easy access to inpatient services and lack of incentives to find alternatives or reduce hospitalisation (Aviram, 1993, p. 205).

It was clear from Aviram's investigation that there were problems with definitions of mental illness, with who was eligible for admission, and with the criteria for commitment. The discretion of the individual worker was the main decision-making tool. The "dangerousness" criteria and criteria for admission remained unclear and undefined. Staff issues, including educational levels, training, and lack of career options, were also significant in terms of

whether or not a person was committed. Consequently, this made screeners “more vulnerable to pressure ... to commit persons under inappropriate circumstances” (Aviram, 1993, p. 207).

Joseph-Kinzelman et al. (1994) used an action research approach with a small sample of 15 subjects to examine clients' perceptions of involuntary hospitalisation, with a focus on understanding the client's experience. They demonstrated that all informants experienced panic level anxiety in the process of getting to the hospital. Concerns were expressed about disrupted family relationships. Fear, confusion and a sense of failure were common. Calm and emotionally supportive approaches from clinicians were valued most at this stage.

Participants reported that at the time of admission they were frightened. The admission process itself exacerbated the extreme anxiety felt. Clients wanted space, privacy, time, and emotional support rather than being bombarded with questions and physical examinations. The Magistrate Hearing made them feel trapped, angry and sad. They expressed dissatisfaction with the court hearing process and wanted more information and explanations beforehand as well as more sharing of the experience with supportive staff. The period of involuntary hospitalisation was “an emotionally painful time and a demanding experience” (Joseph-Kinzelman et al., 1994, p. 29), as it brought up issues of lack of control over their own lives. Furthermore, the study showed that those who were the most dissatisfied with the admission process and treatment did not comply with medication after discharge.

Leaving the hospital and returning to the community was both a hopeful and demanding time. Re-negotiation of personal and household routines had to be faced, and the casemanagers' support and help with relationships, daily life demands, and coping with stigma was valued. For most (73%), life back in the community was difficult due to hearing voices, difficulty with finances, and problems negotiating public transport. From the total sample of 15, 60% indicated they would only ask for someone to be admitted against their wishes if that person was in immediate danger and all else had been tried. The remaining 40% said they would not inform mental health professionals of the need to admit someone involuntarily under any circumstances.

#### Effects of Involuntary Admission

Cohen (1994) described the experience of being in a locked ward as paralleling the trauma of events such as war, domestic violence, torture, and rape. She used the case-scenario of a woman admitted due to a severe emotional illness to illustrate events and feelings experienced that, as described, were seen as evidence of a traumatic experience. Using Herman's (1992)

model, Cohen (1994) proposed that the experience of “captivity” in a locked psychiatric ward produced the essential ingredients of a traumatic experience. Some of the experiences described included the loss of control over one’s fate compromising autonomy, and the subjection to unwanted physical and psychological examinations compromising a sense of self. Furthermore, separation from loved ones and personal possessions signalling loss of autonomy and control, inducement of fear through becoming disoriented and losing track of time, and being exposed to “other patients’ cries, screams, or violent acts” (Cohen, 1994, p. 79) caused intense feelings.

Herman (1992, p. 33) used the *Diagnostic and Statistical Manual of Mental Disorders*, (4<sup>th</sup> Ed.) (DSM IV) definition of trauma as an event that is “outside the range of usual human experience” and stated that only fortunate people find traumatic experiences uncommon, as most people would experience a trauma at some stage of their lives. In looking at causation and predisposition, she states that “traumatic reactions occur when action is of no avail. When neither resistance nor escape is possible, the human system of self-defence becomes overwhelmed and disorganised” (Herman, 1992, p. 34).

In Herman’s view, losses and mourning commonly follow traumatic life events and the potential for pathological grief and severe, persistent depression in people exposed to traumatic events is high. She adds that the response of the community is crucial in its influence on the resolution of the trauma through public acknowledgement and public action that provides recognition and restitution (Herman, 1992, p. 70), and is relevant to the scheduling event.

Parrish (1993) summarises the main arguments for and against the use of involuntary interventions as reported at meetings held with clients, families, and State and local health service decision-makers. The clients’ positive reactions about commitment concerned the easing of suffering, pain and embarrassment; the enhancement of recovery through medication and the shortening of the crisis; the improvement in decision-making capacity for the State and medical systems; and increased access to treatment. Committal was seen as a possible alternative to homelessness and prison.

The arguments against involuntary interventions were that “for every person who is helped, there are many others who suffer damaging short and long term effects resulting from infringements on their liberty and civil rights, loss of decision-making power, exposure to harmful institutional environments, and ineffective treatment” (Parrish, 1993, p. 16). These effects included loss of self-determination; questionable benefits of forced treatment;

reinforced stigma and discrimination, and potential adverse side effects of forced medication. Additionally, Campbell and Schraiber's (1989) study (as cited in Parrish, 1993) found that 47% of former patients avoided mental health services due to previous negative experiences.

Families reported being concerned about the mentally ill family member, other family members and the family unit, concerns that are at times contradictory. Support for involuntary admission related primarily to the need for personal safety due to shorter hospital stays and community living. Relatives were more likely to be on the receiving end of the troubled behaviour of the person affected by mental illness, which at times includes violence. Potential violence is often one of the main reasons why admission is sought. Furthermore, involuntary admission is often seen as the only alternative as "when all else is exhausted and the person is in grave danger, abstract principles such as freedom and self-determination seem irrelevant to desperate families" (Parrish, 1993, p. 18).

Nevertheless, families felt that admission to hospital engendered intense pain. The mental state and behaviour of the person experiencing mental illness were seen as a life-threatening situation, for themselves or the ill relative and, additionally, the possibility of involuntary admission created concerns about its impact on family relationships. Seeing a loved one dragged away by police and having to face the criminal justice system was "no easy task" (Parrish, 1993, p. 19). Another consequence of involuntary admission cited was the damage to the family unit when a family member initiated the commitment process, i.e., when a relative was seen as responsible for calling mental health professionals or the police. Loss of trust and the development of a hostile relationship with the relative were likely consequences.

Representatives of the mental health system described involvement in involuntary admissions as a positive aspect of their work and stated that the mental health legislation permits "doing the right thing" (Parrish, 1993, p. 19). This group generally saw society as having a "paternalistic obligation to care for acutely disordered individuals, and to fulfil its policing responsibility to prevent and control behaviour that is perceived as dangerous or harmful." In these instances, clinicians felt "personally, professionally, and legally responsible" if someone was not committed and later harmed themselves or others. Additionally, they stated that involuntary interventions allowed for the efficient use of limited resources. Less comprehensive resources are needed at a community level if intervention only happens during an acute crisis and support services are kept to a minimum.<sup>6</sup> At the same time, hospital safety

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<sup>6</sup> This is currently happening in some areas in NSW where relationship and support factors are being devolved to voluntary and non-government organisations, with mental health services maintaining only a highly specialised role in the treatment of mental illness.



is ensured through medicating difficult patients and locking doors, thus limiting staff burnout and turnover and ensuring the safety of other patients.

Interviews with mental health system's informants showed that involuntary interventions could, on the other hand, confound "doing the right thing" and made psychiatrists (and therefore mental health professionals in general) an "agent of social control and an enforcer of social mores" rather than a healer (Parrish, 1993, p. 19). This results in conflicting loyalties as to whose interest is served when committing someone to a psychiatric institution.

Additionally, mental health services have been narrowed in many areas to include only basic crisis response, with people allowed to become very unwell before intervening, thus increasing the chances of involuntary admission being necessary.

#### Families' perceptions about commitment

Few studies have sought to examine the perceptions of families regarding commitment. McFarland et al. (1990) surveyed family members of people affected by mental illness and asked about their experiences and opinions with civil commitment.<sup>7</sup> Family members were asked about their relative's involvement with the commitment system and for suggestions for improving the commitment process. The survey consisted of 80 items, mostly multiple-choice or checklist questions.

Generally, family members felt that unusual behaviour (60%), poor judgement (48%), difficulty sleeping (47%), and personality changes (45%) were the main reasons for their relative's involvement with the commitment system. Other signs and symptoms were, in descending order: inability to care for oneself, household disruption, refusal to take medication (36%), giving away possessions, disturbing the peace, damaging property, threatening others (23%) or threatening self (16%). In their most recent experience of the scheduling process the following problems were reported: no problems (17%); harm to relationship with relative (15%); relative being shackled by police officers (15%); relative being released too soon (12%); and relative detained too long (3%). Other problems were that the commitment process was too slow; police refusing to take the client into custody; and mental health staff saying the client did not meet the criteria for involuntary admission. These last three factors all scored at 10%, while 12% said the process of commitment was too complicated. Only 25% of the respondents reported that community clinicians were generally helpful.

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<sup>7</sup> This paper refers to civil commitment relating to mental illness and involuntary hospitalisation rather than legal commitment relating to criminal activity and imprisonment.

Regarding improvement, 57% felt that after inpatient commitment patients should be required to participate in outpatient treatment and take medications; and 55% asked for more education and printed information about the commitment process as well as having a professional assigned to go through it with them. Most respondents felt it should be easier to commit people affected by mental illness, and that people should stay longer in hospital. Fear and inability to care for their relative at home were barriers to supporting outpatient commitment (McFarland et al., 1990).

### Dangerousness criteria

Several concerns have been raised about people who need treatment but who are not dangerous and who, allegedly because of their mental illness, refuse treatment (Sherlock, 1986; Ponderotto, 1987; Malla, 1988; McFarland et al. 1990; Conlon, et al., 1990; Moama & Gagnon, 1991; Miller, 1992; Parrish, 1993; Anderson, & Eppard, 1995).

Miller (1992) reviewed a body of literature looking at the dangerousness criteria versus the need for treatment criteria. They report that those committed according to the need for treatment were much more likely to be committed because of their dangerousness (to self or others). However, the research showed that people deemed dangerous to others seldom require or benefit from treatment.

In this study, Miller (1992) examined state hospital admissions and census data from eight American states that had added "need for treatment" to their legislation between 1975 and 1990 to evaluate whether concerns that this legislation would lead to an increase in involuntary admissions were well founded. While the "need for treatment" criteria was seen as too broad, too open, and too subjective, the "need for protection" or "dangerousness" criteria was felt to leave too many individuals who needed treatment and refused it to deteriorate until they required emergency involuntary admission.

The "dangerousness" criterion was associated with the potential to select the wrong kind of patients. The authors' position was that violent individuals who were not mentally ill would be committed, and mentally disordered people whose disordered state was not recognised (because they were not violent) would be dealt with by the criminal justice system (see also Sherlock, 1986; Parrish, 1993; Joseph-Kinzelman, et al, 1994; Hoyer, 2000; for similar concerns).

Although Miller's study was initiated in response to concerns about an increase in involuntary admissions, it actually showed a decrease in involuntary admissions after the legislative

changes in some states, with some states showing a rise in the number of voluntary admissions. The results were seen as an indication that the prediction of the critics that the “need for treatment” model would lead to an increase in admission rates had no foundation in practice, but further research into the causes of such changes was recommended. These findings could indicate a shift in power relations whereby people, following the changes in legislation, may be more easily persuaded to accept admission by being informed that they can be involuntarily admitted. This “persuasive” tactic and its possible effects were not explored in the study.

The literature also shows that a large number of clients admitted under the criteria of dangerousness fail to show any evidence of violent or suicidal behaviour (Malla, 1988; Moama & Gagnon, 1991). Furthermore, there is evidence of people admitted involuntarily to psychiatric hospitals without meeting the criteria for detention (Anderson & Eppard, 1995).

Kaltiala-Heino et al., (1997) studied the impact of the use of coercion on treatment outcome from the point of view of 87 consecutively admitted psychotic patients in a Finnish University Hospital. The mental health status of people treated involuntarily was compared to those treated voluntarily. The study consisted of two structured interviews, the first after two weeks of treatment and the second approximately six months after discharge.

Coercion was measured according to three defined categories. The legal status of those admitted involuntarily and those admitted voluntarily were compared. Patients who reported being coerced or receiving involuntary treatment were compared to those who did not report experiencing coercive measures. Finally, elements detected in the interviews that showed a perception of coercion were summarised into a definition of coercive admission. They found that, in keeping with the results of this study, coercive treatment measures arouse negative feelings, create negative expectations, and are barriers to the development of a trusting relationship between the person who experiences coercion and clinicians.

#### Ethical and moral issues

Sehdev (1976) discussed the right to treatment and the right to refuse treatment and the serious implications this dichotomy has in psychiatric mental health. Clinicians tend to see mental illness as an outside force that prevents a person from exercising their right to treatment. The possibility of the person being influenced by psychotic symptoms not to accept treatment even if their life is threatened is very real. The intent of legislation today, however, is to end unnecessary, indefinite, and involuntary detention and treatment of individuals

thought to be mentally disordered; to safeguard individual rights through judicial review; and to provide and promote detention and treatment of persons when human life is endangered.

Sehdev (1976) discussed “due process” (also known as “natural justice” – the right to have treatment versus the right to refuse it) and “informed consent.” The associated difficulty of determining the person’s capacity to accurately assess reality, process information, consider several options and choose from among these options was discussed, and Sehdev (1976) drew attention to the dilemmas involving consent by children and what would happen if parents did not have the right to decide. This is related to the ‘parens patriae’ right of psychiatrists to function as parents at a time when the person experiencing mental illness is deemed incapable of making decisions for themselves (paternalism). Sehdev (1976, pp. 664-665) stated that:

*The best results from any treatment are obtained when patient and physician engage in a collaborative effort, based on consent, information and trust. Under certain circumstances, it may not be possible to obtain the co-operation of the patient, let alone informed consent. In all treatment circumstances, however, the clinician must enumerate alternatives with attendant potential risks and benefits.... Treatment should not be a matter of democracy, oligarchy, or autocracy, but a matter of professional judgement.*

Congruent with the legal issues in psychiatry are the dilemmas and concerns surrounding the ethics of mental health law. Ethics has been defined as a branch of philosophy that examines values and human conduct with respect to deciding between good and bad, good and evil, right and wrong, help and harm (Kentsmith, Salladay & Miya, 1986). Within it, there are a number of important elements:

- 1 a responsibility to the client,
- 2 the obligation to act ethically,
- 3 a respect for the client and other professionals,
- 4 a commitment to the client’s good,
- 5 the obligation to tell the truth,
- 6 a respect for the law,
- 7 institutional commitment,
- 8 commitment to improving the community,
- 9 commitment to develop and share knowledge, and
- 10 an obligation to extend or limit professional responsibilities

(Kentsmith et al., 1986, p. 7)

In their chapter on the ethics of surrogate decision making, Buchanan and Brock (1989) point out that the ethics applying to common cases of medical treatment of physical illness also apply to people affected by mental illness and to its treatment. There are differences, however, that require special consideration and discussion. Those outlined in Buchanan and Brock (1989, p. 311) include the opinion that “mental illness often, although by no means always, impairs the person’s ability to make a competent decision about his or her need for treatment” and that, “some psychiatric patients are involuntarily hospitalised who at the same time are deemed competent to refuse treatment for their illness.” Considering these points, it is important to remember that even the effects of mental illness such as delusional beliefs can be quite focused and isolated, in some cases having no effect at all on a person’s capacity for decision making about hospitalisation and treatment.

In discussing the dangerousness criteria, Buchanan and Brock (1989, p. 328) argued that detention for dangerousness to others on grounds of mental illness is “always preventive detention, since even when a history of violence or other harmful acts towards others is required, it is required only as evidence in support of the determination that the person now poses a danger of acting to cause harm to others in the future.” Furthermore, “if the dangerously mentally ill are justifiably treated differently, it must be because they are not capable of responsibly controlling their behaviour that is dangerous to others as required by criminal prohibitions. Therefore, they are not subjected to the ‘do it or else’ criminal law, but instead to a cost / benefit calculus of protection and prevention” (Buchanan & Brock, 1989, p. 329).

Sherlock (1986, p. 184) discussed the idea that “the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their members is self-protection. That the only purpose for which power can be exercised over any member of a civilised community, against his will is to prevent harm to others.” Over the last decade western countries such as the United States, Australia and the United Kingdom have taken as the only justification for civil commitment the likelihood of dangerous behaviour to self or others on the part of the person experiencing a mental disorder.

In 1997, the NSW legislation was amended to include protecting people affected by mental illness from serious harm to their reputation or serious deterioration of their physical and/or mental health (need for treatment criteria). If the person is deemed a danger to self or others unless held and treated the mental health system will commit them. Otherwise, the criminal

justice system exists to handle violent behaviour, thus making prediction of dangerousness to self or others a crucial judgement in the commitment process.

### Secondary morbidity: PTSD and psychotic episodes

PTSD has been shown to occur following a range of extreme stresses including war, rape, and domestic violence (Herman, 1992), natural disasters (Raphael, 1986; Madakasira, & O'Brien, 1987; McFarlane, 1988) and physical illness (Burstein, 1984; Kutz, Garb, & David, 1988). The question of post-psychotic syndromes as psychological responses to a psychotic experience has been raised. Depression as a psychological response to developing a schizophrenic illness has received some attention (McGlashan & Carpenter, 1976) and "raises the question of whether other post-psychotic syndromes of therapeutic and diagnostic significance exist and more generally what the spectrum of post-psychotic symptomatology actually involves" (McGorry et al., 1991, p. 253).

In answer to the above question, McGorry et al. (1991) focused on PTSD as a possible "response syndrome" to acute psychosis, and its relationship to other symptomatology that develops following a psychotic episode such as depression and negative symptoms.<sup>8</sup> The aim of the study was to examine the prevalence of PTSD in recent onset psychosis and explore the relationship between PTSD and other post-psychotic symptoms. The results of the study showed no correlation between PTSD and involuntary admission or negative symptoms. Rather that "this type of symptomatology [PTSD] is experienced by a substantial subgroup of people in the wake of a psychotic episode. Such symptoms seemed to be linked especially to the experience of hospitalisation and less so to the psychotic experience per se" (McGorry et al., 1991, pp. 255-256). Although it is difficult to distinguish between the consequences of a particular event such as a schedule, and the long term traumatic effects of having a mental illness, these effects have been linked to involuntary admission in a more conceptual way (McGorry et al., 1991).

Priebe, Broker, and Gunkel, (1998) looked specifically at the correlation between PTSD and involuntary admission in a sample of 105 people diagnosed with schizophrenia who were being treated in the community. They sought to examine whether the experience and/or the treatment of schizophrenia may cause PTSD. 51% (n. 54) of the sample fulfilled the criteria for a PTSD diagnosis. No association between a diagnosis of PTSD and reports of involuntary admission was found. Neither was there a correlation to the presence of negative symptoms.

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<sup>8</sup> Negative symptoms of a psychotic illness are characterised by the presence of something that is usually absent and include poverty of speech, flat affect, social withdrawal, apathy, and lack of motivation.

Despite the absence of statistical significance in the development of PTSD symptoms following involuntary admission, these symptoms may well develop in some people whose experience of involuntary admission was traumatic. Furthermore, it is suggested that PTSD symptoms in this population may be due to other traumatic experiences not elicited in the studies, or to the overlap of symptoms of PTSD with those of severe mental illness.

Morrison, Bowe, Larkin and Nothard (1999) conducted a study looking at the relationship between compulsory hospitalisation and symptoms of post-traumatic stress disorder. They hypothesised that a number of people admitted to a psychiatric hospital would meet the criteria for PTSD and that those involuntarily admitted would have higher rates of PTSD. Although the response rate was poor the results suggested that first admissions may be more traumatic and that “patients exhibit strong and varied emotional responses to such admissions, supporting the suggestion that psychiatric admission is likely to cause pervasive distress in anyone” (Morrison et al., 1999, p.4 [cited from html. version]).

Meyer, Taiminen, Vuori, Aijala, and Helenius, (1999) assessed the prevalence of PTSD after an acute psychotic episode to explore which psychotic symptoms and aspects of treatment were associated with traumatisation and to compare the extent of the traumatic impact of psychosis and involuntary hospitalisation. Contrary to McGorry et al. (1991) findings, Meyer et al. found that psychotic symptoms were generally more traumatic than involuntary admission or coercive measures. These findings suggest that there is a need to identify PTSD symptoms in people who experience psychosis and who experience an involuntary admission, often under very stressful circumstances.

## **Summary**

Research on the experience and effects of involuntary admission to a psychiatric facility is sparse. No descriptive studies were found that provide readers with a sense of what this experience is like for those most closely involved: the person who experiences the mental illness, other significant people in their lives, and community mental health clinicians. Most studies focus on the experience of hospitalisation itself, ignoring the steps that lead to admission and the very important interventions at a community level, often in the person’s own home and in the presence of police. Furthermore, studies are usually quantitative and leave many questions about the personal experiences of those involved unanswered.

Pertinent issues highlighted in this review of the literature include the complexity of clinical decision-making about whether to admit someone involuntarily, and its frequent correlation to

availability of resources and staff training. The perceptions and opinions of individuals and family members about the commitment process highlight the different agendas held by these stakeholders. They also highlight the need for increased sensitivity and attention to the emotional needs of those who find themselves involved in such a potentially traumatic event. Perceptions held about the use of coercion and its effects require particular attention from clinicians by increasing their own awareness of how and why they use their power. Dangerousness to self or others as an admission criterion; the ethical and moral dilemmas of mental health practice; and the possibility of PTSD as a secondary “response syndrome” add to the complexity of this event. The challenges and barriers to sensitive, effective, and humane mental health service interventions are clear.

Of note is the fact that, in some studies, people affected by severe mental illness were considered capable of providing relevant information even when interviewed soon after admission, and that most psychotic patients were able to complete their questionnaires and give their opinions. These opinions are invaluable to identify the effects of clinical interventions and the need for improved communication between services and service users, no matter what their recalled experience is.

The need for further research and the relevance of the knowledge gained in the clinical and managerial fields is stressed in the literature. The present study focuses on the event of involuntary admission from a community (i.e., non-institutional) perspective in the hope to shed some light on the experiences and needs of mental health consumers and service providers. Despite some methodological limitations, it is unique in its description of events preceding hospitalisation and the views of those involved.



## Chapter III – Methodology

*Ethics has to do with application of a system of moral principles to prevent harming or wronging others, to promote the good, to be respectful, and to be fair. Politics has to do with the methods and strategies used to gain a position of power and control. Ethics and politics are intertwined in sensitive research, especially that performed in community settings.*

Sieber, J.E. (1993, p. 14)

### **Socially sensitive research**

The involuntary admission of people experiencing mental illness is a practice that has been well researched from the perspectives of decision-making and psychological effects (see Chapter II - Background Literature, p. 13). The nature of the subjective experience leading to involuntary psychiatric admission has not, to the best of my knowledge, been recorded in any detail.

The initial interest in exploring the actual involuntary admission event was sparked by the experiences of Leonor and of Lisa, as described earlier. The study seemed relatively easy to complete. Soon, however, came the realisation that the topic was in fact quite sensitive and caused strong reactions in mental health clinicians and managers, as well as amongst those who were scheduled and their relatives.

Mental health professionals were concerned that their own practice was under scrutiny, as though looking at improving the process through honest examination and increased knowledge meant that, in reality, “they were not doing a good job.” Focusing on the scheduling event itself somehow damaged the beneficent image of psychiatry.

In contrast, people who were scheduled and their relatives were happy with the opportunity to tell their stories and put forth their opinions, albeit not without trepidation about the possible outcomes of their participation. Additionally, when the research project was discussed at clinical forums, such as conferences and inservices, fear and/or indignation often arose.

Socially sensitive research has been defined as “studies in which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research” (Sieber & Stanley, 1988, p. 49). Lee and Renzetti (1993a, p. 5) defined a sensitive topic as “one that potentially poses for those

involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding, and/or dissemination of research data.”

This study describes the human experience of those involved in the scheduling event. Fears expressed by mental health clinicians about my conducting this study led to initial difficulties in recruiting informants. These fears included concerns such as: “talking about a sensitive issue may lead people to become unwell due to recalling a stressful event,” “don’t want to re-hash bad experiences,” “they will only complain,” “they might turn against you,” and “they’ll become paranoid.” These concerns turned out to be unfounded and the people who had been scheduled and the relatives of people who had been scheduled were generally eager to share their experiences. None of the behaviours assumed by the mental health professionals were expressed.

The emotional impact, however, of discussing the topic for both groups was, in my view, underestimated. It was not the psychotic, delusional or dissatisfied feelings that were expressed, but rather the human impact of a stressful life event. From a post-traumatic perspective, the informants appeared to have a strong need to talk and “debrief” about the event that preceded hospitalisation, as often happens in the second stage of recovery from a traumatic event that entails telling the story in depth and detail (Herman, 1992, p. 175). This led to deep emotions being disclosed and large amounts of information being gathered during the interviews.

### **Design of the questionnaire**

This study’s methodology underwent a significant transformation from when first discussed through to its implementation, analysis and completion. The advice given initially as to the best approach to the methodology turned out, in the end, to be quite inappropriate. Most advice appeared based on common assumptions and stereotypes about how to collect information on a topic involving people who experienced a mental illness, particularly when the topic involves an intimate and potentially difficult experience.

At the initial planning stages of the study the senior mental health professionals involved in the preliminary discussions and planning thought that the most effective way of collecting information would be through a structured survey questionnaire (see Appendix D, p. 232). The managers at the time, favouring quantitative research, felt that this would be the most valid way of collecting significant data. Some qualitative data would be elicited by questions

such as: “What was done particularly well or needs improving?” and by requesting further comments at the end of the interviews.

Vaus (1991, p. 4) distinguishes surveys from other techniques of inquiry in that the form of data collection and the method of analysis differ. Surveys “collect information about the same variables or characteristics from at least two (normally far more) cases and end up with a data matrix,” obtaining one attribute for each variable. Survey analysis provides a description of the characteristics of a set of cases and additionally tries to locate causes of phenomena by looking at variations across cases.

### Questionnaire development

The survey questionnaire was developed in collaboration with a senior research officer and other senior management staff, and was based on current studies about the experiences of involuntary hospitalisation (Parrish, 1993; Joseph-Kinzelman et al., 1994; and Lucksted & Coursey, 1995). Several techniques can be used to collect data with a survey questionnaire (Sommer & Sommer, 1980). This questionnaire was not given to informants to self-report but, rather, used as a guide for the interviewer who would solicit the information and mark the survey schedule accordingly. The choice of face-to-face interviews was useful to overcome poor response rates (Morrison et al., 1999, p. 5, [cited from html. version]) and to ensure immediate clarification of the feelings and opinions raised.

### Questions content

The nine-question interview guide was designed with structured questions to elicit feelings and opinions about the scheduling event. These questions broadly included Dillman’ s (1978, p. 80) required categories of behaviour, beliefs, attitudes and attributes.

1. Basic demographic information about the informant’s characteristics.
2. Personal experience of the last scheduling event in which they were involved.
3. Feelings at the time.
4. Presence of supports at the time.
5. Explanations given of what was happening.
6. Beliefs and attitudes relating to trust in the mental health system.
7. Opinions regarding improvement of the scheduling process.
8. What was done well and what was the worst part of the event, and
9. Effects on the general wellbeing of the informant.

### Phrasing of questions

Care was taken with the wording of the questions to avoid lengthy, double-barrelled or leading questions. It was important for the questions to be simple and clear and that they could be asked directly. In particular, the question about whether information was provided at the time of the schedule required clarification with both the relatives and the people scheduled. In several cases they had no idea of what information or alternatives there could have been. In some cases, the question came as a shock, somehow adding to the informant's feeling of not having fully participated in the event. Initially, the questionnaire contained a number of closed questions and rating scales (or forced-choice format). Likert scales and agree-disagree statements were used as rating scales (Vaus, 1991).

### Testing the questionnaire

The questionnaire was completed and approved by the senior managers and an informal test was run with three clinicians and two service clients. The interview was expected to take half an hour. As most of the questions came from previous research studies, the senior managers and I assumed that they would work with our target group. None of the professionals involved in the development of the final document questioned its applicability. The test interviews were uneventful and only a few minor changes were required to the wording of the questions. In hindsight, the fact that those who participated were aware that the tool was being tested might have caused a bias in responses. Both the clinicians and the clients may have felt that they had to "perform" and be supportive. Additionally, the clients may have been keen to present positively to a person they identified as of higher status within the service.

As soon as the first interview – with a person who was scheduled – commenced, it became apparent that the structured survey was not a suitable format for this sensitive topic. The experience of being scheduled, or having a loved one scheduled, can arouse strong feelings and emotions. The description of one single event brought up a whole lifetime of experience with mental illness and involuntary admissions and its impact on the life and relationships of those involved. Talking about these experiences, and about the lack of control over how one's own life unfolds, is emotionally charged. The tendency is then to tell a story, their own story, as they experienced it, and the interview took an in-depth course. Minichiello, Aroni, Timewell and Alexander (1995, p. 61) defined in-depth interviewing as "a conversation between researcher and informant focusing on the informant's perception of self, life and experience, and expressed in his or her own words." These "conversations with a specific purpose" can assist in understanding how individuals interpret their social reality.

In view of this finding, we decided to allow for a more free-flowing interview. The survey was used to guide the conversation, while at the same time allowing the informant to digress or move on to other areas of interest. Consequently, most of the questions changed to become more open-ended, and prompts were added, allowing the informants to talk about events and feelings more freely. One of the problems of closed questions is that "they can create false opinions either by giving an insufficient range of alternatives from which to choose or by prompting people with 'acceptable' answers" (Vaus, 1991, p. 86). This was clear with the belief question about believing that scheduling is necessary where all respondents answered "yes", as their reservations about the way it was done would not have been elicited without an explanatory option.

### **Background literature search**

The literature was reviewed throughout the research process. The first literature search was conducted using main keywords, such as mental\*, ill\*, involuntary admission, commitment, effects, community intervention, and many other combinations. Four initial Medline searches provided poor results. None of the articles identified examined the experience of being scheduled from a community perspective, i.e., the experience of assessment as it happens at home or in the community. Studies related to the topic looked at the decision making process in crisis situations and the management of "at risk" behaviours, not at what happened and how people experienced the events.

Other databases were searched, such as the Cumulative Index to Nursing and Allied Health Literature (CINHAL), Mental Health Abstracts (NIMH), Sociological Abstracts (Sociological Abstracts), and Psychological Abstracts (PsychInfo). Several related articles and books were uncovered. Reviewing the reference section of other articles identified additional articles and books of interest, the majority in fact. This extensive literature search made it clear that a very large body of literature exists on mental illness and hospitalisation, medication issues, biological theories, clinical practice, and clinical issues. Most of this research is of a quantitative nature. To the best of my knowledge, however, no literature is available on the topic of my study from the three informants' perspectives.

### **Interviewing process**

Interviewing people who have experienced such a significant life event was demanding on the interviewing process itself. When talking about a sensitive topic, people can be either restricted or free flowing in the information giving, or they can flow from one to the other in a

continuum. This may be due to difficulties with rapport and trust; the need to talk and debrief; the enjoyment of company and attention; the opportunity to complain about the service or treatment received; or a slowing down of cognitive processes and the effect of medication (Badger, 1994, p.10). This seemed to be the case with most interviews conducted, with the need to talk and debrief, and the opportunity to talk about the service, as the most common reasons for agreeing to the interview.

It was important for this survey to be administered face to face, not only to ensure a good response and being able to clarify both questions and answers (Vaus, 1991), but also because of the sensitive topic at hand. I obtained the data for this study as a single interviewer. This controlled for data discrepancy and provided automatic internal consistency. My clinical skills in engagement, interviewing, assessing behaviours and providing reassurance and containment developed over twenty years in the field proved useful. Some people became upset and wept, while others openly expressed their anger and frustration. Challenging expressions of emotion included pacing, walking in and out of the room, shouting and gesticulating, and sobbing.

Rogers, Pilgrim and Lacey (1993, p. 196) noted these expressions of emotion in their study of users' views of services and the ensuing uncertainties and difficulties for the interviewers. The interviewers used were untrained and they found themselves not knowing whether to end the interviews with upset respondents. The authors felt that ending the interviews would be somehow paternalistic "by preventing the full force of emotions being expressed about this area of people's life." Additionally they realised that "it is the feelings invoked in others (that is, not the patients themselves) which often governs or informs decision-making in conditions of uncertainty about mental distress." Moreover, my skills assisted in minimising the chances of "socially desirable" answers, that is, answers that might be more acceptable rather than true (Vaus, 1991, p. 110). The candid disclosures of the informants are evident in the long transcripts of their narratives.

Conducting the interviews with people who were scheduled once they were back home was a useful way to collect information on this sensitive topic. Most research to date is conducted when people are in hospital rather than at home, limiting the findings to one area and one setting.

## **Sample**

To explore the experiences of being scheduled, interviews were held with the three main participants of the event: people who had been scheduled, the relatives of people who had been scheduled, and clinicians who were involved in scheduling. Consideration was given to other important participants such as police and ambulance officers. Including these key participants, however, was beyond the scope of this study. A decision was made to limit the number of interviews to ten for each group.

### Clinicians

A simple random sample technique was used to select from the existing 52 clinicians. A table of random numbers was used (Vaus, 1991, p. 63) and each staff member was given a unique number starting at one. A pattern was developed to move through the table and select the informants. A number was selected, and then the last two digits of every tenth number running down each column were marked. The clinician with the corresponding number was approached to participate in the interviews. All clinicians approached consented to the interview.

### People who were scheduled and their relatives

A non-probability convenience sample (Vaus, 1991, p. 77) was chosen as the most suitable method of recruiting people who were scheduled and relatives of people who were scheduled due to the small size required for the study. With such a vast and diverse population, probability samples would be too impractical. Additionally, I was not particularly concerned about generalising from this sample to the general population. Rather, I wanted to get a glimpse of the factors and influences involved in the scheduling event in an exploratory way.

Due to the small sample required, the aim of the study, and the resistance encountered among many clinicians, the decision was made to solicit voluntary referral of people who were scheduled and relatives of people who were scheduled. Clinicians could then decide whom to ask to participate, and refer to the researcher once consent to be interviewed was obtained.

Although all the informants other than clinicians were selected in this way, the relevance of theoretical sampling was noted. This requires the selection of informants to identify the whole range of possibilities in the feelings about, and responses to, the events. In this case “persons, places and situations can be purposefully selected because these have been identified as relevant” (Minichiello et al., 1995, p. 163). As I had mothers, a father, and a sibling in the relatives’ group, I thought I needed to include the son/daughter category to look at emerging

differences due to a shift in their relationship with the person being scheduled. Identification of this last informant was achieved through a clinician from the local Early Psychosis Outreach Community Health team (EPOCH).

With the group involving people who were scheduled, an attempt was made to interview someone with a non-psychotic diagnosis such as depression. This, however, was not possible to achieve and the sample includes only people scheduled due to the experience of a psychotic illness. In this case, the sample became an “availability sample” (Vaus, 1991, p. 78-79), useful for the purpose of exploratory research. Although this sample may not be statistically representative, it sheds some light on aspects of this social phenomenon through the experiences of those who lived it (Minichiello et al., 1995).

#### Criteria for inclusion

The main criteria for inclusion in the study was having a personal experience with the scheduling event as a person who was scheduled; a relative, or significant other, of a person who was scheduled; or a clinician directly involved in scheduling people. Additionally, those people who were scheduled had to be, at the time of the interview, well enough to participate and provide informed consent. Their competence to do so was determined informally, as with relatives and clinicians, by their willingness and ability to follow the process of recruitment and interviewing.

### **Recruitment of informants**

#### Mental health clinicians

Ten mental health clinicians were approached following a simple random sample selection from a complete staff list. Administrative and Rehabilitation staff were excluded as scheduling was not part of their job description. All clinicians selected were either casemanagers or crisis team members. This included a range of professional disciplines: nurses, psychologists, social workers and medical doctors. All had been involved in scheduling people. Some of those who were selected left the service before being interviewed. Interviews were then held with the clinicians employed in these positions. Interviews were completed over a period of twelve months and averaged sixty minutes.

#### Relatives of people who had been scheduled

Interviews were conducted with ten people who had a significant person in their life scheduled. Eight informants were present at the time of the schedule and, in all but one case,



were responsible for calling the mental health service and initiating the process of involuntary hospitalisation. These participants were contacted through the local Schizophrenia Fellowship meetings and mental health clinicians. These interviews were completed within twelve months and averaged two hours each.

#### People who had been scheduled

Finally, ten interviews were conducted with people who, at some time in their lives, experienced mental illness of such severity that transportation to a psychiatric facility for further assessment was sought on an involuntary basis. To facilitate the transport of the person, either a Schedule II (see definition on p. 15) - Section 21 – Detention on certificate of medical practitioner or a Section 24 – Detention after apprehension by police, of *The NSW MHA, 1990* (p. 11 and p. 13 of the *Act*, respectively) were written. These informants were selected by their casemanagers. Interviews were completed over a period of twelve months and averaged one and half-hours each.

#### Access to people who had been scheduled and significant others

Casemanagers were asked to assist in recruiting people who had been scheduled and significant others by approaching their clients and relatives and requesting their consent to participate. Voluntary consent was sought by the casemanagers themselves to ensure that no overt or covert pressure was placed on the potential informants by the researcher (Fulford & Howse, 1993, p. 89). Each clinician was asked to provide the names of one client and one relative. This was a minimal request, requiring very little time and attention. When referring a potential informant, clinicians assured me that the purpose of the study was explained and that the informant expected my contact in the near future.

Individuals in this group were approached by their casemanagers either because they were “good talkers” and were identified as “having a lot to contribute,” or because they had experiences they themselves defined as “terrible” and had made complaints about the service. Clinicians felt that the participation of these selected individuals would provide an opportunity to acknowledge their complaints as “being heard and validated,” and to ventilate their anger and frustration.

Of those initially referred, one person refused to participate, launching into an angry discussion about “how terrible” the local mental health service was and how it was “trying to ruin my life” and he was “not going to collaborate.” Another refused to participate because she had just turned eighty years old, her son had been settled in his mental state for quite

sometime, and she did not want “to rehash it all.” The third one refused when contacted by telephone, stating quietly: “I’d rather not.”

Access to informants seemed to be a real issue. Attending the local Schizophrenia Fellowship and Association of Relatives and Friends of the Mentally Ill (ARAFMI) meetings did not prove successful. Most of the people involved with these groups had no experience with the scheduling event. Only two relatives were recruited this way.

Regular reminders to clinicians continued to bring no results. Concerns regarding gate keeping (Lee & Renzetti, 1993b, p. 27) were raised and, surprisingly, comments were made about the research being critical of work practices, pointing the finger at inadequacies of the service, and as generally threatening to the *status quo*. At the time, several presentations of the project were made in clinical and public forums. Some comments received from experienced mental health clinicians over that period included: “Are you implying that when we schedule a person we should just drop everything to attend to the family as well?” or “What’s traumatic about a schedule? It has to happen!” Others would say: “Clients will complain anyway, they are never satisfied!” Another would reassure me whenever someone was scheduled that “We didn’t traumatise that one. He went like a lamb!” My presence became a reminder to clinicians that practices were in fact under scrutiny, although that was not at any time the intention of the study (see also Fielding, 1993, p.152).<sup>9</sup> This realisation required me to look for potential allies within clinicians in order to access further informants.

Clinicians’ interpretation of the purpose of my study led to two further referrals. Following two difficult schedules, the clinicians involved referred a relative and a support worker. In these events the person scheduled was restrained and “dragged away” and the significant others present were shocked by the way deception and the element of surprise (see p. 59 for a discussion of this topic) were used. The mental health professionals involved believed that these relatives needed to “tell their story” and the interviews would provide this opportunity and have a “debriefing effect.” Both these interviews were longer than most and emotionally charged.

Eventually, a clinician from EPOCH was identified as a strong ally with a proven commitment to high quality care and high motivation to implement changes in health practice. This team functioned according to guidelines that emphasise a comprehensive bio-psycho-social model of care based on the concepts of recovery and empowerment. This includes a

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<sup>9</sup> In this article, Fielding illustrates attribution of meaning by senior police officers to fieldwork being conducted with patrol officers in London, and the question of when to take action on encountering malpractice.

strong educational and supportive role with both the person experiencing mental illness and their significant others, following the recommendations from *The Australian Clinical Guidelines for Early Psychosis* (National Mental Health Strategy, 1998) At a clinical level, the team used a cognitive-oriented psychotherapeutic model of treatment (Jackson, McGorry, Edwards & Hulbert, 1996).

I approached this senior clinician with a request to provide further referrals. With an understanding of the value of studies such as this, she was keen to help. Within a short time, a further five relatives and four people who had been scheduled were recruited. The sampling was complete.

#### Characteristics of informants

An overview of the people involved in each story is provided in Table 2.

The demographic characteristics of the thirty informants within the three groups are described in Table 3. All interviews were conducted in English as the preferred language of the informants. The experiences described occurred within twelve months and as recently as six weeks before the interviews. For the mental health professionals, the schedules were as recent as a few days before the interview. The time since initial diagnosis of the person experiencing mental illness ranged from over thirty years to three months.

**Table 2.****List of People Involved in Each Story**

Story	Person scheduled	Relatives present	Clinicians	Other	Medical Doctors	Ambulance	Police
1	Gwen	No	<b>Sandra</b>	No	Yes	Yes	Yes
2	Margaret	Parents	<b>Doug</b>	Emma & Sherrie	Dr. Walton	No	Yes
3	Eva	Bill	<b>Elinor</b>	Carol	Dr. Bates	No	Yes
4	Anne	No	*EHT staff	No	<b>Dr. Swallow</b> Dr. Watts	No	No
5	Wagner	No	<b>Amanda</b>	No	Yes	No	No
6	Beverly	Gordon	<b>John</b>	No	Dr. Berry	No	Yes
7	Liz	No	<b>Angela</b>	No	Dr. James	No	No
8	Penny	No	<b>Louise</b>	No	Yes	No	Yes
9	Peter	Uncle	Luke & Lisa	Sister, aunties, cousins	<b>Dr. James</b>	No	Yes
10	Caroline	No	Yes	No	<b>Dr. Penford</b>	No	Yes
11	Grant	<b>Eileen</b>	No	No	Local GP	No	Yes
12	Nora	<b>Jan</b>	Yes	Mary	Yes	No	Yes
13	Paula	<b>Elena</b>	Yes	Father	No	No	Yes
14	Brian	<b>Kerri</b>	Yes	Rebecca		No	No
15	Vincent	<b>Terry</b>	Yes	No	Dr. Smart	Yes	Yes
16	Jaime	<b>Pedro</b>	Norelle	No	Dr. Priestley	No	Yes
17	Steve	<b>Betty</b> <sup>^</sup>	John	No	Yes	No	No
18	Tony	<b>Maureen</b> <sup>^</sup>	Dylan	Amy & Bill	Dr. Berry	No	Yes
19	Tom	<b>Sandra</b> <sup>^</sup>	Dylan	David	Yes	No	No
20	Alex	<b>Violet</b>	Chris	No	Yes	No	No
21	<b>Penny</b>	No	No	No	No	No	Yes
22	<b>Susan</b>	No	John	No	No	No	Yes
23	<b>Rosa</b>	Tony	Norelle	Mario	Yes	No	Yes
24	<b>Alfred</b>	Mother	John	Sister	No	No	Yes
25	<b>Paul</b>	Family	Yes	Yes	Dr. Berry	Yes	Yes
26	<b>Steve</b> <sup>^</sup>	Betty	John	No	Yes	No	No
27	<b>Teresa</b> <sup>^</sup>	No	Olwyn	Brad	Dr. Finley	No	Yes
28	<b>Tom</b> <sup>^</sup>	Sandra	Dylan	David	Yes	No	No
29	<b>Mike</b> <sup>^</sup>	Sister	No	Sister	No	No	Yes
30	<b>Alex</b>	Violet	Chris	No	Yes	No	No

Note. \*EHT – Extended Hours Team. ^ EPOCH client. The name of the person interviewed appears in bold. Stories 17 and 26; 19 and 28; and 20 and 30 each relate to one event. Names are used only if identified at interview.

**Table 3.**  
**Characteristics of Informants in the Three Groups Interviewed**

<b>Characteristics</b>	<b>Clients</b>	<b>Relatives</b>	<b>Staff</b>
Gender	Males: 6. Females: 4.	Males: 2. Females: 8.	Males: 3. Females: 7.
Age	22 – 56.	17 – 70.	25 – 52.
Relationship to person scheduled	Self.	Mother (6); Father (1); Brother (1); Daughter (1); Support worker (1).	Casemanagers (4); Crisis Team (3); Doctors (3).
Ethnic Background	Australian (6); English (1); Italian (1); Irish (1); New Zealand (1).	Australian (6); Italian (1); Spanish (1); English (1); New Zealand (1).	Australian (7); New Zealand (2); Greek (1).
Occupation	Business part-owner (1); Nurses' Aid (1); General duties (2); Driver (1); Unemployed (5).	Full-time student (2); Home Duties (4); Graphic Arts (1); Supplemental. Work (1); Secretarial (2).	Psychiatrist (1); Registrars (2); Registered Nurses (3); Psychologists (2); Social Workers (2).
Source of income	Disability benefits; Supported employment; Permanent part-time; Wealthy parents.	Aged pension; Superannuation; Disability benefit; Full- time and part-time work; Business ownership.	Full time work.
Housing	Department of Housing units; Own home; Supported accommodation; Private rental.	Rented units; Ownership; Sharing.	N/A
Living arrangements	Living alone (2); With the family (3); Sharing (5).	Two parent families (4); One parent families (3); Living separately from relative (2); No parents (1).	N/A
Number of schedules involved in	Once to each time (24).	One to "half a dozen."	One to "uncountable."
Diagnosis of self or person discussed	Bipolar Disorder; Schizophrenia; Schizo- affective Disorder and Schizophreniform Psychosis.	Schizo-affective disorder; Schizophrenia; Borderline Personality Disorder/psychosis; Developmental Disability with Schizophrenia.	Schizophrenia; Bipolar disorder; Schizo- affective Disorder.
Police involvement	Seven out of ten	Six out of ten	Seven out of ten

## **Data collection**

An initial plan to tape-record the interviews was not supported by the senior managers. Some of the reasons given were that the interviews were quantitative and based on a structured survey and therefore would not require taping. Additionally, as for the clinicians, there were concerns that taping interviews on a sensitive topic with people who experienced mental illness or their relatives could have serious consequences. Some possible consequences mentioned were that the clients could become suspicious (paranoid) and accuse the service or mental health clinicians of "being part of a conspiracy." They also suggested that informants would think that the tapes could be used improperly, i.e., to "blackmail" or "disadvantage" them on the basis of information given or opinions expressed. Some of these concerns are identified in the literature on interviews with people affected by mental illness, but have not been substantiated (Fulford & Howse, 1993, p. 85).

Perceptions among mental health clinicians that people experiencing a mental illness "would not be reliable story tellers," "would misinterpret events," and "would provide untrustworthy information" were common. Relatives were described as being "constantly dissatisfied with the service provided," and "demanding provision of care that is well beyond the current health services' resources." These opinions are not supported by current literature, clearly showing that the opinions of consumers are both valid and important (Rogers et al., 1993; Davidhizar, 1985; Van Putten, May & Marders, 1984).

As it became apparent that a quantitative approach to this topic was unsatisfactory and interviews had already evolved towards an open, semi-structured format, the data collection and interview process were modified to better suit the nature of the research. Semi-structured questionnaires have been widely used in social science inquiry (Holstein & Gubrium, 1995). Therefore, although still using the same questionnaire format, the interview began with an open question asking the informant to describe the last scheduling event they were involved in, and subsequent questions were asked in the context of the ensuing discussion. Thus, all informants were encouraged to speak freely and prompts were used when necessary. It was apparent that in a discursive narrative people needed to answer the questions in their own way. Additionally, the answers were more complex than anticipated, contained emotionally laden material, and were, at times, very detailed and over-inclusive. This needed addressing and at this point taping of interviews commenced, as otherwise too much information would be lost.

Field notes were kept for all the interviews. Field notes “contain a record of conversations the researcher has had with people, observations about their actions in every day life and procedures for collecting such information” (Minichiello et. al., 1995, p. 215). This provided a wealth of information that would not otherwise be available, particularly for the initial interviews. The notes were entered on computer to assist in coding and analysing the data. The taped interviews were transcribed fully within forty-eight hours to ensure accuracy of content. Although a questionnaire was used for the interviews and the sample was small, a large amount of data was obtained, reflecting the breadth and complexity of the topic.

### **Data storage**

Throughout the period of data collection, analysis and writing up, data have been stored in locked files. As the researcher, I have sole access to these files.

### **Ethical issues**

A proposal was submitted to the local Area Health Service Research Ethics Committee and was approved without amendments. Soon afterwards, the study was accepted as part of the requirement for a Masters degree by research thesis at The University of Sydney, Australia, and further approval was obtained from the University of Sydney Research Ethics Committee. This was also approved without amendments, despite previous advice from a senior lecturer that interviews with people affected by mental illness would not be approved.

It is well known that research involving people who experience mental illness has been considered fraught with difficulties (Fulford & Howse, 1993). Therefore, it is very important that the researcher maintains very high standards of practice. Three main areas of concern were addressed when seeking approval from the Ethics Committees: the principle of least harm; informed consent and confidentiality.

#### The principle of least harm

The main aim of clinical research with human subjects is to advance knowledge and, therefore, the interests of those it seeks to understand should come first. Additionally, there must be evidence that this knowledge cannot be advanced by other means, and the potential benefits to be gained by the research must be of enough importance to outweigh any possible risks (Wing, 1991).

Therefore, all participants were informed of the purpose of the study and made aware that, although no serious risks would come from their participation, they may experience some

emotional discomfort from being exposed to recalling a difficult event. Additionally, they were informed of a debriefing mechanism that was in place in case they needed it, and of the option to withdraw consent at any time (see Appendix E, p. 235).

### Informed consent

The purpose of the research and the questionnaire were fully explained to all informants before commencing the interview. A hard copy of the research purpose and a consent form (Appendix E, p. 235) were provided. This included the telephone number of a senior mental health clinician who agreed to being available should clarification of the research purpose, or debriefing from the interview, be required. The possibility of withdrawing consent at any time, if so wished, was discussed, and provision was made on the form to withdraw consent in writing to the Deputy Director of the service where the research took place.

Concerns regarding research with people who experience a mental illness in the area of informed consent are generally the same as for anyone else. If the person, however, is considered incompetent to make an informed decision at the time of the study, complex legislation and ethical issues come into play (Wing, 1991, pp. 422-424). These will not be discussed here, as the people who were scheduled were not, at the time, experiencing a mental illness. They were living at home independently and were able to provide informed consent as any other community member. Steps were taken however, to ensure that consent was freely given. The possibility of covert (and unintentional) pressures derived from the power imbalance between the people who had been scheduled and the researcher as a senior member of the mental health service (Fulford & Howse, 1993, p. 86) were noted. To ensure this was not the case, casemanagers were asked to seek the initial consent.

Each informant was individually approached to provide informed consent to participate. Clinicians' participation was based on verbal consent with participation in the interview used as evidence of valid consent. All others signed a written consent form. Additional explanations were given to all informants regarding location of the interview, data collection methods (i.e., taping and/or note-taking), expected length of time taken to complete the interview, and possible inconvenience caused from recalling a stressful event. Freedom to terminate the interview at any time, benefits from participating, how the data will be maintained anonymous, and what will happen to the report were also discussed.



## Confidentiality

During the transcribing of the interviews, each participant was given a pseudonym to ensure confidentiality and anonymity. The limits of confidentiality were discussed with each participant. For most, confidentiality was acknowledged as a relative concept within health services, whereby many people have access to offices and files.

Concerns were expressed by some people in all groups about ease of identification of their story and that the information could be used inappropriately. These concerns appeared based on the fact that information is freely shared among health professionals involved in the care of a person. Wing (1991, p. 425) quotes a statement made on behalf of the British Medical Association to a government Committee on Privacy that stated: "It is no longer practicable to look upon the single physician as the patient's sole confidant in any serious illness and it is assumed by public and profession alike that any contact with the complex medical machinery of today implies acquiescence in some degree of extended confidence." Informants were reassured of the different purpose of this information and its being unrelated to everyday clinical practice. Assurance was given that no records were kept at the centre, and the data would not be seen by anyone other than my supervisor and I until depersonalised. Requests for consent to tape were received positively in all but one instance (a clinician).

## **Interview setting and process**

### Interviews with professionals

Interviews were held wherever the informants elected to ensure they felt comfortable and at ease. Seven interviews were conducted in the health centre where the study was based. Six clinician interviews were held in counselling rooms that were thought to provide privacy and quiet – the last assumption proved wrong as construction work around the centre interfered with sound and taping. Three interviews were held in coffee shops. One interview was held in the Intake Room during the intake duties of that clinician; the telephone or people walking in constantly interrupted the interview held in the Intake Room. At one point, the clinician decided to go on a call with the duty doctor and I was left to do Intake while waiting. This clinician also persisted in checking every note I took and answered the questions in a dictating tone. The coffee shop interviews were difficult to transcribe due to background noise. One of these interviews was held over two different meetings as the clinician was called on a crisis half way through the first meeting.

## Interviews with clients and relatives

The interviews with people who had been scheduled and relatives were conducted in many different environments: in their homes, the community health centre, in coffee shops. Availability to interview in different settings was important in ensuring choice, developing a more balanced power relationship, and ensuring that all informants felt comfortable. This in some way influenced the way the interviews proceeded as we moved from my “territory” to theirs, or to more neutral settings with varying degrees of distractions and interruptions.

My extensive experience as a health professional enabled me to establish rapport and harmonise with the informants. I believe, however, that some clinicians felt a little threatened by my conducting the interview as an insider of the service. One result of this defensiveness was that in three cases the stories presented were not their most recent scheduling event. They *seemed* to have chosen a situation where the events related to the schedule had been very straightforward according to the clinician’s interpretation of the *NSWMHA 1990*.

Analysing the data was a challenging and time-consuming activity. The data analysis evolved with the interviews and adjustments were made to reach a satisfactory discourse. This evolution is presented next.

### **Data Analysis**

The data analysis followed an evolutionary process. Due to the initial plan of using a semi-structured interview to collect data, Epi-Info was initially used to collate the data from the completed questionnaires. A process of coding each question and each answer was undertaken, and a clerical support person from the local Health Promotion Unit completed the data entry. This soon proved unhelpful, as a series of tables were drawn with little meaning of the context within which the information was given, and the qualitative information gathered. With such a small sample and varied and complex topics covered, the quantitative information looked useless.

In their study on the views of service users of a STD (sexually transmitted disease) Clinic, Evans and Farquhar (1996, p. 2 [cited from html. version]) tested a qualitative semi-structured questionnaire as an alternative approach to identify the expressed needs and views of the public and service users. They found that most reports to date were based on structured surveys that were limited and superficial in nature and “do not allow or encourage users to identify or discuss the issues that are of real importance to them.” Several issues were identified that had not been previously identified in the department’s own questionnaire

surveys of users. This gap was obvious in the data I collected, and a new method of analysis was sought.

Due to the amount of data collected and my lack of experience in research at the time, it seemed that a descriptive approach to analysis would be useful. The purpose of the research had been, after all, to describe the events of being scheduled, how those involved felt, and whether the process could be improved. Vaus (1991, p. 24) defines descriptive research as dealing “with questions of *what* things are like, not *why* they are that way” (emphasis in the original). To describe the event and its consequences accurately, time was devoted to writing up the stories as they were told, and collating the answers to each question within each of the three groups. This way, I ended up with ten answers to each question in each group – clinicians, relatives, and those who were scheduled.

As I reached the end of this process, the content emerged more clearly. There were several similarities in the answers across groups that puzzled me. I had assumed that each group would have different experiences and different agendas, but this did not seem to be the case. At this point, I attempted to code the data. This had not been attempted before due to the quantitative nature of the initial study, and this late coding could have weakened the analysis at this stage (Minichiello et al., 1995, p. 257). The data as presented, however, is very strong and speaks for itself.

A qualitative approach to data analysis began to make sense. Throughout the data collection, a sequential analysis of the data as it presented came naturally. I continuously attempted to give it meaning as “such continuous analysis is almost inevitable in qualitative research: because the researcher is ‘in the field’ collecting the data, it is impossible not to start thinking about what is being heard and seen” (Pope, Ziebland & Mays, 2000, p. 2 [cited from html. version]). For instance, it was striking that Susan, the first scheduled person interviewed, talked about her schedule, although “involuntary” and with police, as both expected and acceptable.

A content analysis of each question was attempted. Consideration was given to the use of computer-based data analysis such as NUDIST and Qwalitan. Following a cursory attempt at coding by word frequency, the limitations of this method were obvious as “the computer does not replace the analytical thinking processes underpinning ‘interpretative’ research ..., rather, computer software programs have been mostly designed to be an aid for data-retrieval purposes” (Minichiello et al., 1995, p.269). The first stage of qualitative data analysis – comprehending (Morse, 1994) – had been achieved regardless, as the stories were heard, clarified and transcribed and I began to give them meaning.

An attempt was then made to categorise the data by hand, by developing a list of coding categories, revising those categories and collapsing those that overlapped, and giving each category a name and each sub-category a number. Each transcript was printed out in hard copy, carefully coded, read through, and numbers assigned to each unit of data before sorting them by cutting and pasting into sub-files (Minichiello et al., 1995, pp. 259-260).

A large number of themes and sub-themes were identified, and many words, sentences and paragraphs fitted into several of these codes. This was proving to be yet another nightmare and again this coding did not satisfy me. Minichiello et al. (1995, p. 258) stated that: “some codes will not work because the way in which they describe the phenomena is not the way these phenomena appear empirically. When this happens you will need to either revise your coding scheme or get rid of it.”

To test my perceptions that, in fact, the themes between groups were not so different I went back to the “cut and paste” functions on the computer and re-organised the data according to each group under one answer. Therefore, for instance, for the question about police involvement, I had all thirty answers together. This gave me a clearer idea of all the situations and feelings encountered and how different groups both differed and were the same in their experiences. This way the information was easier to synthesise into similar themes (Morse, 1994).

This way the demographic data was easier to place in a table, providing an overview of the interviewee characteristics. Other quantifiable data was also easier to gather in this format. Pearson (1997) discusses the advantages and some of the problems of combining qualitative and quantitative methods of analysis. Qualitative analysis, she says, in focusing on the perceptions and meanings of events rather than on whether data is generalisable, differs from quantitative analysis that is more concerned with testing a hypothesis and being able to replicate a study. She gives an example of a study exploring hospital discharge whereby the records of 1,500 patients were examined and a database constructed. While the initial intention was to undertake a quantitative analysis only, it was found that some data needed further clarification in order to be entered correctly. This led to recognising “how a qualitative approach can help in understanding the way in which errors creep into the system” (Pearson, 1997, p. 3 [cited from html. version]).

In a second example, Pearson (1997) described a two-stage Delphi questionnaire approach to determine indicators of effective teamwork in primary care. Questionnaires were sent out to 237 experts, with a response rate of 58%. A second questionnaire was sent out to these

respondents to distribute 100 points between items, with a response rate of 64% of the initial returns. A simple thematic analysis of the initial data collected was undertaken, and the qualitative data was counted in order to develop the second questionnaire. The final result, however, failed to incorporate any concept of order or relative importance.

Pearson (1997, p. 7 [cited from html. version]) proceeded to discuss some studies that combined methods of analysis, and theoretical thought that defends or condemns the integration of methods of analysis. She concluded that: "In bringing together two approaches to analysis, integration may occur sequentially or contemporaneously. One type of analysis may inform the setting up of the next phase of the study, or the two may run alongside each other and enable sense to be made of a whole data set . . . . At a practical level, utilising both qualitative and quantitative techniques does appear to result in an analytical product which is enhanced, whether sequentially or concurrently." Pearson, however, warns that there can be problems in blending theoretical approaches, and that "there has been considerable debate even within qualitative research as to how far different perceptions of 'fact' can be compared."

In view of this knowledge subsequent data analysis was undertaken. Each question and related thirty answers were collated, printed on hard copy and photocopied. The data was then re-coded according to themes, and concepts within themes, by running through each sentence or paragraph, slowly reading down each transcript, identifying what is this about; what is it telling me; what is behind the words she/he said (Minichiello et al., 1995).

In the process of completing this task, the whole text was read time and time again until I was so familiar with it I could easily find any quote I wanted within the thirty full transcripts. I then began to see the different concepts and themes within the whole conversations. The text read like a narrative and it began interconnecting and making sense in terms of the whole scheduling experience. Many of the concepts and themes intertwined and overlapped. Some of these were stigma, deceit, betrayal, ethical issues, loss and grief, shame and humiliation, relationships, power, crime or illness, information and education, trust and many more.

Savage (2000) explores the relationship between the way data are analysed and the findings that emerge by subjecting to alternative forms of analysis an interview with a nurse – "Ann." The data were analysed with both a thematic and narrative approach, and Savage was particularly concerned with the plurality of meanings that can be found, particularly in narrative texts. A narrative approach is defined as "concerned with understanding how people use cultural resources to construct stories that describe locally produced, and more ambiguous

realities” (Savage, 2000, p. 2 [cited from html. version]). Nevertheless, it is not only the interpretation given to texts that can be ambiguous. As Tom, one of the people interviewed, states (p. 119), feelings and opinions vary according to when people are asked the questions. Savage identifies some post-modernist approaches that have recognised such a multiplicity of views and opinions. Moreover, Coffey and Atkinson (1996) suggest that multiple methods of analysis can be used to help interpret the data in different layers to allow for the discovery of different and even contradictory meanings. Vallis and Tierney (1999) also maintain that these multifaceted methods of analysis are useful and do not compromise basic research principles.

Whichever methodological position is adopted, the findings of this study cannot be devalued by its methodology. The language used and the accounts given speak for themselves and bring to life a very stressful experience. These human experiences must be heard. With this data theories can be built and new, positive practices can be developed.

### **Validity**

As the interviews were conducted face-to-face by an experienced interviewer and conducted from the beginning as an open-ended interview, probing and cross-checking were used throughout to check that I interpreted or understood what I was hearing correctly. This is evident in some verbatim quotes within the text where it was important to include the clarification within the quote (see Tom, p. 102 and Pedro, p. 167). This way, as Minichiello et al. (1995, p. 177) commented, “the interviewer will sooner or later discover the discrepancies in the informant’s story.” This was particularly the case with the stories of those who were scheduled, and the diathesis of trauma and support experienced through the process of being scheduled and the consequent treatment outcome.

External validity was tested through comments from several readers of the final draft. In order to understand the phenomena being studied, I needed to talk to people who could articulate that experience, and that experience was validated by the readers as “ringing true” to them. The data, although not reflecting all the possible experiences, identifies some of the key features of this phenomenon. The similarities of experience between groups add to the credence of the findings and what is said about the event. The results can therefore be generalised.

Kellehear (1993) argued that quantitative research emphasises theory construction and is more concerned with validity and reliability, building on a theory and testing the results. On the other hand, qualitative research often views cause and effect as artificial concepts. It seeks

explanations from the point of view of those who experience it, believing that the experience is the individual's reality. This is particularly important for this study, as we will see that the concepts of reality and experience are challenged in psychiatry.

Inter-rater reliability in qualitative research has been identified as useful "where researcher bias is especially likely to be perceived to be a problem – for example where social scientists are investigating the work of clinicians" (Pope et al., 2000, p. 4 [cited from html. version]). To avoid such criticism, strategies were employed to ensure that the interpretation of the data accurately reflected the phenomena. These included checking interpretations with informants, and having colleagues separately coding segments of the transcripts to confirm the categories identified. This was a useful process, with only a few codes requiring some discussion. Furthermore, several highly experienced colleagues and mental health consumers read either the full study or parts of it, further validating the descriptions.

The main themes chosen for discussion in this study are power, crime or mental illness, provision of education and information, and relationships. Several concepts were identified within those themes emerging from the narrative and providing an understanding of how individuals experience their world at that moment in time, and how they were affected by what happened in their personal lives. It is anticipated that the remaining information gathered and not presented here will be presented in future professional forums and for publication.

In the next four chapters, the analysed data is presented concurrently with the discussion. This is a better way of getting the information across, as otherwise the narratives are disconnected from their meaning.

## Chapter IV – Power

*For people who love liberty, nothing can change the fact that a person detained against his will is a prisoner, regardless of how his guards define his status or describe his place of detention. A person can be deprived of liberty for good or bad reasons, but deprived of liberty he is.*

Thomas Szasz (1994, p. 24)

This chapter focuses on power as a decision-making tool within the scheduling event. Psychiatric power is discussed extensively in the literature (Goffman, 1961; Bates, 1977; Scheff, 1984; Buchanan & Brock, 1989; Block & Chodoff, 1991; Barker & Baldwin, 1991; Szasz, 1987; 1994; Foucault, 1963; 1975; 1977; 1994; Diamond, 1995; Cohen, 1995). Power is a constant theme throughout the data analysis and is a central feature within many of the themes presented in this study.

Foucault (1977, p. 220) believed that power and knowledge in medicine are inseparable, and that power itself not only creates new knowledge and information, but “insidiously objectifies those on whom it is applied.” He saw the decline of the therapeutic models of psychiatric care of the 19<sup>th</sup> century (the moral era) as due to the expansion of power through the newly formed medical profession, and stated that “the decline began when writing and secrecy were introduced, that is, the concentration of this knowledge in a privileged group, and the dissociation of the immediate relationship.... What was known was no longer communicated to others” (Foucault, 1963, p. 55). Foucault (1967), unlike Szasz (1987, 1994) did not deny the existence of mental illness. Rather, he was concerned with the role society, and health professionals within it, has had in constructing the concept first in the attempt to contain it and, second, in seeking ways of treating it throughout history.

Throughout this study there is evidence of the power of psychiatry, its assumed knowledge and its secrecy, and the role power, knowledge and secrecy have in scheduling. I must note, however, that I am describing an event fraught with both ethical and clinical challenges, and I am not judging whether practices are right or wrong. Reich (1991, p. 101) stated that: “For something – a set of powers, say, or an institution, or a technology – to be capable of posing ethical problems, it must be capable of creating good or harm. In addition, it must be under the control, to a greater or lesser extent, of human will: it must be carried out, supervised, or participated in by persons who at some point possess, or believe themselves to possess, knowledge of their actions and the freedom to carry them out.” This is the case with this topic.



*The National Inquiry into the Human Rights of People with Mental Illness* (1993, p. 230) states that “involuntary detention — for any reason and under any circumstances — is an extremely serious matter involving curtailment of several fundamental rights, the most important of which is the right to liberty.” This loss of freedom, and the way it is taken away, impacts on those who are involved either as facilitators and/or enforcers of the process or as its subjects. The event itself has the potential for good as well as harm and it therefore satisfies the criteria for ethical concerns. After all, abuses in psychiatry have been documented (Block & Chodoff, 1991).

As discussed in the Introduction to this study, admission to a psychiatric facility in NSW can happen on a voluntary or involuntary basis, according to criteria defined within the *NSWMHA, 1990*. A Schedule II becomes possible once a mental health service is contacted. This often follows family or other concerned community members defining a person’s behaviour and/or speech as a possible cause of harm to self or others or to their reputation (Rogers et al., 1993). This judgement, particularly when made by people who are not familiar with the person experiencing a mental disorder, is in itself fraught with ethical dilemmas. The impact of feelings evoked in clinicians by the person experiencing mental illness (see pp. 59-63), as well as the differences in culturally bound psychiatric presentations (Marsella & White, 1982; Block & Chodoff, 1991; Marsella, 1998), are only two areas requiring caution in decision-making.

It is clear within this study that mental health clinicians are aware of the power they have to make decisions about initiating a schedule. They are also aware of the necessary caution required to ensure everyone's safety at that time. On the other hand, family members are aware of their power in initiating and influencing the event, as well as their powerlessness to help the person experiencing mental illness. Additionally, people who are scheduled struggle in their attempts to maintain some power and self-determination or, at least, some dignity and self-respect when their liberty is taken away.

In the majority of stories described, no alternatives to hospitalisation were provided, and no options were considered. Additionally, the powers invested in the mental health clinicians by the *NSWMHA, 1990* and the possible outcome of the assessment, including the involvement of police, were not usually discussed. The risk posed to self or others was, in most cases, the main reason for the decision to admit. This is congruent with decision-making based on dangerousness rather than need for treatment as discussed previously (pp. 26-30). In most cases, mental health professionals attended to calls following a thorough background

assessment of the situation and at the time of decision-making they believed there were no least restrictive options available.

There were a number of reasons for choosing to not provide information or discuss options. When asked about possible reasons for failing to provide all the information necessary for an informed decision about treatment clinicians stated that:

*Telling people they are very unwell and in need of hospitalisation often frightens them.*

*They may react by running away!*

And,

*I would prefer not to have to deal with this kind of response!*

Anyone who has worked in acute psychiatry knows that the reactions of people who experience a mental illness described above are real and at times undesirable. When people flee their homes to avoid hospitalisation and treatment there may be serious consequences, such as harm to self or others or deterioration to a more acute stage of the illness. However, it is the health professional's *assumptions* about the responses of those being scheduled that leads to withholding information. The evidence from this study suggests that often giving information may in fact lead to a less restrictive outcome, such as consent to treatment at home or admission to hospital on a voluntary basis.

It is taking the risk that mental health professionals find difficult. Sartorius, (1979, cited in Sherlock, 1986, p. 190) stated that: "If in the criminal law it is better that ten guilty men go free than that one innocent man suffer, how can we say in the civil commitment area that it is better that fifty four harmless people be incarcerated lest one dangerous man be free?"

This ethical dilemma is alive in today's psychiatric practice, and based on a paternalistic view of the individual who, due to a mental disorder, is considered incompetent and therefore incapable of providing informed consent (Eth & Robb, 1986).

Foucault (1975) argued that knowledge is power. This is evidenced in Chapter VI – Information and Education (p. 88), where those who were scheduled stated that information would have better enabled them to make choices about treatment, even if, strictly speaking, under some form of coercion. Coercion is defined as covering "those situations in which

threats or forced manipulation is applied” (Eth & Robb, 1986, p. 97) and includes a wide range of actions taken without consent of the individual involved (Blanch & Parrish, 1993).<sup>10</sup>

The stories told show practices frequently driven by lack of resources, a primary concern with the personal safety of others and a relinquishment of therapeutic principles such as engagement, communication and negotiation, and development of trust relationships (see Chapter VII – Relationships, p. 108). Clinicians described three main power relationships used in their clinical work in acute psychiatry.

### **Power relationships in acute community psychiatry**

#### The element of surprise

The element of surprise is based on a safe practice (occupational health and safety) stance that protects clinicians from liability and injury. The outcome of some schedules described is based on withholding information about what can happen, thus enabling health professionals and police to maintain the element of surprise, the “ace up the sleeve.” For example, Dr. Penford (Story 10, p. 204) was worried about the consequences of informing Caroline that she was going to be admitted. He saw her, made the decision about her need for admission, and then tried to arrange for the police to pick her up and transport her to hospital.

*I made the decision [to admit her] but didn't tell Caroline. I was positive that she would just leave the unit if we'd told her. She was unwell and needed hospitalisation. And she disagreed with it.*

Dr. James (Story 9, p. 202), on the other hand, knew that medication was offered to Peter as an alternative to hospitalisation, and was refused. She felt that hospitalisation was the only option left, and she considered the possible power struggle if she were to inform Peter of her decision.

*Peter could have at that point said: "I'm not going and you can't make me go." Then I would have explained to him in more details what his rights were. But at that point, someone doesn't have a great many rights until they are in hospital. And that is rights as a person basically! They are going to be transported to hospital and there's not much they can do about it!*

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<sup>10</sup> See also Hiday (1992) on p. 17

## Partnership

The development of a partnership, or therapeutic alliance, enables people affected by mental illness to take some control over their life and their treatment options. However, ultimately, the power of decision-making remains with the health professional.

Louise (Story 8, p. 201) was working with people affected by mental illness within a model that involved intense advocacy and a focus on empowering the individual. She worked in close partnership in setting goals, identifying early warning signs, and developing plans to manage both the illness and the resulting disabilities (Anthony, 1993). Foucault described power as a quality that exists only in the moment it is exercised and that it is activated and practised within social relationships (in Wickham, 1986). Louise believed that her power lay within her duty of care. She believed this was clearly understood by Penny, who was expected to keep to her part of the care contract, namely monitor her own mental state and titrate<sup>11</sup> her medication as required.

*At a certain point, when Penny was experiencing certain early warning signs she was to start taking medication. [But she'd say]: "I'm fine today. And I'm really keeping a check on it. No! I'm not going to take medication." I'd say to her: "I really think it would be a good thing for you to take medication now. But if you are not going to, I'm obligated at some point to make sure you are safe and in hospital."*

This social relationship between Penny and Louise led later, when Penny had to be scheduled again, to Louise feeling "betrayed" by Penny who, somehow, had failed her in that relationship (p. 116).

## Social control

This form of power involves the awareness and attitudes held by clinicians that reflect the way psychiatry and psychiatric work has been described in the literature, the arts, and the media over the centuries. This perception continues to have an impact both within and outside the psychiatric arena. "One Flew Over the Coochoo's Nest", "Psycho", and stories of people killed by police or locked up forever in totalitarian countries have been some of the contributors to this perception (Barker & Baldwin, 1991, p.7).<sup>12</sup> Intellectuals such as Ervin Goffman (1961) and Thomas Szasz (1994) have shaped the social perception of psychiatric

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<sup>11</sup> Titration is a medical term meaning the monitoring of a medication's effectiveness and increasing or decreasing its dosage as required.

<sup>12</sup> See also Brandon, D. (1991, pp. 7-8) for a discussion on how symbols and imagery are used by the media in devaluing disabled people.

hospitals as totalitarian institutions and psychiatry as a discipline of social control.

Additionally, Foucault (1961, 1973) provided the world with a cogent explanation of the historical developments of psychiatry within medicine, and of how medicine has served the interests of the medical profession and the State. These ideas are reflected in the defensive or self-justifying answers given by some clinicians.

Doug (Story 2, p. 192) enjoyed what he called “real work,” namely, assessing people who were acutely psychotic and in need of immediate containment and treatment. This gave him a greater sense of importance than the more “psychosocial” work whereby people who were usually quite well functioning found themselves in acute crisis requiring psychosocial intervention. The latter were known as the “worried well” (Barker & Jackson, 1996) or sometimes labelled as those with a “personality disorder.” The experience of psychosis therefore is explained within the confines of biological psychiatry and this seems to make the person affected “more deserving” while the intervention becomes “more valid.”

*Margaret was unwell and clearly, she needed to go into hospital. I didn't think there was any other alternative so I probably didn't have any particularly strong feelings either way. If anything [I felt] a bit patronising. I guess I was pleased that I had a student with me and [she] was seeing someone who was clearly as psychotic as you can see. It was good for the student that she saw someone who was very unwell and really got the idea that we are not [working] in a Nazi level or anything like that, dragging off people who are just minding their own business. I don't think that any fair-minded person could have seen Margaret and not thought that she needed some sort of intervention. You'd need to be very extreme in your views.*

Power took many forms and engendered many feelings. This was evident in the clinical decisions about competence and risk; in its experience by relatives through anger and powerlessness; and in the complete powerlessness of those people who were scheduled.

## **The experience of power**

### Clinicians and the concept of competence

Dr. Penford was aware throughout the interview that power relationships were at the core of the discussion. He was concerned about the meaning ascribed to his answers. He was at times flippant and made jokes indicating that he knew of the popular perceptions of acute psychiatric work. He acknowledged that personal feelings do come into the interaction, and that it is important for those with the greatest power, the health professionals, to keep these feelings in check. He admitted to feeling confronted by Caroline's attitude towards him and to experiencing a sense of superiority due to his position.

I had a mild counter-transference towards Caroline. She became mildly abusive, wouldn't answer my questions. She'd rephrase the questions back to me. When I asked: "Are you feeling a bit manic today?" she would say it back to me: "Are you feeling a bit manic today?" [Own emphasis]. She is very high functioning and has excellent verbal skills.

Other health professionals felt very comfortable in their clinical roles. The assumptions about people's reactions to information by fleeing (see p. 58) seemed to be closely related to the health professionals' views about competency and the capacity of people experiencing mental illness to give informed consent. Eth and Robb (1986, p. 93) stated that defining competency is a very difficult task, but a person "does not automatically become incompetent because of mental illness, retardation, or any other disease." Furthermore, the authors identified non-compliance with treatment as "the most common trigger for questioning a patient's competence." They added: "It is as though the failure to co-operate with a physician means that a patient does not comprehend the benefits of accepting the treatment or does not appreciate the dangers of refusing to consent. The result is a 'Catch 22' situation for patients refusing treatment. Patients are considered competent and treated if they consent, and are deemed incompetent and treated anyway if they refuse."

Therefore, it is apparent that the concept of *incompetence* influences the way those who participate in a schedule communicate with the person experiencing mental illness and the decisions that are made (see Chapter VI – Information and Education, p. 88). If the dialogue is based on an assumption of competence, it is easy to identify those who require treatment against their wishes. This position is supported by Katz (1980, p. 105) who added: "A presumption of competence would alert psychiatrists not to fall victim to the temptation of listening with a third ear to manifestations of the irrational, so appropriate for therapeutic purposes but not necessarily for decisional ones."

For informed consent to be possible, information must be given at the earliest possible time. However, the idea of informing people in general about the power of psychiatry is seen as dangerous by some. Amanda (Story 5, p. 196), a highly experienced clinician, believes that her clinical background entitles her to decide "what is best." Her view of psychiatry is based on law and legislation and the rights of society rather than individuals, and on the traditional emphasis professionals have given to "the dangers of truthtelling" (Gadow, 1990, p. 34). Some of the words Amanda uses reflect both her power and her clinical stance.

*We can tell them we have the legal right to assess how ill [they] are. Would you tell the snake before it gets in the bag that you're going to tie the knot? On the other hand, if someone has chronic non-compliance, make them aware this is the penalty they'll probably have to pay! And some doctors don't believe in telling people of their diagnosis for fear of reaction. We shouldn't tell if it is someone who cannot comprehend. I wouldn't bother to confuse someone who is cognitively impaired, developmentally disabled or psychotic. Information would be [given] depending on the capacity [of the client] to absorb information. If the diagnosis is one of schizophrenia, bipolar disorder, or major depression, the client should be told as part of proper psycho-education.*

Doug portrayed the popular fears about the power of psychiatry when he added, in the context of informing communities:

*Sure you want people informed! I don't think you really want to be like the police though, when you get read that bit about your rights! I probably think that it would be a good idea to give every new client a brochure explaining the Mental Health Act and things like that. I guess we'd have to be a little bit certain [they would need it]! Otherwise people who would never fall in that category could very easily misinterpret that they might be taken away to hospital against their will by the police... Which they might! [Laughs].*

#### Relatives and the power dichotomy

For relatives, the experience of power differs. Lefley (1996) discussed the families' experiences with initiating and/or facilitating coercive treatment (see also Chapter VII – Relationships, p. 108). As the data demonstrate, these experiences generate intense and unwanted feelings. Families are at the forefront of the consequences of their loved one's behaviour. They live with the constant threat of harm to self or others, they are often at the receiving end of displaced hostility, and they frequently have to advocate for (and at times financially rescue) the person, who may have squandered family and/or business assets.

The relatives interviewed remembered the looks of disbelief and powerlessness on the faces of their loved ones, and felt powerless themselves. They felt their inability to protect the person experiencing mental illness from both the impact of that illness and its consequences. The scheduling event triggered a grief reaction, a deep sense of loss. When mental health clinicians took the time to explain the unfolding events, when they asked relevant questions about their unwell relative's behaviour, and when they answered their multitude of anxious questions calmly and reassuringly, relatives felt supported and validated. They felt reassured in their own mind that they were in fact doing what was best for the person being scheduled. There were times, however, when mental health professionals behaved in a manner that reinforced the relative's feelings of powerlessness and grief.

For instance, Pedro (Story 16, p. 212) was highly anxious about what was happening to his brother, Jaime. He was expecting a call from mental health clinicians to support Jaime when taken into hospital. Instead he received a telephone call from his flatmates informing him that Jaime had been taken away by police. Adding insult to injury, in Pedro's view, the clinician involved failed to return his call. The lack of opportunity to express his feelings angered him even more.

Anger has been identified as a coping mechanism for family members when they cannot get the information and support they feel they require from mental health professionals (Lefley, 1996, p. 122). Pedro was also angry at the mental health clinicians that attended to his brother and then left him alone at home while sending the police to pick him up. He thought that the attitude of clinicians whose job involves caring for people who experience mental illness is comparable to that of department store employees, whose job entails customer satisfaction through availability of goods, not emotional support.

*I knew that was going to [happen]! But it was about two or three hours later when I got a phone call from my flatmate and I was very upset obviously! I called the contact number, the mobile number where Norelle [the crisis team member] was. I called her and she gave me excuses. Supermarket excuses: "We don't have it" or "I'm sorry you're out of luck," things like that. Basically, she didn't have the time to call me! Or our communication was very bad on the phone to the point that her excuse to me was too cheap. She didn't come out with any calming answers. That's what annoyed me more still! That she was not doing what she was being paid for basically! Anyway, the phone cut out because she was on a mobile. She never called me back to carry on the conversation! When you complain to them they put you on to somewhere else and they try to dismiss you! And I felt that this is not on! Apart from what's happened to my brother, I don't think people who work caring for other people should behave like that. But that's very personal. I guess she got up and had a bad day and whatever! But you can't [behave like that]! I mean, I was in a very bad situation! And my brother also expressed that and said: "That is ridiculous! Six policemen to arrest me!"*

Relatives stated that they received no education or information about the *NSWMH, 1990*, their rights as consumers, or the powers of health professionals and police regarding mental state assessments and facilitating involuntary admission to a psychiatric institution. The paradoxical situation of facing their own lack of control over their lives and, at the same time, having to take control of a loved one's life was confronting. Lefley (1996, p. 188) stated that: "Family members are almost always reluctant to call the police and even more reluctant to initiate involuntary commitment procedures. Both of these not only are humiliating and



dehumanising to a loved one but can also have consequences that are counterproductive” (see Chapter VII – Relationships, p. 108).

Maureen (Story 18, p. 215), albeit relieved that the legislation exists and protects individuals, was shaken by the thought that it can be used with such flexibility. No matter what the presenting circumstances are, the legislation can be used to deprive someone of their liberty.

*I didn't know [this could happen]. And it is still a bit of a worry to me in a way when Dylan said to Tony that day that he had the right to say: "Because you have refused your medication we can now put you in hospital." That still frightens me! It frightens me to think that because you had a psychosis at some time that they can say: "Well, Ok! You've been psychotic before so now we've got the power, because we think you're a danger to yourself or someone else, to put you in a hospital." That part of it worries me! But there's the other part. When I needed the help and that law is in place to protect him. And me I suppose.*

Sandra (Story 19, p. 216) felt fortunate in her involvement in Tom's admission. The nurses on the ward and the treating psychiatrist spent a lot of time reassuring her and providing her with information and educational material. Her experience with the community mental health professionals was also positive. She wondered whether this was just luck. Tom was only twenty-one and having his first experience of psychosis. However, as for others, full explanations about the powers of mental health professionals and the possible outcomes were not given.

*I don't recall schedules and hospitalisation being explained to me here [at home]. Oh, yes! I think we had a conversation about he had two choices: he could either go of his own free will or he would need to be scheduled. They didn't explain [about the Mental Health Act] then but they explained that more fully at the hospital. The on-call registrar sat down and went through that with me and explained to me that if he didn't volunteer to be there by Tuesday he would have to go in front of the magistrate, and what would happen then: that he would be scheduled. So, we understood that fully before it was due to happen on the Tuesday. Nothing [was said] about his rights. That's clear in my memory at the moment. I don't think anybody actually voiced those to me.*

The thought that mental health clinicians could just knock on somebody's door and initiate the admission process was frightening for many relatives. However, there was a general acceptance that this was a painful necessity. Just cause for such actions was acknowledged, but the idea that mental health professionals have such discretion caused discomfort, particularly for those with less positive experiences.

*I think it's probably important that everybody becomes more aware of all sorts of mental illness. It's a message you'd have to deliver quite carefully because there would be people who would be frightened by that, who thought you just had the right to knock on their door and take them away without just cause. You wouldn't do that unless there was something in their behaviour that would indicate that they needed to be taken away! I still think it's important to have that power because there are a lot of people who are on their own, who don't have someone who can call for help. It's important that people understand the right message as opposed to being terrified that someone is going to come and knock on their door and take them away at their whim.<sup>13</sup>*

Most people who consult a doctor expect them to have adequate knowledge and expertise. There is an expectation that the doctor will hold all the answers to one's ailments and discomforts (see for example the review by Lupton, 1996). Pedro needed to believe that doctors hold all knowledge, power, and responsibility for the care and treatment of people experiencing mental illness. The thought that doctors might be mistaken or, worse yet, fail in providing the right answers and treatments scared him. He felt that if Jaime were to trust him, then he needed to trust that the doctor could ensure a positive outcome. He would rather devolve both his power and his responsibility onto the treating doctor and concentrate solely on supporting Jaime.

*I keep asking myself: "When one human being can put another one in hospital, what's worse?" I don't want to be responsible for that. It has to be somebody responsible, and that's the doctor, no? I trust the doctor somehow! I trust the doctor and I don't accept a doctor telling me: "Oh, I could be wrong." That's the way I think! I would never accept the doctor telling me: "I could be wrong!" I can see them telling me that they are human! It's like an excuse!*

All the relatives interviewed, except for Eileen (Story 11, p. 205) who stated that she felt in control because she was "education and information minded," experienced feeling powerlessness. Some expressed their powerlessness with statements such as: "There is nothing I can do to make him better." Not understanding what was going on, and not receiving reassuring answers, increased the relatives' sense of powerlessness. Close family members often protected and supported one another. Mental illness was likened to an incredibly powerful enemy against which there was no hope. Pedro identified his powerlessness as due to his inability to understand the inner world of his brother and feeling that he could not protect him the same way he had done when they were children.

*When you talk to the doctor, you feel you ask a lot of questions and you don't get the right answers. You don't have the opportunity to talk about [things]!*

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<sup>13</sup> See Doug's opinion about this being possible on p. 63

*This is when you lose control basically! Because you don't comprehend the way that the patient talks to you because he's in another [world]. What I'm saying is that as far as I'm concerned there's nothing we can do about it! Sometimes I think: "My God! When I was very young, if my brother had a fight I was there: don't you touch my little brother!" Now you feel you want to do something like this but you can't! You cannot help him! It's not like that!*

In Sandra's case, her inability to fulfil her maternal role of "making her child better" added to her distress and powerlessness. She, like Pedro with Jaime, wanted to protect Tom from harm. Like many others, she found that seeking help in psychiatry often means losing, and grieving, the parental role.

*I'm a control freak and being out of control is just totally out for me! Even though I did something by calling for help and supporting him through the process as best I could, you still got some sense of: "I just want to make you better and I can't!" And that is tough! [I cry about] everything, but mostly the scheduling because that's something that's out of your hands. If you take someone to a hospital and you say: "I'm bringing my son in because he's sick" but they just take him away you think to yourself: "Maybe I could keep him at home." There's a lot of hurt. Because you feel sometimes that you failed them: "I couldn't protect you!" And as a parent and as a mother, the worst thing that can happen is that you can't protect your child. And I always felt if anyone ever threatened my child I could kill! And I actually feel like that. I could kill for a child that's threatened.*

Although Sandra had quite a good experience with support once Tom was in hospital, others did not share this experience. Having learned about involuntary admissions and the power of the *NSWMHA*, 1990 through experiencing it first hand, some relatives had the impression that they had no right to expect anything at all from the mental health service. The need to maintain confidentiality about the contact with, and treatment of, people experiencing a mental illness is part of public health policy. It is generally accepted that information will be shared amongst health professionals involved in a person's care. Sharing information with family members, however, requires consent from the person experiencing mental illness, especially when the family member requesting the information is not the primary care giver (Furlong & Leggatt, 1996; Atkinson, 1991).

Furlong and Leggatt (1996, p. 615) developed practical options to enable clinicians to negotiate information sharing in a manner that is sensitive to families. They suggest that, when maintaining confidentiality may be a problem, the clinician be guided by the question: "What is the nature of the relationship I am attempting to develop with the client and their family?" Furthermore, the current view of relatives as partners and resources could be argued to mean that information can (and should) be shared.

Terry (see Story 15, p. 210) was not considered a carer, as he did not live at home anymore. Vincent (his son) was discharged to the care of his mother after his last hospitalisation and she did not want Terry involved. This distressed Terry, as he was unable to get any information about Vincent's current situation. Mental health clinicians told him that as he was no longer involved in Vincent's care they could not disclose any information to him. The psychiatrist he had previously had a good relationship with had since left, and he was no longer accorded the same regard.

*I knew about the Mental Health Act 1990 through my son's psychiatrist - of the possibility of Vincent being taken to hospital and of police involvement. I feel that de facto I have no rights as a relative of a mentally ill person as I had no information about my son. Confidentiality is not treated with judgement and discretion. I don't feel I have any rights. I'm not given any consideration since the psychiatrist I knew left. This place has no resources, and I have no right to expect anything.*

This distancing of family members is seen throughout the study, causing them undue distress. The important element of trust between relatives and the mental health system will be further discussed in Chapter IX – Relationships (p. 108).

#### Being scheduled and powerlessness

Those who are subjected to psychiatric scrutiny experience power quite differently from clinicians and relatives. Its absence causes the most intense feelings. Although some people try to maintain some control over what happens to them, most attempts are met by a show of greater power on the part of mental health clinicians and, at times, relatives. The experiences of institutionalisation and of care and control by mental health services have been blamed for robbing people of their autonomy, independence, and often their ability to give informed consent (Mills, 1962; Goffman, 1963; Eth & Robb, 1986). There is no evidence that this is any different outside of total institutions, as psychiatric care remains a benevolent system that often reverts to coercion and control in the best interest of the client (Diamond, 1995).

Frequently, a genuine concern for the well being of the person experiencing mental illness, their relatives, and society leads mental health clinicians to practice according to a safety model (see p. 79). This involves not taking any actions that may lead to physical or psychological harm, even when those actions may preserve dignity and self-respect. When situations are potentially ambiguous, mental health clinicians find it difficult to take risks, especially when working within the current reductionist model of mental health care that

leaves little room for trust and familiarity, essential components of comfortable risk taking (Luhmann, 1988; Diamond, 1995).

Appelbaum (1985) recommended that mental health professionals' reliance on instincts in decision-making about the need for hospitalisation and treatment is maintained. He is of the opinion that it is justified to commit someone when there is the possibility of improvement. This is supported by evidence that once people are treated against their wishes and they improve, they realise that treatment was necessary and in their best interest (see for instance Teresa, Story 27, p. 227). Much of the research on people's attitudes to commitment shows that people's attitude changes once they get better, supporting the view that control and coercion are justified and that people affected by mental illness are in fact unable to make informed decisions. This acceptance is referred to as the "Thank you" theory described by Stone (1976). This theory implies that a retrospective acceptance or even gratitude for being civilly committed can be interpreted as no harm done. Gardener, Lidz, Hoge, Monahan, Eisenberg, Bennett, Mulvey, & Roth (1999), in a study of prospective patients who refused hospitalisations and who revised their beliefs following discharge despite their perceptions of coercion, found that acceptance of hospitalisation does not minimise the stressful impact the event has on a person's psychological well-being.

Additional to the clinical decision-making power is the use of deception in the practice of psychiatry (see Chapter VI – Information and Education, p. 88). Paul (Story 25, p. 224) was perturbed by his powerlessness and the deception used by his family on the day he was scheduled. It disturbed him that other services had informed his local community mental health centre of his move to their area and by his relatives' involvement in the planning and initiating of his schedule. He was confronted by the realisation that his reaction to being given information was not trusted, and police officers were involved to prevent any attempts of him fleeing. Deemed mentally ill, a danger to others, and a risk to his reputation, he was considered incapable of participating in the planning of his own treatment.

*Dr. Berry said: "I have a piece of paper here, the Mental Health Act bla bla bla." [I asked]: "Can I see it?" He said: "No, you can't see it." That was difficult! Probably [they don't let you see it] because they've given people the schedule and they've torn it up. But if they have another copy of it, they could give people a schedule so they could realise: "Ah, it's okay. I've been scheduled."*

When asked about his powerlessness Paul, after giving it some thought, admitted that "some things can and do happen unexpectedly and are beyond one's control." This thought worried

him, as he was often fearful that deception could be used against him again, such as with my presence at his unit.

*I wouldn't say that [I feel powerless]. I don't fear being scheduled. I thought maybe your visit was another trick to get me scheduled, but I didn't think that was necessary. I do live in fear of being scheduled by deception actually, in a way. I had a reasonable good day, I can't remember the exact happenings [that day], but it is a worry [how it can happen].*

Powerlessness about the illness and the mental health services' involvement was evident in the reply given by Tom (Story 28, p. 229). Tom felt trapped in his body, his mind, and the mental health system. He expressed this with anger and sarcasm.

*If they are going to do it, they are going to do it! If it happens, it's going to happen! And I'll make sure I'll do my damndest to prevent it happening. But if they've got to do it, they've got the shit on you, right? They've got the files, and they've got all the tests, and they've got all the shit, and they can just prove it. They can just say: "Look, this dummy is defective, we're putting him away now." They can do that anytime they want. Any time they want! [His voice starts to rise]. I could walk out of here and not get five hundred meters down the street! And they could have me in hospital like that [snaps his fingers] if they wanted. Why? Because they can! They've got no reason to! There's nothing wrong with me at the moment! But they could if they wanted to. So, I mean, really, I don't have a choice. I really don't have a choice [own emphasis].*

Steve (Story 26, p. 226) could not believe this could happen to him. It was like a dream. He had been unwell for the first time the previous year and had taken medication prescribed by his GP. As he became symptom free, he decided he no longer needed it and eventually became unwell again. This time he had no choice. His history was known to the mental health clinicians, his family were concerned, and he could no longer control his own behaviour.

*Knowing that you can just be taken from your home there's a definite feeling of powerlessness. And that at any time, depending on how you are behaving, you can be put back in [to hospital]. I wouldn't want to go to the acute ward again. It's not a nice place.*

Susan (Story 22, p. 220) appeared unperturbed by her powerlessness. She believed in the role of psychiatry and police services to guarantee her safety, and accepted their intervention without question. She described the scheduling event in a matter of fact way as "just a change of routine." Her feelings towards "older", less sympathetic police officers who worked "by the book" were evidence of the little control she had (see Chapter V – Crime or Illness, p. 73).

*I felt powerless to do anything else [but go with them]. I have always had a good image of the police. There was another time when the police were here and they were more stereotypes, older policemen. One held me by the wrist, and inside me, I didn't like that. I hadn't moved away! I was going towards them. I have never attempted to run away from police. Younger police are more relaxed.*

While in Susan's story the police were familiar figures, for Teresa they were unwelcome enforcers of an unwarranted event. *Parens patriae* has been defined as the power of the State to act in the place of a parent (Simon, 1987). It is used in psychiatry when medicine and the law combine in allowing mental health professionals the power of decision-making necessary to care and treat people affected by mental illness if they are at risk and incompetent. Relatives, although frequently willing to take responsibility for the care and control of their loved one, are often told that the decision is "out of their hands."

Teresa told of how her brother, Brad, tried to protect her and intervene when she was taken by the police officers. He had been left out of the decision-making process about her need for care, treatment and control. She felt that Brad knew she would have agreed to a voluntary admission if she were given more time and information about the consequences of her refusal, but he was not allowed to advocate on her behalf. She also believed that he could and would have transported her safely to hospital had he been given the opportunity, thus avoiding the police experience. His opinions and attempts at co-operative participation were interpreted by the clinicians present as "interference," although Teresa had desperately wanted him to be involved. Commonly, the possibility of negotiation with relatives or the people being scheduled themselves was disregarded as clinicians felt that their own opinion and decisions would "lead to a better outcome" for the client (Diamond, 1995, p. 9).

*[The worst was] the actual certification. Taking my rights. And particularly when my brother was informed of our rights and stressed: "I have rights to organise these sorts of things." He said at one stage: "If I felt Teresa needs hospitalisation I would be the first to say take her. She's got to go." But we had no rights.*

As discussed, some people felt that their personal territory and their autonomy were invaded and that they were not able to control what was happening. This feeling increased with the inpatient experience and the degradation some people were subjected to. Teresa felt strongly about this.

*You feel like everything has been taken from you! It's like someone has put their hand in and ripped out your heart! You're totally powerless, totally at*

*their mercy: "Don't want to talk to us? Fine, don't" [they say]. I had a warden take me in, she was a nurse's aid, and she threatened to lock me up when I was in hospital. Because I asked for a drink! I couldn't speak! I was so frightened my mouth was all dry.*

All three groups interviewed acknowledged the feelings of power and powerlessness involved in this event. Schedules often happen "out of the blue," without a warning, and that seems to be how people learn about the power of mental health services and the *NSWMHA 1990*. Police involvement adds to the power of clinicians, the power-powerlessness dichotomy of the relatives, and the powerlessness of those who are scheduled. The most poignant power issue for all is the question of whether mental illness is a crime or an illness. If an illness "like any other illness"<sup>14</sup> then why the deception? Why are police and magistrates involved?

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<sup>14</sup> This statement was also used by Erica Bates (1977, p. 76) as early as 1971.



## Chapter V – Crime or Illness?

*Transport of a mentally ill person by police reinforces to the police and to the general public that mental illness is a criminal problem. They've been taken away by police, they've been put in divisional vans and then [sometimes] put in cells, so that even the best efforts of an enlightened group who are saying that mental illness is a health problem are being destroyed by that action.*

Dr. David Wells in *Human Rights and Mental Illness* (1993, p. 233)

Theories of deviance and social control take a broad perspective of the causative factors of mental illness. They complement psychological and biological theories in that they attempt to provide explanations of “deviant” behaviour, such as that exhibited by people affected by mental illness, in terms that include the societal responses to that behaviour. The interface between psychiatry and the criminal justice systems has been studied, particularly since the de-institutionalisation phenomena in western industrial countries, namely Australia, the United Kingdom and the United States of America. Of particular importance on this topic are the works of Thomas Szasz (1987, 1994), Stanley Cohen (1985) and Thomas Scheff (1984). Scheff (1984, pp. 19-20) described both psychiatrists and police as “experts on deviance,” defining deviance as “the violation of those rules which are felt to be worthy of high respect.” He also described social control as the setting of norms, or social expectations, as well as the punishments and rewards to enforce those norms.

As described earlier (p. 15) schedules apply to people who are considered a danger to self and/or others and who are unwilling or unable to consent to treatment. Therefore, for a schedule to be enacted a number of social norms have to be broken. Dangerousness to oneself or others is unacceptable to society. When a person displays dangerous behaviours and, arising from these behaviours, they come to the attention of police or psychiatric professionals, it is interesting how often both “experts” become involved.

The concept of dangerousness in mental health has been extensively studied. Of interest to this topic are studies on the prediction of dangerousness (see Chapter II – Background Literature, p. 13), as this influences decision-making about hospitalisation. Steadman (1980) reviewed the literature on prediction of violent behaviour amongst mentally ill populations. Although most data related to patients discharged from maximum-security facilities, the results showed poor predictor factors in both the dangerous and non-dangerous populations and “there was no indication from these data of any ability on the part of the staff to identify accurately those who would be dangerous ... beyond the accuracy anyone could attain simply by the probabilities of chance” (Steadman, 1980, pp.89-91).

Police services are used for the protection of society and as law enforcers. Additionally, they are often the first to respond when an individual's behaviour causes community concern. In most of the stories told in this study, mental health professionals called police officers to provide protection to clinicians and others present, to ensure the safety and well-being of the person experiencing mental illness, and to assist in hospitalisation. None of the individuals being assessed had committed a crime or had acted, or threatened to act, in a violent way.

When a person is mentally ill to a degree whereby they may require hospitalisation the law states that the person must be transported to a place of safety to be assessed by a medical officer with experience in psychiatry. Under Section 22 (*NSWMHA 1990*, p.12), if the person is refusing admission and no other less restrictive means of transport is available, police officers may be required to ensure that safe and timely transportation takes place.

Furthermore, to prevent any situation escalating into greater risk for those involved, mental health professionals often request preventative police escort. This is in fact, as demonstrated by the data, the most common reason for police involvement in a schedule.

## **Feelings about police involvement**

### Clinical support

The feelings described by the clinicians interviewed regarding police involvement related to their previous experiences of schedules. As a rule, clinicians felt supported by police presence. They knew that little could go wrong and that the assessment and transportation would happen with less trouble. Some clinicians, however, expressed concerns about police behaviours, while others saw police involvement as "just a tool" for a task to be accomplished. Clinicians sometimes described police officers as "rough." While usually officers complied with requests by mental health clinicians in attendance to wait out of sight or maintain a more passive, protective role, stories abound of police behaving quite forcefully in using physical restraint. Clinicians generally reported a dislike for such tactics and empathy for the feelings of shame, humiliation and powerlessness expressed by the person being scheduled and their relatives. Surprisingly, only one staff member interviewed stressed the need for mental health staff to be present when police apprehend a person for transport to a psychiatric facility. The remaining clinicians felt quite comfortable with requesting police to attend by themselves, not sure of what their role could be when faced with potentially violent situations.

## Memorandum of Understanding

The *Memorandum of Understanding between NSW Police and NSW Health (1998)* was developed between mental health services and police services to formalise their collaboration when working with people affected by mental illness. The mental health services' practice of expecting police to attend to a person experiencing mental illness without mental health support is strongly discouraged in this *Memorandum*. This practice, however, still occurs despite clinicians knowing that police officers frequently work "by the book" and receive little or no specialised training on how to deal with people experiencing mental illness. Whether police officers attend without mental health support usually depends on the Senior Officer in charge.<sup>15</sup>

Following the assessment of a person requiring scheduling, Dr. Penford usually "dropped off" the Schedule II document to the police station. He was under the impression that this was common practice and this was how he had usually arranged for people to be hospitalised. In this instance, the Senior Officer refused to comply with his request.

*The woman [the senior police officer] was put off when I wanted to just drop the schedule off. She wanted the mental health staff to go with them. As far as I know this is common practice though, to drop the schedule and move on to see another client. But she was very nice, and persuasive [laughs], so we ended up going back with them. There was nothing urgent so...*

Louise was still recovering from the traumatic experience of using deceit, the police, and the element of surprise to schedule Penny. She was the only clinician to acknowledge that mental health professionals ought to be present at a schedule when police are involved. Dr. James, on the other hand, was concerned about the police officers' possible behaviour during the assessment, and when the time came to transport Peter. Experience had shown that some police officers, in working "by the book," deal with disturbed behaviours of those experiencing mental illness in a similar manner as they do with people involved in criminal activities. The skills and expertise required to de-escalate and/or contain a person experiencing mental illness are quite different (Stuart & Sundeen, 1987, pp. 562-587). Luckily, Dr. James' experience was a positive one.

*I felt they managed the case exceptionally. I was concerned that once we called them they would come barging in. At that stage, we hadn't fully discussed all the options, and I didn't feel I'd given the patient enough time to*

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<sup>15</sup> See Price and Denner (1973) for a description of police practices. Although the study is quite old, the events described are still common in community mental health practice.

*consent to come into hospital. They weren't forceful. They were very stern, but I think they acted in a very calm, appropriate manner.*

### Psychiatric police

Clinicians identified the need for police to receive specialist training in attending to people severely affected by mental illness, and suggested the use of specially trained "psychiatric police." Some of the people who were scheduled made a similar suggestion (p. 85), as did their relatives (p. 80). This would entail having professionals trained with both clinical and law enforcing skills, not wearing a uniform, and driving an unidentifiable car. This notion is not new as emergency outreach teams comprising a specially trained police officer and a mental health professional were established in Los Angeles (USA) and were able to deal effectively with people experiencing mental illness who were at high risk of criminalization. Combining specialised knowledge increased appropriate access to mental health services and facilitated "the expeditious and humane handling of psychiatric patients who are violent" (Lamb, Shaner, Elliott, DeCuir & Foltz, 1995, p. 1271). In NSW, the Police Academy (Goulburn) now provides mental health placements to trainees.

The use of the mental health service cars and ambulances to maintain the respect and dignity of the person being scheduled were suggested by many as alternatives to the use of a police van. Twenty out of the thirty schedules discussed in this study involved police presence (see Table 2, p. 44), confirming the idea that "police should be thought of as 'frontline' mental health workers" (Rogers et al., 1993, p. 31). Their presence added to the stigma and outcasting by neighbours and local communities, and to the person's own feelings of "being treated as a criminal."

Scheff (1984, p. 30) stated that "deviance is a normative violation, which may obtain all three of the following responses: moral outrage or stigma, segregation, and labelling. The possibility that these three responses will follow a violation can be used to define deviance." Segregation and labelling are easier concepts to understand than stigma. According to Scheff, stigma is present when "the emotional reaction to deviance is usually in excess of the appropriate response. I call this excess, which may be quite small or very large, the *surplus emotional response*. Stigma occurs because of the response" (emphasis in the original).

## The relatives' experience

### Support, stigma and distress

Relatives experienced police involvement in ways similar to clinicians. Deveson (1998, p. 77), in describing her experience with Jonathan, her son, acknowledged the impact of police presence on the stigma attached to mental illness. She stated that "the only way to get Jonathan to hospital against his will would be by calling the police which seemed such a hostile thing to do. If Jonathan had appendicitis, he would have been taken to hospital by ambulance. Only the mentally ill are treated as if they have committed a crime. Physical illness is met with sympathy, mental illness with shame."

Sandra felt she was lucky in being spared the police experience. She was able, however, to empathise with relatives and people whom had been scheduled with police involvement. During Tom's hospital stay, Sandra had witnessed several people admitted under police escort and described the experience as "probably very distressing."

*That would distress me more [police involvement] because that would distress him. I think the person must find it frightening! I certainly didn't see anybody coming [into hospital] with the police peacefully! Anybody that the police brought in the six weeks I was there were distressed, and the police were trying their best. You're dealing with someone who's obviously somewhere else! And so they all came in kicking and screaming and protesting quite loudly. I guess my observation is that it must be frightening for someone who clearly isn't rational! And Tom made mention a couple of times when we saw people coming like that: "Why do they call the police when they haven't done anything wrong?" And I'm thinking to myself: "Maybe that's what goes through people's minds?" They associate being taken away by police as: "I've broken the law, I've done something wrong" and their protest is: "But I haven't done anything wrong!" That's all it takes! You would have had them resisting going in! If Tom had said: "No, I'm not going in" the chances are that the police would have been called. If I had to and had no other choice, I would do it. But it would have to be absolutely the last resort. Absolutely! I would choose not to unless there was no other way to help him.*

The involvement of police officers seemed to add a different dimension to the event, that is the potential for violence, real or assumed. In the scenarios where police attended the event but did not take any action the person being scheduled displayed no resistance. They seemed to realise that there were no other options and agreed to transport to hospital. Although people were considered acutely psychotic at the time, most did recognise police officers as figures of authority that made the event "real."

Table 4 shows the amount of resistance expressed by the person being scheduled as rated by each informant, based on their subjective experience. Interestingly, in Alex and Tom's cases, both their rating and their mothers' were that no resistance was expressed. In Steve's case, however, Betty (Story 17 p. 214) rated him as not expressing any resistance, while he saw himself as mildly resistant. Two-thirds (n. 20) of the people scheduled were described as exhibiting mild or no resistance.

**Table 4.**  
**Resistance Rating** (All schedules, N. 30).

Not At All	Mildly	Moderately	Extremely
53% (n.16)	13% (n.4)	17% (n.5)	17% (n.5)

Awareness of reality and ability to control their behaviour despite the psychotic symptoms experienced could be demonstrated. Maureen said about Tony:

*The first time the police were involved. And then Tony still went with us to hospital in the car. The police didn't have to take him. I think this time he wanted to avoid that. And Dylan [the casemanager] said: "Well, look, we were going to give you medication at home but now you ripped the phones out." He said: "Well, I won't do that again," having a go. But Dylan said: "Well, we feel that your mother is in danger now. She can't contact anyone, so you have to come." And his friend drove him. I think he went with his friend and I went with Dylan.*

Betty described Steve's disbelief at the finality of the intervention when faced by police officers. Again, Steve was aware of his situational reality and able to behave competently.

*The [police] said nothing. They gave nothing. They were just quietly there. And I think that he might have thought that this was a bad practical joke. But he knew this was for real! There was a lady and two guys. Steve just couldn't believe it! Couldn't believe it was happening to him. So when he really realised that this was happening to him he said: "Can I go upstairs and get a few belongings?" And one of the police officers went up with him. I think he was just like a stunned mullet! He didn't believe that could happen to him!*

The potential for violence to erupt in these situations is generally given high consideration by mental health clinicians. Resorting to police assistance is a common strategy to ward off any aggressive potential. Several theories of aggression have been put forth as to its causative factors (Stuart & Sundeen, 1987). When assessing risk to self or others the person's potential

for violence is considered, and often assumed, according to a practice model that ensures the safety of both the clinicians and the public. This model gives lower priority to concerns about maintaining the personal dignity and respect of the person being scheduled.

As we have seen (p. 73), it is not easy to judge whether someone is going to be violent, regardless of a past history. Steadman (1980) discussed the important issue of being considered a "false positive" (someone who is incorrectly considered dangerous) and its implications for care and he supports the view that mental health services and police are more concerned with community safety than respect for the person. He states: "The real issue in the commitment of the person for dangerousness is the state's justifiable right to protect its members. However, it is usually done as though it were in the best interest of the person committed, which it may also be" (Steadman, 1980, p. 97).

Concerns about potential dangerousness and maintaining the safety and wellbeing of all increased as the person experiencing mental illness deteriorated. Often relatives had contacted mental health services but assistance was not forthcoming. In a climate of low resources, including availability of experienced clinicians, mental health services rationalise their work, often to the detriment of those who are not "unwell enough."

Maureen had tried to get Tony seen by community mental health services once before. At that time, Tony was unwell and his irritability was a concern to her. She provided information about Tony's behaviour to the hospital she contacted and Tony was considered high risk to the safety of clinicians. Therefore, they declined sending community staff for an assessment at their home and Maureen was advised to either ring the police or take Tony directly to a hospital. Tony was seen at the local hospital Emergency Department and sent home. No follow-up referral was made to mental health services. He then deteriorated to the point where he required involuntary admission. Maureen comments:

*Tony had never been diagnosed as anything! We just knew! He wouldn't go and see the doctor. He was breaking the windows and he was threatening to smash up the bathroom at that stage, because he really felt that the [workmen] were keeping something under the spa bath. I'd taken him to a few doctors at that time, private psychiatrists that I knew, and they said: "He is definitely in a psychosis now." But he wouldn't go to see the [mental health staff] so all they said was: "You have to ring up the crisis team." Which is what we did and they advised us to ring the police. They said: "We can't do much either really." And [they added]: "Get him to a hospital!" And I did! I can't remember actually what happened but I took Tony down the hospital and the doctor said: "Look, I think he's all right. He doesn't need to come back and see a psychiatrist," and they gave him some Valium or something.*

In some instances, police were not involved. When the person displayed no aggressive (angry) behaviours whatsoever, such as not throwing objects or slamming doors or shouting and not expressing unwillingness to go to hospital, there seemed to be a greater likelihood that transport would happen smoothly. In Sandra's case, the only means of transport considered at the time of Tom's schedule was with the clinicians, and this proceeded uneventfully.

*I never even considered calling the police! I never ever thought that he was going to hurt me or David [his brother]. I only became concerned one day that he was going to hurt himself! And I just wasn't sure how I was going to be able to stop that. He's a very big boy. A very big boy! He's a very sweet boy.*

Lack of information led Violet (Story 20, p. 218) to have police involved on several occasions at the beginning of Alex's psychiatric career. Violet did not know about mental health teams at the time, but once she found out that they could be called instead, admissions had always been with them, albeit on a schedule.

*I've only included [the police] a couple of times because I didn't realise I could call the emergency team. So as soon as I found that you could call the emergency team it made it a lot easier.*

Police involvement in schedules remained a controversial issue with families. Reconciling the potential for violence and the need for immediate specialist attention with the need to maintain the privacy, dignity, respect, and self-determination of the person being scheduled was a difficult thing to do. Relatives also found that the presence of police officers and police vehicles in a neighbourhood call for the unwelcome attention of neighbours and passers by, adding to the stigma of the illness. For some people, alternatives to the police presence were difficult to identify due to the potential for violence or behaviours that would place them or those around them at risk and relatives understood this need. However, like some of the people who were scheduled (p. 85) and the clinicians (p.76), relatives suggested the use of "psychiatric police" instead, and reiterated the need for their presence as "bringing reality" into the situation. Elena (Story 13, p. 208) described her experience with having her mother taken away in the back of a paddy wagon in such a public way.

*I think it's good that the police are involved because I've heard that some people can get very violent in these situations. But I don't think they should be police wearing the uniform. I think there should be some privacy when it comes to people's health. When the police came down the whole street was watching it. I just felt a bit like "aaaaah!" [Cries out as though in horror]. Not that I'm ashamed at my mum! No one's perfect! But I reckon there should be some crisis team-like police, but not in uniform. And the paddy wagon comes in with the uniforms. It's going to be hard getting out of uniform if you're*



*going to have a paddy wagon. I think it would be better if there was a van or something rather than the paddy wagon. [My mum] could have gone in the car with two social workers. Men. But she wouldn't have gone with just one! She's a big woman too so, I think I would be a bit scared. If there was a driver and two men [from the service], she wouldn't fight. But if it was just one and she was aggravated, probably. The police [are like] figure heads. They've got power. She feels a bit: "I can't really do anything because they are stronger than me, they've got weapons."*

For Terry, police presence was inevitable. No one other than Vincent's psychiatrist was available to help. The situation was urgent and something needed doing immediately. He felt helpless about the lack of options at the time.

*I knew that police involvement was inevitable! They had to be involved. The crisis team were not involved because it was a very busy time for them. Christmas Eve! And there couldn't have been anyone else there to support us. Vincent was in between casemanagers and I would have called everyone I knew! I needed to get help as I was past being desperate.*

Terry felt particularly supported by the police officers that attended to his son. He described them as "kind and gentle" and they said "all the right things" to get Vincent into the paddy wagon without any problems. His only regret was to not having accompanied his son into hospital.

*The police were courteous, kind, and gentle. I was impressed with the way they dealt with it. But thinking about how it all happened so quickly, I feel I'll have a lifelong regret that I didn't go to hospital with Vincent. I wasn't asked to accompany my son into hospital. He was very sick and I couldn't have been thought of at the time. It must have been so terrifying for him! But Vincent was spoken to in a way that could not have been better given the circumstances. The police particularly impressed me. Everyone said the right things the right way.*

For Jan (Story 12, p. 205), police involvement added to her distress about what was happening with Nora. Like Sandra at the time of Tom's enforced sedation, she felt frightened and alone. The intervention was beyond her control and different from what she had expected. However, unlike Sandra, previous disappointing experiences with the mental health service influenced her feelings about the police officers' presence, seeing them as part of an unhelpful mental health establishment.

*It was like talking to robots. I was angry they were there. I hadn't realised you'd [writer's note: identifies me as part of the mental health system] go away and come back with the police. I think the police felt they had no*

*alternative! They didn't appear to realise this was a suffering human being!  
Police don't care about anything. They are so corrupt!*

The data are clear about police officers' role as persuasion agents. As discussed throughout this section, their presence brought a sense of finality and reality to the event. The ability of some of the officers to work according to the immediate needs of those involved rather than "by the book" was appreciated.

*I felt the police were pretty good. The first time they came, and Steve wasn't there, I said to John: "Look, can you please just get them to go very quickly because if he sees them he won't come home. So, they did that. They went very quickly and when they came back, they tried to talk him into some sense. All the things that one says in those circumstances! And the police officers stood quietly and waited. And then this other one explained that their presence was actually required, so that the person believes what is happening to them, that it's not a joke, and they are there to protect him. They just stood there quietly. [If they hadn't been there, he would have resisted more]. I don't think physically, but I think he would have argued that he didn't want to go.*

For some relatives, police involvement signified in some way that the person had committed a crime, or that having a mental illness was in itself a crime. This feeling was reinforced by the use of the paddy wagon as a means of safely transporting the person to hospital, as "those who are ill are usually transported by ambulance." These feelings were in keeping with the information provided by those who were scheduled. Elena and Pedro commented:

*I didn't like the scene of the police coming here. I thought it was a bit weird to have the whole street see that my mum was taken in the paddy wagon. It was just weird! And we were following behind! It was like she was a criminal or something. It made me feel a bit like: "Why can't the [mental health staff] handle it on their own? Why do they have to drag the police into it?" That made me feel like my mother was treated like a criminal when she was taken in the paddy wagon [laughs uncomfortably]. Her little hands sticking out [of the paddy wagon's air flaps at the back]! I just laughed because she's so innocent and she was in the back of a paddy wagon. It was funny!*

*I feel ashamed for the police, or for the mental health centre that they have to do that. Even my brother noted that it was not necessary. I feel a concern at so much wastage, unnecessary wastage of resources! And my brother said: "I can't believe it! Like a criminal!" Even my flatmate had some sympathy and she said: "Oh my God! It's like a crime!" when she saw that. Because it wasn't necessary!*

Alex often engaged in law breaking behaviours when unwell. This led to Violet's long held perception that police involvement in dealing with people experiencing mental illness was due

to the general presence of these behaviours. She did not realise that many people who experience mental illness do not break the law, and that police are involved on the assumption that the person might be violent or flee the scene.

*I must admit when the police are there and they are outside my house I think: "I hope people don't think he's done something wrong." That was in my mind. I felt like saying to them: "He's sick!" So, that is there! And it's usually when they've done something wrong that the police get called out. And even sometimes when they are sick it's still the same reason. They might have hit someone or done something.*

The whole process of scheduling and police involvement shocked Pedro. He acknowledged his own lack of understanding of mental illness and made assumptions about how people so affected behaved in certain circumstances. He believed that his brother would have resisted admission even if he had been well as a protest to police presence (as reflected by Sandra on p. 77). There was no "real" reason for their presence. Additionally, Pedro believed that mental illness prevented Jaime from having "normal" responses. He recounts Jaime's disbelief at being "arrested."

*The issue was he was at home and the team came to assess him. They said it was not that he needed to go to hospital. He needed medication! And if he wasn't going to take the medication, he needed to go to hospital. They were going to call the police. Anybody in their right mind must feel angry about it if they don't believe they are sick! To me it doesn't make sense: they are trying to reason with somebody who's not well, they have already assessed that he's not well, and they say: "Don't move. We are going to send you the police?" If my brother was more aggressive, he's not aggressive obviously! He would have gone! He would have been frightened of the police. I don't think he's normal! He told me: "I didn't resist anything you know? The police arrested me! You shouldn't be allowed to take me away because I've done nothing wrong!"*

### The personal experience

#### Crime and humiliation

For people who are scheduled, police involvement has a different significance. Being transported in the back of a paddy wagon criminalizes their illness and is very humiliating. There is a section on the Schedule II form for the medical officer examining the person's mental state to complete stating that the assistance of police is required to transport the person to hospital (see p. 74 – Section 22). The *NSW Memorandum of Understanding* (1998, p. 11) clearly states that: "If police assistance is required the police escort should accompany the person in an ambulance. Police vehicles should only be used in extreme cases, for example where there is a risk to the safety of Ambulance officers and/or their vehicle. If a police

vehicle is used, a mental health worker should accompany the person in the police vehicle.” For those who are scheduled, however, police involvement brings a feeling of being “a criminal.” The use of the paddy wagon confirms the “criminal status” of experiencing a mental illness. This is supported by the remarks of Paul, Teresa, and Rosa (Story 23, p. 222).

*When taken by police you feel like a criminal. It is very humiliating to go with the paddy wagon.*

*I felt very embarrassed. I felt like a criminal. I felt like a dog in a cage. And as I said, out here it was sort of open. People coming up behind us, truck drivers looking at me, and I felt just so denigrated! Like they had taken everything from me: my respect, my dignity, the whole lot. And I just think it's wrong. The police were pretty rough.*

*I was in hospital for nothing. [It was] like a crime because [there's] supposed to be more talking, more understanding of the people and what they say, but this doesn't happen.*

Some people found it hard to understand why the legal system is involved at all when dealing with someone who is ill. Penny (Story 21, p. 219) knew she needed to be in hospital, but wondered about the need to be scheduled and go before a magistrate.

*When I've been scheduled I've needed to go to hospital, [but] why scheduled? It is something to do with my rights. I don't understand why a magistrate [is involved]. It is a waste of legal resources. At the time I needed to be there and, in hindsight, I believe there was something wrong, but why involve the legal system?*

Teresa worried that she would now be recognised by police officers out on the street. Her anger resurfaced temporarily when she saw officers on the beat, wanting to see the faces of those who made her suffer.

*You [do] feel like a criminal. And I saw the police [when] I was staying at [a friend's] last night. [We were walking around] just chatting. We went for a long walk, and every time I saw a police car, my heart started to race. It's like [I tell myself]: “Don't worry about it,” and then I want to get out and look at their motorbikes. My heart races, and I'll always wonder: “Are they going to recognise me? The hair! The blond hair!” But I want to find out who they are exactly, and then I ask [myself]: “Why am I doing this? This is ridiculous!” It's pent up anger, so I'll get over it in time.*

Those who were scheduled described going in the back of a paddy wagon as a frightening and humiliating experience. People often walked into the police van feeling frightened and

powerless. There were times when they were forcefully “thrown” into the wagon. Other times they were deceived into getting in. Upon arrival at the hospital, the assumption that being scheduled and transported by police implies potential for violence and/or attempts at fleeing is common. The person frequently arrives at the hospital in a highly agitated state (Sandra, p. 77) due to the fear and humiliation experienced. In this case, restraining and intravenous sedation are commonly required procedures. These actions often add insult to injury.

The way police officers dealt with the person at the time of transportation and admission was seen as important in easing the transition from home to hospital. A gentle, concerned manner ensured that the dignity and self-respect of the person scheduled were maintained and the potential for violence appeared to decrease. Humiliation was the most common feeling described. Rosa was deceived into entering the wagon. She found this humiliating and a betrayal on her husband's part.

*I said: “I don’t want to go in the truck, I want a car.” They said: “You can’t!” I said: “I don’t want to go alone.” So my husband went into the back of the paddy wagon and as I followed him in he got out and they locked the door and I was alone like a dog. When you go by police, they give you an injection in the arm all the time [at the hospital]. Terrible to go through the bloody injection. The nurses push you down. They are all over you! [Often] they cannot find the vein. It’s Terrible the pain you go through! [The experience of being sedated on admission]. The police this time were good. Other times they yell at me, like I’m a dog. I felt sad that there was no one there to help me. I needed to change the pad [she was menstruating] and they wouldn’t let me do it. They just wanted me in the wagon.*

Teresa on the other hand was forced into the wagon by two female police officers. She was uncomfortable and scared. She felt treated like a criminal, having no other companions but the officers sitting at the front of the wagon. She felt degraded and humiliated.

*I was on my own in full view of everyone. Every Tom, Dick and Harry who’s passing by in cars and trucks and didn’t know who I was and why [this was happening]. The guys here [mental health staff] they’ve all got cars, and I think that could have been much [better]. My brother was saying to Olwyn as they were dragging me away: “Olwyn, can I take her? I’ll take her to the hospital.” And I think that would have been a nicer option but I [wasn’t allowed]. [And as my brother] said to [the policewomen]: “Loosen the grip! You’re hurting her! She’s not violent, she in pain.” They said: “Take your hands off or you’ll be charged.”*

Alternative transport options were high on the agenda of the people who were scheduled. The frequent use of the paddy wagon and the lack of discussion about transport by ambulance, or in someone else’s car, were topics raised. Health service providers or the police made all the

decisions, without consultation or negotiation. Police officers seemed to ignore or fail to identify the “patient” status of the person they were transporting, rather dealing with them as if they were “some kind of criminals.” Teresa added:

*I'm just angry because I was thrown into a paddy wagon and left on my own. I thought for someone who's sick to be dumped in the back of a paddy wagon! That's most uncomfortable! I felt I was a very sick person and would have liked to have thought they'd allow me at least to go with Olwyn. Going together, or put me in the back of the car and lock the door, or do whatever. Sit side by side. But just the police was very scary, definitely. And then the long journey to hospital. There was a bit of a distance [to walk to the unit] and I said: "Fucking dick, just allow me to walk on my own without being manhandled." And the policewoman said: "OK." And I did. I walked by myself [into the unit].*

Mike (Story 29, p. 230) was not sure whether the officers' seemingly jovial behaviour in the wagon was about him or not. Conversation between those sitting in the front and those in the back of the wagon is rare. Discomfort and apprehension are felt as the wagon bounces the person around. Although many found the police van humiliating and undesirable, Mike had mixed feelings.

*The going in [the paddy wagon] was all right. The first time I was getting really psychotic and was having all these hallucinations, dreams that I was very famous and would meet people and do things, so I was quite happy. The second time I was pretty aware of what was going on and it was a short trip. That was okay, the short trip. Then they wouldn't accept me at the [local psychiatric unit] so they transferred me to [the major psychiatric hospital]. I wasn't happy to go in the back of a paddy wagon 'cause I couldn't hang on. They stopped suddenly and I went from the back to the front. I kicked up a big stink and they [the police officers] started laughing. I don't know if they were laughing at me or just talking in general but they didn't seem to have much respect for [the passenger]. I was a bit upset about being transported from a hospital to another hospital in the back of a paddy wagon. [An ambulance] would have been preferable, a bit more comfortable.*

Powerlessness, humiliation, anger, apprehension, and stigmatisation were some of the negative feelings described. Acceptance of police presence and the rough behaviours used underlined feelings of powerlessness, lack of control and passivity. As described by relatives, police presence brought a sense of reality to a seemingly unreal situation, that is, that one person can remove another from their home against their wishes.

Rogers et al. (1993, pp. 163-165) consider four aspects of ethical information giving to people who have a mental illness. These are self-awareness, information, control and coercion, and specificity. The authors argue that coercion is a powerful form of persuasion frequently used

by mental health professionals both with formal and informal patients and that this form of control plays on the vulnerability of individuals and their families. Paul believed that mental health clinicians ought to attend without the overt presence of police. He was aware that he might have been more argumentative had they not been there, but he felt that the threat of using them might be sufficient. He also believed that for people whose active symptoms include being paranoid and out of touch with reality, the presence of police may be threatening and frightening. However, he saw their role as beneficial as “sometimes when you go to schedule people they really do need the police there, as they need the uniform, car, and they need the muscle.”

It is clear that much suffering is involved in the scheduling event, particularly for the people scheduled and their relatives. The finality of police presence is recognised by all and the issues of power and powerlessness discussed in the previous chapter become clearer. All the people interviewed learned about these powers and about the mental health system through first hand experience. As time went by they all become more familiar with the process, they came to expect it and accept it. For many, like Alex (Story 30, p. 231) and Penny, it has become a way of life.

Throughout the western world mental health systems have moved to an illness centred, outcome focused service provision. Evaluations of services and data collection have become essential management tools to ensure adequate resource allocations. Alongside reductionist market-economy strategies, State governments have called for increased partnerships between primary and secondary consumers, other agencies involved in service provision to this group, and mental health services. Clinicians, consumer and agencies’ education programs are being developed in all area health services in NSW. Little has been done, however, to inform communities generally about mental illness, its effects on all involved, and the powers and extent of care provided by mental health services. The next chapter will look at the attitudes and beliefs of those interviewed regarding provision of information and education.

## Chapter VI – Information and Education

*There is an overabundance of things to be known: fundamental, terrible, wonderful, funny, insignificant, and crucial at the same time. And there is an enormous curiosity, a need, a desire to know.... Curiosity is seen as futility. However, ... it evokes "care;" it evokes the care one takes of what exists and what might exist; a sharpened sense of reality but one that is never immobilized before it; a readiness to find what surrounds us strange and odd; a certain determination to throw off familiar ways of thought and to look at the same thing in a different way; a passion for seizing what is happening now and what is disappearing; a lack of respect for traditional hierarchies of what is important and fundamental. I dream of a new age of curiosity.*

Michel Foucault (1994, p. 325)

### Informing communities

Information to the general community about mental illness, and its impact on people's lives has been forthcoming through the media since the awareness raising campaigns began following the Burdekin Report on *Human Rights and Mental Illness* in 1993. The *NSWMHA, 1990* and the powers invested by the *Act* on health professionals and police services, however, have not had the same widespread campaigns. Neither have there been campaigns or formal information sessions about the mental health system and how to access it effectively, except in small, localised initiatives.

Informing people about the full extent of psychiatric power is a topic fraught with conflict between those who support a benevolent view of psychiatry and those who support autonomy and self-determination. It is clear that many clinicians look at what the law holds to be right, rather than what may be of greater benefit when making decisions about dangerousness to self or others and hospitalisation (Fiorillo, 2001). In the foreword of Ebrahim Kermani's *Handbook on Psychiatry and the Law* (1989, p. vi), Dr. Robert Cancro, in discussing the decisions clinicians make about warning third parties of the danger posed by their clients and the influence of the law in this decision states that:

*The clinician must judge which action in fact will provide the greatest safety for the potential object of the attack. Can the clinician be infallible? Obviously not. Yet, if the court holds that the duty is to warn whenever there may be a danger, there is little doubt that clinicians will tend to err on the side of protecting themselves rather than their patients' welfare.*

This practice to limit personal liability, known as "defensive psychiatry" (Brown & Rayne, 1989), is common today in all areas of psychiatric practice. Clinicians often have an



underlying motivation to avoid lawsuits when making decisions about someone's level of risk and need for hospitalisation. It is considered much more costly for clinicians to err in not admitting and be wrong than to admit erroneously. This, however, ignores the human cost of such actions to the person who is erroneously admitted — and to their significant others. The same conflict between the clinician's self-protection (from liability or injury) and the person's welfare arises when making decisions about what information to provide to communities and individuals. It is generally assumed that the provision of such information may lead to rejection or avoidance of the psychiatric system, although such a claim is not supported by evidence.

### **Informed consent**

Informed consent is a concept slow to reach the realms of psychiatry and mental health. The assumptions that people affected by mental illness are incompetent to make reasonable decisions about their own care (Bates, 1977) and "may not be capable of ordinary participation in the planning of their medical treatment" (Caplan, 1989, p. 53) are dominant among clinicians when deciding what information to provide. The paradoxical expectation that people affected by mental illness understand their rights once the Form 4<sup>16</sup> is given to them on the ward, and are able to initiate legal proceedings such as appeals against the decisions made (Brown & Rayne, 1989), is often ignored (see also Dr. Penford's account on p. 92).

Davies (1990, p. 28) stated that informed consent "says that we give the information that a reasonable person would want, plus what the individual wants to know. This allows persons to make their own decisions." Eth and Robb (1986, p. 90) support this statement by saying that: "The responsibility of the physician is to disclose not what other physicians are mentioning, but what patients want to know."

The difficult questions raised are: Should persons who are, by nature of their mental illness or disorder, incompetent to make reasonable decisions and plan their own care, be given information about the care that mental health professionals judge to be needed and is about to be provided against their wishes? Does providing information to people living with a mental illness, in contrast to those with a physical illness, lead to coerced choices rather than informed consent? Why is it different? Does consent to treatment after information about possible forced treatment is given make the voluntary choice involuntary? Moreover, if the

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<sup>16</sup> Provides inpatients in NSW with information about their right as inpatients, including the right to appeal against the treatment order.

person is mentally ill and therefore (supposedly) incapable of informed consent, is whatever they agree to invalid? (See also the discussion on p. 17 – Perception and effects of the use of coercion)

These are not easy questions to answer. As observed by Spiro (1975, a gastroenterologist cited in Eth & Robb, 1986, p. 97):

*Indeed, I doubt if any physician care for any patient can ever get really informed consent from the patient; the patient-physician relationship is, or should be, so strong as to make the likelihood of free consent about the same as that of prisoners.*

### Competence and informed consent

Appelbaum, Mirkin and Bateman (1981) studied a group of 50 newly admitted voluntary psychiatric patients to assess their level of competency to consent to admission. The authors found that most patients were in fact not competent to consent (see also Stanley, (1981) for similar results with medical patients). The authors cautioned clinicians about the frequent practice of using contracts based on the presumption that all individuals will act “reasonably,” and the voluntary admission of individuals considered incompetent to provide informed consent. Two possible alternatives are suggested. Firstly, using the simple requirement of an “assent” to voluntary admission, thus lowering the requirement of “informed” consent or, secondly, the legal substitution of the right to consent altogether through the application of guardianship. In this case, whenever a person is considered mentally ill a guardian will be appointed to either provide consent to treatment or not. The authors caution against the belief that competency is determined solely by the presence or absence of mental illness as many other factors, such as stress, may lead to thinking and behaviours that are interpreted as due to irrational thought.

Eth and Robb (1986) discussed the problems of informed consent in psychiatry and the need for the development of trust in the therapeutic relationship between clinician and consumer (see Chapter VII – Relationships, p. 108). Seeking consent to treatment encourages independence and co-operation on the part of the individual and, in any case, involuntary admission ought to be based solely on “the joint determination of mental illness and dangerousness, not on the competency to make rational decisions” (Eth & Robb, 1986, p. 97) Incompetence in itself does not justify involuntary admission.

To clarify the meaning of informed consent, competence, and “voluntariness”<sup>17</sup> as encountered in every day practice, I quote two authors. Anne Davies (1990, p. 28) sums up the meaning of competency for people living with a mental illness:

*Competency is sometimes in the eye of the beholder. That is, provided that you, the patient, make the decision that I, the health professional, think you ought to make, you are competent in my opinion.*

Erica Bates (1977, p. 97), in discussing the legal framework of psychiatric treatment, informed consent and voluntariness states that:

*A most important aspect is whether the patient is in a position to give informed consent. It is well known that many patients classified as voluntary are still trapped, since if they refuse treatment or apply for discharge they are told they will be committed if they don't stay and obey the directives of the doctor in charge (emphasis in the original).*

### **Information, deception or coercion?**

The data from this study show a variety of reasons for health professionals to either withhold or provide information. All groups agree that information ought to be given but they have concerns about when, to whom, and how it is given. In some cases, clinicians gave the person experiencing mental illness and their significant others some explanation about what was happening and the reasons for scheduling. In most stories recounted, however, information about the possible consequences of treatment refusal, and how these consequences would be enacted, was not given. Frequently, this fuller explanation was not provided due to the perceived behavioural and/or cognitive disturbance of the person being scheduled, as judged by the attending clinicians and because of limited time and poor clarity of roles. Often the assumption was made that the person already knew what was happening because they had been through the process before or that provision of information would cause them to become violent or attempt to flee. Dr. James was surprised by the question of whether explanations and information were given. She had not considered this role in her everyday practice in acute community psychiatry.

*[I am] not sure whether the client's rights were explained at any time. I'd say no. One, because of the rush, to get in before he changed his mind, and two, because I am not clear of when to do it.*

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<sup>17</sup> A term used by Rogers et al., 1993, p. 16. The choice of being voluntary.

Routinely providing information and explanations about what is happening is not part of service protocols. The question about whether information was given came as a surprise to some mental health clinicians who could not even remember whether they had provided it. To my knowledge, there is no onus on mental health clinicians to provide explanations about the process itself. Explanations are given at the discretion of those involved depending on their practising style, value systems, experience in dealing with disturbed behaviours, and relationship with the individuals involved. As discussed, at the time of the schedule people were seen as having lost all their rights and being "at the mercy" of the legislation and professional judgement.

Dr. Penford had been involved in scheduling Caroline, a woman he knew very little about. He had a previous negative experience when a client attacked him during a home visit and this influenced his actions this time. He was very wary of Caroline. In fact, he felt at risk for his safety and did not want to spend any more time with her than was strictly necessary. He requested the police to transport her to hospital and presented to the Station to provide them with the Schedule II form. However, the Senior Officer in charge requested that he stay involved and accompany the police officers back to Caroline's house to inform her of his decision. He felt uncomfortable with this, as he had not developed any rapport with Caroline, intending to get her into hospital as soon as possible. He usually relied on nursing staff to provide the necessary information on the ward, upon admission. He had never considered the need for people to know about their rights and the legislation that empowers mental health services to act and enforce admission.

*When the police got there, I explained to Caroline that she had to go to hospital. I think she was probably familiar with the legislation as she had been scheduled previously. I didn't know there was an onus on us to explain. Clients' rights were not explained. They have none! [Laughs leaning forward in the chair]. I don't have a preference to do that in the community. Usually it happens in hospital and the nursing staff do that. They give them a Form 4. I just said: "In my opinion you're unwell."*

Dr. Swallow made the same assumption as Dr. Penford, this time about Anne's knowledge of the event, that is, that as Anne had been through a schedule before she would know what it was about and what could happen. This example substantiates Brown and Rayne's (1989) position regarding the competence paradox of being incompetent to make decisions but able to comprehend and act upon an appeal process (p. 89).

*[I] explained to Anne about the schedule. That another doctor at the hospital would have to uphold it. And that when she got to hospital she could fill in a*

*Form 4 to the Magistrate and protest the schedule. And that she could protest it now but that wouldn't be sensible. [I am] not sure whether Anne had been told previously what might happen. But I think she would be aware because of her previous relationship with the system.*

Liz received more information. This appeared to be due to her well-established relationship with her casemanager, Angela (Story 7, p. 199). The explanations given, however, were more about the process of the schedule than about the legislation and hospitalisation in general. Again, this knowledge was assumed.

*[We discussed the] need to have an admission to hospital and the reasons why Liz was going to have to be involuntary — because of our concerns. She's actually had previous involuntary admissions so she would be aware of that, but it's never happened with me initiating it. I don't know if she was aware of the [Mental Health Act]. I could have given her that information but I didn't do that.*

Louise, with her experience in advocacy, reiterated that the role of casemanagement is to remain in contact with the person throughout their "well" periods, and monitoring their mental state. Time spent with the well person can be used to discuss some of these issues and increase people's awareness of available options to ensure treatment and recovery. The amount of information and education received during this period may result in increased compliance with medication and treatment follow-up.

*It depends on how much education they are given afterwards. Because they may feel that it is less likely [to be scheduled] if they comply with medication and they agree to see a casemanager or a registrar. The chances of them being hospitalised are much less then. In which case it is good to stay in contact with the community [service].*

In her article on "truthtelling," Gadow (1990, p. 34) looked at the current reductionist approach to psychiatric care that considers the possible harm of disclosure and the use of deception. It is clear from the data collected in this research that deception as a means to an end is common in psychiatry. She stated that:

*Deception is not the only therapeutic option, but until recently it has been the treatment of choice for most patients. Traditionally, professionals have emphasised the dangers of truthtelling — the risk that patients may relapse, become depressed, or even attempt suicide upon learning their prognosis. Some may become so distressed over what they perceive as an unalterable outcome that they refuse treatment while a cure is still possible. In light of these dangers, truth has been administered with great caution.*

In psychiatry, the issue is complicated by the assumption of incompetence and the person's assumed inability to "understand" the information given. In most cases described in this study the person being scheduled was not considered so disturbed that they could not be provided with full information. Psychotic symptoms did cause a degree of difficulty in communication and this was acknowledged, however, the time factor to ensure a smooth outcome and the fear of consequences primarily guided the clinicians' decision (see the discussion on defensive psychiatry on pp. 88-89). There was an assumption, also noted by Gadow (1990), that knowledge of what was happening might cause further problems, such as increased resistance to hospitalisation and a negative impact on the relationship between the person and the caregiver. Dr. Penford and Dr. James had this to say respectively.

*I think Caroline could have [understood but] not fully. She was not unwell enough not to be able to absorb at least some information.*

*Peter was not too disturbed to be told, but there wasn't a lot of point explaining other options at that time. It can be confusing to the patient to explain too much at that point in time. When obviously they are distracted.*

#### Impact of information

Opinions regarding whether mental health consumers, or the community in general, should be told about the powers of the mental health system and the scheduling process varied widely. Mental health professionals' beliefs about the impact information would have on individuals, and how the public would respond, were based on their own experience working with people who refused treatment and follow-up.

#### Clarification and concern

Sandra (Story 1, p. 192) gave some thought to the question about who to inform. She felt that information ought not to be given to all consumers, as many would never need to be scheduled and the information might frighten them.

*[I am] unsure of whether it would be beneficial to tell clients in advance. [It's] a bit heavy. It should be done at a more individual, personalised level. Clients should be told when they are becoming unwell. At that time, the options should be discussed. I would say: "It seems like things are not quite right at the moment." And then look at the options such as the hospital: "If you're telling me that you are a risk to yourself or others then the option is to go to hospital." With a diagnosis related to emotional problems it would be too scary and inappropriate. And if they are told when psychotic, or at the time of the crisis, it would be like pissing in the wind. The options need to be examined individually.*

Sandra also stressed the need for family members to have this knowledge, as they are often the first to realise something is wrong. She added that relatives' understanding of the *NSWMHA, 1990* must include its limitations as well as its powers, so that everybody works effectively together.

*The family needs to be involved before and after. They should be given all the necessary information about the schedule. And why/how it happens. The casemanager should have gone through the Mental Health Act with them so that they understand the limits of the same. I had to deal with a son who constantly asked me: "Do something about my mother. Why can't you take her to hospital?" I gave him a copy of the Act and discussed it with him. He knows now what is required for involuntary hospitalisation. I'm guided by the Act. Then after the admission it should be discussed: "This is what happened, and this is why."*

Other clinicians suggested that there is a need to ensure provision of information and education about the *NSWMHA, 1990* to the community generally, including what can happen when it is invoked and enacted. It was generally acknowledged that the *Act* is quite a powerful piece of legislation that may cause people to feel powerless over their own lives once they have experienced it, and that current knowledge is gained through painful first hand experience. Dr. Penford and Doug stated respectively:

*I think the first time someone is confronted with the Mental Health Act there should be some effort made to ensure people's questions are answered. I think [that] if they are scheduled they worry it may happen again. Any doubts and fears they may have should be clearly explained. So that if it happens again they are aware of the outcome.*

*People find out about the Mental Health Act through experience. Like this Margaret who had many admissions. She obviously knows it very well, I would imagine. And I guess the family does as well! But it's probably unfortunate to find out the hard way.*

#### Secrecy and social control

Some clinicians felt that informing people about the power of the mental health system and the scheduling process would make them aware of behavioural and social control mechanisms that have the potential to be used against anyone, at any time. The social perception of psychiatry would be challenged. Munro (1984), in discussing the conflict between civil libertarians and paternalistic psychiatry regarding involuntary commitment, was open about the fact that psychiatric secrecy has ended and psychiatry is now under constant public scrutiny. He believed that conceding "that the current process (of involuntary commitment)

may be inherently wrong in present-day circumstances” can assist in changing this perception (Munro, 1984, p. 372). Dr. James’ answer about informing the general community encapsulated both the totalitarian view of psychiatry and the secrecy that still surrounds it (see Szasz, 1987; and Scheff, 1984).

*I think you'd have to be very careful on how you went about an educational program. The case might be that people think then that people come knocking on their door and scheduling them to hospital and they'll never be released. I think that's one of the misconceptions. People think once they get to hospital they are committed and they'll be there until the age of fifty and they'll never be out again. I think you have to be very careful in how you inform people of that. And not to sensationalise it! But just to make sure that you don't damage the image of psychiatry.*

Like everyone else, relatives and significant others learned about mental illness and the *NSWMHA 1990* through experience. Events such as being visited by mental health staff or having their ill relative scheduled often came out of the blue, without any warning. There was consensus amongst the study participants about the need to provide information, education, and discussions after the event and the need for ongoing relationships with mental health service providers. These were seen as essential elements to increase the capacity of both relatives and the person affected by mental illness to make informed decisions about the available options and to take more responsibility for the care and treatment required.

### **Capacity to consent**

As discussed, the capacity of individuals to make informed decisions is not easy to establish. Although “Outcome” and “Status” approaches to assessing capacity prevail in the stories recounted, it is undoubtedly the “Functional” approach that is supported by these data. Wong et al. (1999, p. 4, [cited from html. version]), defined the “outcome” approach as based on the consequences of decision-making where “the individual who makes a decision that is contrary to conventional wisdom or the opinion of the treatment-provider is likely to be viewed as being without capacity” (see Davies, 1990, p. 96). The “status” approach determines a person’s capacity “by his or her membership of a specific population. Assumptions are made about an individual’s decision-making on the basis of some characteristic, for example, chronological age, estimated ‘mental age’ or psychiatric diagnosis.” Both these approaches are described in this study as practised by clinicians.

The “functional” approach to determining a person’s capacity to make informed decisions “is based on establishing the extent to which the person’s understanding, knowledge, skills and



abilities meet the demands of the task involved in making a particular decision within a given legal context. Capacity is, therefore, decision-specific and time-specific, rather than global or permanent” (Wong et al., 1999, p. 4, [cited from html. version]). This position is supported by other studies such as those by Hoyer (2000), Grisso and Appelbaum (1995), and Appelbaum and Grisso (1995). However, this approach is time-consuming and well beyond the available resources in many community mental health services. Information giving is not part of mental health practice at the time of a schedule, but could certainly become so once the person experiencing mental illness is stable enough to understand and retain information.

Information about the *NSWMHA, 1990*, the rights of relatives, how schedules can unfold, or mental illness in general was not obtained until relatives were themselves touched by the effects and consequences of mental illness. Relatives and society in general are likely to ignore the issue, too fearful to acknowledge it could happen to them. This fear, stigma, and ignorance affect the way the person experiencing mental illness is viewed.

## **Learning through experience**

### Relatives

Most relatives received very little or no explanations at the time of the schedule. In some cases, hospitalisation of their loved one was sought due to refusal to take medication at home. In other cases, there were acts or threats of aggression towards the relatives, self, or others. Relatives perceived the explanations given as an “either/or” situation, such as “either he/she takes medication or...” and “either she/he goes voluntarily or...” Violet on the other hand felt that she was quite clear about the whole procedure and had been able to keep up with the changes in legislation. Alex’s illness was repetitively predictable and Violet worked well in partnership with mental health clinicians to ensure Alex’s safety and treatment once the symptoms and behaviour reached a certain level. Scheduling was the result of a sequence of events related to his illness.

*It was always explained. I wasn't aware of the amendments [to the Act] though. Apparently, even with the amendments under the Act a patient must reach a certain stage before he can be scheduled anyway. Usually it's all arranged with the casemanager before it happens. It's always pre-arranged. So we talk about it and we both agree that he needs to be scheduled before they actually go there. And I arrange to meet them there.*

Relatives who became involved with the mental health service since the establishment of the EPOCH team were very happy with the service they received both at those critical times

when admission was unavoidable and thereafter. However, those who had earlier experiences with the mainstream system expressed anger at the service they received. Unlike those involved with EPOCH, these relatives reported receiving no support or information and being "treated as alien" to the process. Good communication, advocacy roles, repeating information at regular intervals, and ongoing support of relatives who have an active role in the care of the person affected by mental illness were important areas needing attention in mainstream services, albeit an integral part of the EPOCH's practice. Jan, who had witnessed Nora, one of the women who frequented her church-based house, being scheduled, felt very strongly that information should be given in a clear, comprehensive and timely manner. She had poor experiences with the mental health service, and this was evident in her reply.

*Giving information before it happens would be good. About what are the options, the different levels of assistance. The crisis team are often rude and say: "If you have a problem with violence call the police!" I think it would be very beneficial to know in advance. When it's becoming clear that they are becoming unwell. This doesn't happen overnight. If it is quick and violent then sure, do something quick. Also, it must be repeated at regular intervals. When they are well, tell them what can happen. It is the only way to have credibility and trust. A total wimp out when people are afraid of telling others what the reality is. I thought that things would get better since 1982 when they were first set up. But they haven't!*

Kerri (Story 14, p. 209) vented her anger at the mental health system that she saw as just taking her rights as a parent away. She felt her helplessness to assist her son, Brian, and believed that her estranged role had impacted on her relationship with him.

*This is what makes me angry! They don't tell you anything! They just take him and that's it! At the Hearing, the solicitor pretended he was on Brian's side. She was useless. A waste of time! The way it was done was terrible! The doctor ignored me as I sat right next to him. He could have explained what was happening during that time. I then asked for advice from the Schizophrenia Fellowship and decided to agree with what the doctor was saying to the Magistrate. Brian was very angry with me and asked me to leave. I left him to manage his anger with the nurses. I feel that essential information should be given to clients and relatives often. After coming into contact with the service. Because once the illness has developed they are in such an emotional state that it is difficult to remember.*

Most relatives agreed that information ought to be provided before the illness got to the point that people need to be scheduled. Ideally, information should come even before the illness develops at all. The general community ought to be informed about mental illness and the powers invested in health professionals by the *NSWMHA, 1990*, of the possibility of police officers being involved, and that the person can be taken against his or her wishes. As for

clinicians and people who were scheduled, relatives believed that great care would need to be exercised in providing this information as people lacked basic knowledge about mental health promotion, availability and access to services, and mental illness. Pedro was quite clear as to why society needs information.

*My flatmate got really upset when the police got involved the other day, but that is what we need to do. And provided we tell [people], provided we explain to them that somebody has to be a watchdog here, [otherwise] who do we trust? So at least at the beginning, if it's explained to me: "Look, there are laws!" I didn't know there was a Mental [Health] Act before I got involved with all this. I knew there was something, but I didn't find out what it was really [until then]! And it was so complicated I cannot read it! That's how it happens! Most of the time people find out once it's happened. I don't think you should be told at five or six or seven [years of age] but maybe a bit later on! It's like business plans or business management. There are things you're going to need [to know] no matter what you do. Even if you are a doctor! Even if you are a painter, you need to know these things. Why don't you learn that at school instead of learning what happened twenty years ago in England?*

Maureen believed she saw several mental health problems amongst the girls at the school where she worked. Neither the students nor the teachers had much understanding of what they were dealing with or what to do about it, and this was a concern for her. There was a definite stigma and, as Tom himself expressed (p. 106), Maureen believed that school children can be very cruel when it comes to dealing with difference and disability.

*I do think it's essential that people start to understand about mental illness! That it is like a broken arm, it just affects the brain. 'Cause I didn't understand either until my mother really got sick. I know myself it's going to become more and more [common] now because it's happening more and more. We have girls who have breakdowns before they do the HSC. There's a lot of pressure on them. And that's where I think the mental health teams can come into schools and say to girls and boys: "You are under pressure. Now certain people with imbalances could react this way." Instead of having them going and jumping off cliffs! These people really don't understand it! So, you can't expect people to pick it up. That's where I think education helps as a lot of people put it down as behaviour. But I think if there is education, the children themselves realise what it is! I've heard my son say: "Mum, I know there's a problem. What I'm doing is not right." So I think until they get really bad they know themselves that things are changing. So I think they do personal development and health where they look after their bodies [at school] but there's not a lot into the brain. I see people calling the Community Services team when they should be calling the mental health team. In particular in high schools, because that's where a lot of it starts to come out. With children that have got it, teachers treat them badly! And I think if they knew how to access the mental health team, they could help the family as well. It's a frightening thing, but then they have to know their rights as well. It has to be a good*

*proper campaign if you're going to do something like that because that would frighten people. It is frightening!*

Elena, who was young and lived with her mother, Paula, and grandfather, had the main responsibility of caring for her mother. She felt that if young adolescents knew about mental illness and the treatment options, including the *NSWMHA, 1990*, they would not be so scared if their parents became unwell.

*Especially kids from the age of twelve and up should be told the procedures and the Act so that even though they don't understand they'll get an idea and they won't be so scared when their mums are delusional and stuff. I don't know about [whole] school education because not everyone would be interested. I guess you could add it in the courses, a one-week thing when kids are learning about health and nutrition.*

Violet blamed Alex's illness on his use of marijuana. She felt that school education programs ought to include the most serious effects of drug misuse such as drug-induced psychosis.

*I reckon they could be told around about high school age. What I've been reading is that a lot of students develop schizophrenia when they reach puberty. Perhaps they should be aware, if there is any drug rehabilitation going on in the school; they should be advised that having marijuana can bring on schizophrenia. I don't think many people know that but they should be told it's a drug-induced illness. The parents should be aware too that smoking pot can bring on mental illness. Definitely should be told. And I think that's where education in schools and among teachers [is needed]. And when teachers don't understand what happens it's very sad. And that's where you need professional people. And for teachers to know where to get that help.*

Awareness raising campaigns, such as those related to HIV/AIDS, have proved successful in the past (Bingham & Stewart, 1997). Although not able to eradicate stigma, discrimination and intolerance completely, they proved successful in guaranteeing the rights of people living with HIV/AIDS. Likewise, relatives felt that people affected by mental illness ought to have their cause and their rights addressed just as vigorously.

*Everyone should be told. The patient and the family should be told. And told the alternatives. And the patients should, for their own benefit, agree to be scheduled. [I think there should be] more documentaries. I've been told that there isn't as much [money] given to the research on mental health as other illnesses such as AIDS which makes me angry because more people have mental health problems than AIDS.*

Eileen expressed concerns about parents, and mothers in particular, not having the necessary knowledge to identify problems related to mental illness early enough to seek assistance. The

need for informing schools and for addressing specific issues of minority groups, such as those from culturally and linguistically diverse backgrounds, was highlighted.

*If the person is already an adult when the illness develops, they should be told as soon as they come into contact with the service [that this can happen]. I feel that information should be made available to all mothers to empower them to work with their child or relative. Also much more liaison is needed between schools and mental health workers so that children, teachers and parents are informed before things happen. I see a lot of difficulties with people from NESB [non-English speaking background] in this area where the approach needs to be subtle, simple, but empowering, as they often get treated as idiots due to language difficulties.*

This topic is further complicated today by the heightened awareness of different ethical dilemmas between cultures. Concepts such as liberty, integrity and autonomy are challenged by the concepts of health and medical responsibility in different cultures (Okasha, 2000). Rogers et al (1993), in their survey of users of mental health services, expressed the same concerns as found in this research (see Pedro's belief about medical knowledge, p. 66). Well into the era of consumer participation and partnership in the care and treatment of people affected by mental illness and of public scrutiny of psychiatric practices, information and consent remain unclear areas. Their results showed the same neglect of individual rights, cultural sensitivity, and clinicians' responsibilities and support this research in stating that: "In order to have a choice, patients need both multiple options and adequate, understandable and accurate information about those options in terms of their advantages and disadvantages" (Rogers et al., 1993, p. 173).

#### People who were scheduled

Consistent with the information given by the clinicians interviewed, none of the people scheduled recalled being given explanations about the events before or after they happened. At the time of their first schedule, none had any knowledge of the *NSWMHA, 1990*, their rights as people affected by severe mental illness, or that police could be involved to enable an involuntary admission to hospital. Some individuals acknowledged that their memories of the day might have been disturbed by psychotic symptoms, while others were quite certain that no explanation was given. The question itself brought up issues about how passive their participation in the mental health system really was.

*They might have [told me], but I don't think so. It is something I picked up myself, through experience. I can't remember anyone sitting down and explaining it to me.*

Tom described his learning about the mental health system in words that leave little doubt as to how actions that spring from a duty of care can be experienced as brutal and impersonal by those subjected to them.

*No! I was not aware [of the Mental Health Act or clients' rights]! Well, you don't have any! Ok? Full stop, end of story! You don't have any! When you're scheduled, you don't have any! As simple as that! They [mental health clinicians] are allowed to assault you, they are allowed to abduct you, they are allowed to invade your home, they are allowed to do anything they like so long as under the excuse of scheduling. That you are a security risk!*

Mike was not even aware that he was not a voluntary patient when he was admitted. He remembered agreeing to hospitalisation to gain what he saw as a much-needed rest. However, once he found out he was scheduled he had to ask to see the *Act* to confirm in his own mind what he was told, days after admission, about his status. A more assertive person, used to working independently, he did not feel intimidated by authority figures.

*It was only when I got to hospital and I said: "You can't keep me here" that they said: "Well, under the Mental Health Act we can." I said: "I'd like to see a copy of that!" And I had to ask for the Act to see what rights I had as a consumer. And as well as a mental health patient. Had to ask for that! They didn't say: "These are your rights!" Or anything! Even the Form 4 wasn't shown until I demanded it.*

Tom expressed feelings of intense anger and helplessness at the scheduling event and admission process, and at his mother's lack of knowledge and understanding required to deal with the situation effectively and protect his autonomy. He expected his mother, Sandra, not to resort to outside help, but to deal with the situation "like a mother." Somehow, Tom's world had failed him.<sup>18</sup>

*Tom: They gave no explanations. They thought: "This kid, there's something wrong with him. There's something very wrong with him". [My mother said]: "We didn't know what the hell to do, so we just ring someone up! I can't deal with the problem, make it someone else's problem!" That's what happened [getting angry]. And that's all that happens! I went from here to there to there [points his finger around, going in circles]. Like that! Like switching heads with people and shit, and [pause. Interviewer: And you had no control, no trust? Tom, sullen:] Not really, not really. But it's just [pause] I don't suppose it matters anyway.*

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<sup>18</sup> See Sandra's account of how she felt a failure as a mother herself, p. 67.

When asked about public awareness needs, responses reflected beliefs about authority figures and paternalism versus autonomy and self-determination (Kultgen, 1995; Davies, 1990; Gadow, 1990). Wong et al. (1999, p. 2, [cited from html. version]) stated that:

*A basic legal and ethical principle in democratic countries is that adults have the right to make decisions affecting their own lives. However, this right to self-determination is only meaningful if the person is appropriately informed, is free to make decisions without coercion and has the ability or 'capacity' to make the decision.*

The public, however, remains unaware of mental health legislation that would enable them to take preventative steps in avoiding coercive treatment methods. Most informants believed they ought to have known in advance, as by the time they came into contact with mental health services they "may be too far gone," and other options would no longer be viable. Only Susan agreed with the point of view of some of the clinicians that people should not be told. The interview questions, however, raised her awareness of her own powerlessness uncomfortably.

*I never really looked at it that way [that schedules are admissions against one's wishes]. As I said, hospital is where people go when they are sick, to get better. It's my responsibility to know what happens. But staff do need to make sure that patients get the right information in the hospital, and that they understand it. I feel that it would be detrimental for me to be given information about my rights and about the Mental Health Act. I was not even aware that legislation even existed initially. I prefer to learn as I go along, without questions.*

People who were scheduled felt that if they knew what could happen on their first contact with mental health services, they could use this knowledge to remain well and avoid admission. When admission was unavoidable, knowledge of the process and the different scenarios leading to hospitalisation could be used to enhance coping skills and minimise fear and anger. However, scheduling is not an event in which people have a choice about participation. Whatever way information is given it can always be used, or interpreted, as coercive. Paul pointed out:

*There's that point too! There's always the possibility that you get more scared to go and talk to anyone, seek help in case you got committed! Or scheduled. So maybe it's better that you don't know. Up until the time that you're going to go in. Then have it explained, that you can go voluntarily or involuntary. But it's nice to have that knowledge, that if things go off kilter you can be taken away, so it modifies the behaviour. I hope some people want to modify their behaviour.*

Penny saw the availability of thorough information as essential in preventing relapse. Full understanding of the impact of mental illness on a person's behaviour would enable informed choices. However, as we have seen, Penny was unable to prevent a re-admission, evidence of the need for ongoing support and information to enable the learning process to become fully established.

*The earlier [people are told] the better. People, when they are becoming unwell, if they have access to services, they don't need to go to hospital. Or may even want to go of their own accord. People definitely need to be reminded [of the possibility of admission] if they are becoming unwell. Anyone who's ever been in hospital should be aware. This way you can look at ways to avoid re-admissions. And those who have not been to hospital should still be aware. I didn't even know how [this could happen]! I thought that when I was out I was free.... There is no truth in being voluntary; there is no freedom. I knew it went on, but no one told me that [it could happen to me].... If this is what can happen, I have a right to know. People need to know in advance that they can just turn up at my door.*

Teresa was adamant that, had she known of all the possible options and consequences, she would have agreed to a voluntary admission to avoid the humiliation of her experience. Whether this would constitute informed consent or coercion (see p. 17) is a matter of opinion.

*It gives you a better position to make decisions, and as I say, at the end of the day, had I not been able to talk my way out of going to hospital, I would rather have gone voluntarily than by been dragged in by the police. So, had I known of this, it would have been different. I just wish that the whole system had been different! And I wish that someone had sat me down and just told me about it all.... And I think that, if in particular a psychiatric person comes in, they should have some data. So at least we know what exactly is going on, what can be done, and the steps to be taken. And if you do get bad, what are the options. I guess it gives you time to think [about it], and no one knows better than yourself what is good for you. I know the laws, but I never actually thought it would happen to me! Never once! Cross my heart!*

Paul recounted the story of a swimming teacher to illustrate this point. His comments highlighted the difficulties inherent in working with individuals who, due to different personalities and experiences, may well react differently to similar events and interpret information differently.

*I used to write in a sports magazine. Sports training. And there was a story from a swimming coach. An Australian swimming coach who explained how to teach people to swim. And that is, you give them a complete picture of it before they go into the swimming pool. About what it's going to happen in the pool. It reduces the trauma. And, I think that is a good idea in some respects.... On the other hand, it might increase the trauma. The fear that, if you don't [comply*



*with what you're told] there will be consequences. [Mental health staff] give them the option either of "If you don't come into hospital we'll come and get you" or "This might happen and if you don't pull your socks up then it will happen." If you give people a picture of what will happen, such as "You become an involuntary patient unless you take the medication," then [people might get scared].*

As stated, most people who had been scheduled felt, at the time of the schedule, that they were possibly unable to absorb, or fully understand, the information given to them. However, it was apparent during the interviews that this belief was not strongly held. It seemed to originate from being told by both mental health staff and relatives that they were incompetent to make decisions about themselves when experiencing symptoms of mental illness. Proving otherwise was not easy, restricted to "one word against the other." Tom made the following comments resentfully and sarcastically.

*We are not told: "We'll take you to hospital, and give you drugs, and we'll force you to take them." We are not told that! And probably for a very good reason! People are likely to object and get violent! The trouble with mentally ill people, tell them anything, tell them as often as you like, and it still doesn't sink in. It's part of mental illness! The receptiveness to that sort of thing disappears! And that's why they are put away.*

Given a choice, most informants said they might have gone in voluntarily, but this may have been their feeling at the time of the interview, in the knowledge of the little power they actually had. A state of "coerced voluntariness" (Rogers et al., 1993, 16) was described (see p. 91). Steve believed he might have agreed to go voluntarily had he known he had no choice.

*I may have [gone voluntarily]. That's not to say that I would have. Because at the time I was pretty far-gone. So, I may not have gone in voluntarily! But if you know what could happen that may make a difference. No one said: "We would like you to go to hospital." Just: "You are going to hospital" (emphasis in the answer). At least then, [if you have all the information] you have the option of putting yourself in voluntarily, instead of going through all the trauma with police and stuff. You could say: "Well, if this is going to happen then I'll go of my own free will.... But no one at the time had explained that I could be taken against my will.*

Mental illness and psychiatric hospitalisation were intertwined in their impact on those who experienced them (McGorry et al., 1991). For Tom, experiencing this for the first time at an age when he needed to meet his need for belonging and strive for esteem and self-actualisation (Maslow, cited in Alloy, Acocella & Bootzin (1996, p. 45)) added to his feelings

of powerlessness. The unexpected and unwelcome maturity and the forced independence came at a time when he needed the support of his family the most.

*It's very confusing. You ask yourself: "I didn't have the choice of whether or not I was put to this earth," right? That wasn't my choice! That I was put on this earth anyway! And now I'm supposed to think: "Wow, isn't life great! I've just been inflicted with something else on top of any of the other conditions I may have had." It's just inflicted upon me! So the question I've got to ask myself now is: "I've been given a defective body, I've been given a defective mind" [tears running down his cheeks]. It just really pisses me off how I've got dealt all the crap! And it's just not fair! So, why should I want to know about it? [Very quiet, tears streaming down his face].*

Education programs in schools were seen by those who were scheduled as essential to empower and inform young people about mental illness and how to access services in a timely manner. Mike was very level-headed about the whole issue, having learned how to use his newly acquired knowledge to his advantage, as a consumer advocate.

*I guess the only way I would have found out the first time was if there had been education about it at school. The second time I found out because I'd been through the system and been involved in other things. Then I found out about the Mental Health Act and various things. That seems to be the only way that you find out about it. I certainly see a lot of people who say: "Oh, the Mental Health Act! I'm here under the Mental Health Act and it's the first time I've ever heard of it!" It would be good if it was different! If you got education about it in school! One of those additional things they could teach you about at school. Things for later on in life!*

Stigma and a feeling of alienation are often consequences of living with a mental illness. Scheff (1984, p. 20) defined alienation as "the sense that elements of one's own life are meaningless." Tom's opinion about information giving in schools changed very quickly from positive to negative. His emotional pain and experiences with what he called "a defective body" highlighted for him the dangers of such information being given amongst a group that may not take kindly to difference and disability.

*That's a touchy one because there are, what, one in a hundred people are going to have what I have. So, you go to any high school, and any high school is going to have two hundred kids in a year. And every year two kids are going to leave with the probability that they are fated to have what I have. I suppose it would help, but again, it comes down to how kids are! There'll be kids who have seen it. Now they'll be out, and they'll talk about it here and there, and then you get people walking along the street having a whole new list of diseases to inflict on a person they don't like! Because that's just the way kids are. They are nasty little shits! So the way you've got to go about it is gently and slowly, and controlled. If it goes out of control, it can get out of hand.*

Most people who were scheduled reported shock and fear when first exposed to the event. Those who had been scheduled or hospitalised on several occasions appeared numbed to the experience, having internalised it and normalised it (Morrison et al., 1999) as an integral part of their life. Alex was in his early thirties and had been in hospital over twenty times. He was scheduled on every occasion, except the last one when he agreed to a short admission to commence Clozapine treatment. He had always gone voluntarily, stating that he had never resisted hospitalisation, not even after his mother found out she did not need to call the police as the mental health team were available to transport him. His mother, Violet, corroborates this information (p. 80). However, as for many others in the stories recounted, a Schedule II was applied to avoid the consequences of the person changing her or his mind. Alex's long history of hospitalisations was reflected in his passive, quasi-monosyllabic answers throughout the interview. Hospitalisation was a normal part of his life and he no longer had strong feelings about it either way.

*Oh it's all right [to go to hospital]! I'm used to going to hospital now. I just packed my bags and off I went.*

Being confronted with practices and events that have such a serious impact on people's lives created a range of emotions from anger to relief in all three groups interviewed. These feelings were clearly independent of the position each individual held in terms of power and control, or lack thereof, over the sequence of events culminating in an involuntary admission. It is clear, from the stories recounted and the feelings expressed, that ultimately the outcome of such an event is dependent on the relationships between all the players and how involved, acknowledged and validated each one feels at the time. The next chapter describes some of the ways in which relationships between players are affected and the impact of the scheduling event on relationship with the mental health system.

## Chapter VII – Relationships

*The essential qualities in an attendant or nurse are patience, gentleness, and firmness, with constant perseverance in all efforts to induce the patients to work, to join in recreation, to take the food and medicine considered necessary and to [undertake properly][sic] the duties of everyday life. It is absolutely necessary that attendants and nurses should observe the ... character and take a personal ... interest in the patients under their care, since it is only by becoming acquainted with their habits, tendencies and delusions that they can manage them properly.*

*Rules for the Attendants, Nurses, Servants and Others,  
Hospital for the Insane, Kenmore, Sydney (1897, p.5)*

The term “therapeutic alliance” (also known as working alliance or therapeutic relationship) was originally defined as an essential element of relationships that influences the “capacity to maintain therapeutic work, even in the context of resistance and negative transference. More recently, the concept ... has been expanded ... to generally apply to the patient and therapist working together with shared responsibility for achieving treatment goals” (Beauford, McNiel & Binder, 1997, p.2).

A vast body of literature is available, particularly in the psychotherapy and psychiatric nursing literature, looking at the importance of therapeutic relationships. These relationships are founded on warmth and genuineness and focus on collaboration between people who experience mental disorders and service providers (e.g., Sullivan, 1953; Peplau, 1978; Barker, 1990; Orvath & Symonds, 1991; Stuart & Sundeen, 1987; Anderson & Eppard, 1995; Bradshaw & Haddock, 1998; Svensson & Hansson, 1999; Hoyer, 2000). The *Human Rights and Mental Illness Report* (1993, pp. 255-263) devotes several pages to the topic of relationships between staff and patients in inpatient settings. Literature on the benefits of social supports, and the importance of social and family relationships is also available (Alloway & Bebbinton, 1987; Simmons, 1994; Bradshaw & Haddock, 1998).

A vast body of literature exists looking at the burden of care and disruption to familial relationships caused by the behaviours of people experiencing mental illness (e.g., Falloon, Boyd & McGill, 1984; Leff & Vaughn, 1985; Human Rights and Mental Illness Report, 1993; Lefley, 1996; Mueser, Webb, Pfeiffer, Gladis & Levinson, 1996). The opinions of family members about involuntary admission and legislation have been sought (McFarland et al., 1990). To my knowledge, however, no literature is available looking at the effect of a scheduling event on the relationship between individuals and mental health services. Nor is there much literature on the feelings of family members about initiating and/or participating

in the scheduling event. In other words, the impact of this kind of event on relationships is scarcely documented (see Deveson, 1998, p. 77 for a personal account of the consequence of initiating a schedule, and Lefley, 1996 for the family perspective about involuntary admission).

In discussing the recovery and secondary prevention needs of individuals who have experienced a first episode psychosis, McGorry (1992, p. 12) stated that "the central importance of human relationships to the recovery process in all its phases cannot be over-emphasised . . . . Psychotic illness puts social and professional relationships under great strain and many of these are likely to be damaged or lost over time if preventative action is not taken." He added: "The value of psychotherapeutic relationships in all phases of psychotic illness cannot be underestimated, though the difficulty of this task for the clinician often is." McGorry and Kulkarni (1994, p. 62) pointed out that the experience of psychosis impacts on the interpersonal, financial, and social areas of life and may cause "risk of personal injury" to the individual. They saw this as more so in schizophrenia as "damage to the person's relationships with their families, their fellow workers, and their friends may be severe and insidious."

McGorry and Kulkarni (1994, p. 62) further identified the quality of relationships as important in people with secondary morbidity, such as in the development of post-traumatic stress disorder in individuals who experienced involuntary treatment. Secondary morbidity is seen as arising directly from "the circumstances, process and context of treatment. Key syndromes here include post-traumatic stress disorder and depression, which arise from a number of factors, including the location, the events surrounding admission . . . and the characteristics and quality of the relationship with staff." It is also known that schizophrenia in particular, as well as other severe mental disorders, impacts on the individual's ability to form and maintain relationships (Hamilton, Ponzoha, Cutler & Weigel, 1989).

One of the aims of this study was to identify the impact, if any, of the scheduling event on relationships between the main stakeholders. The questions posed elicited information that evidenced either a breakdown or a strengthening of relationships. In all cases, as evidenced in the literature (e.g., McGorry et al., 1991; Morisson et al., 1999), it was difficult to separate the effect of a specific event, such as scheduling, from the lifelong effects of living with mental illness and the overall experience with mental health services. However, some comments were made that clarified the distinction, such as: "Living with mental illness is traumatic in

itself and the scheduling experience only seems to increase the sense of frustration and powerlessness for the family.”

A number of relationships were mentioned as important during the scheduling event. Desirable circumstances at the time; feelings experienced between those involved; the impact on relationships; and consequent beliefs about contacting services, being scheduled again, and schedules being necessary are discussed. Trust between clinicians and people who were scheduled is important in mental health. Its' importance for family members is discussed further on page 141 as it engendered additional discussion.

Scheduling is a time of intense feelings and emotions. These do not differ as much as we might believe between clinicians, relatives, and those who are scheduled. Mental health clinicians described a range of feelings before attending an assessment leading to a schedule ranging from relaxed to extremely anxious depending on their familiarity with those involved and the person's willingness to be seen. Concerns increased when the person to be assessed was new to the service. A number of elements were identified by the three groups as desirable for a positive outcome of scheduling.

### **Desirable circumstances**

#### For clinicians

Clinicians described a sense of “togetherness” among colleagues during these times. Poor relationships were seen as affecting both their level of confidence and their sense of personal safety. Therefore, while Elinor (Story 3, p. 194) felt supported by her colleague, Dr. Swallow (Story 4, p. 195) was ambivalent about how the members of the crisis team would take her request to attend to Anne's assessment. She was acting on Dr. Watts' (Anne's GP) request, had not met Anne before, and felt she somehow needed to justify agreeing to this assessment to her colleagues: “I felt I was well supported, both by the GP and the EHT (Extended Hours Team) staff. I also felt anxious about the EHT. More about them than the client as they weren't happy to be there.”

Clinicians mentioned “feeling confident” as an important and desired emotional state. This confidence was based primarily on the quality of their relationships with colleagues. Later (p. 141) we will see that for relatives “trust” was the most valued emotion that was either present or absent from their interaction with the mental health clinicians. Luhmann (1988, pp. 97-98) drew the distinction between confidence and trust by qualifying that it:

*Depends on perception and attribution. If you do not consider alternatives (every morning you leave the house without a weapon!), you are in a situation of confidence. If you choose one action in preference to others, you define the situation as one of trust. In the case of confidence you will react to disappointment by external attribution. In the case of trust you will have to consider an internal attribution and eventually regret your trusting choice. Moreover, trust is only possible in a situation where the possible damage may be greater than the advantage you seek .... Trust is only required if a bad outcome would make you regret your action.*

The potential for clinicians to regret decisions made about a person's level of risk to self and/or others in acute community work is high. A negative outcome, such as the death of a person who experienced mental illness or a death they may have caused, is never easy to accept. Thus, understandably, the common practice of defensive psychiatry (p. 88), which is not in the interest of the person experiencing mental illness (Brown & Rayne, 1989; Roy, Lelliot & Guite, 1996), is more often seen in our stories than the practice of therapeutic relationships and the fostering of trust. Monahan et al., (1995) reviewed experiences with coercion and found that coercion had a negative impact on interpersonal relationships. Siegel and Tuckel (1987) found a relationship between completed suicide and the use of coercion and strict rules in involuntary (inpatient) treatment.

Angela was concerned because she had not seen Liz for a couple of weeks and did not expect her to be unwell when she presented for her regular medical review. A good relationship between them meant that, when the doctor made the decision to admit Liz, Angela could explain this decision as based on care and concern rather than a need to control Liz' potential for harmful behaviours. Lidz et al (1997) suggest that the perception of coercion is reduced when the clinician acts out of concern for the well-being of the person experiencing mental illness, and when the person is given the opportunity to express their opinion. This appeared to be the case in Angela's experience of scheduling Liz.

Amanda, on the other hand, felt very sure of herself at the time of the schedule. She had a good relationship with Wagner, and she knew he trusted and respected her knowledge and could be convinced "by any story I chose to tell him." Deception is common in psychiatry (see pp. 91-94). Wagner would not have agreed to hospitalisation, and would almost certainly have fled and/or become aggressive, if Amanda had chosen to tell him the truth about admission. Deception was the best option within their therapeutic relationship in ensuring timely and safe treatment for Wagner.

*I felt relaxed and a bit of a con artist! I felt confident that I can talk almost anyone into doing almost anything I ask. I also felt empathic because I am fond of him. I didn't want him to get upset. I basically had a plan and I knew what I wanted to happen.*

Being able to provide individualised and sensitive care was important. Concerns were expressed about the feelings of the person and their family members, and the impact of their previous experiences with the mental health system and involuntary admissions. Peter's family had already experienced his mother being scheduled and transported by police on several occasions. Peter himself had been a witness to these events. Now his turn had come. Dr. James was touched by the family situation and was sensitive to the way she and the crisis team clinicians approached his admission and transport to hospital.

*I suppose I was concerned that [we] would need to involve the police, especially since they told me that Peter's mum had been taken to hospital by police several times. I was very conscious of the fact that it would be a really delicate issue and that Peter was likely to just become upset. I could basically see that, although he was quite psychotic, he was very aware of what was going on. I felt comfortable in scheduling him but still sad that was the extreme we had to go to.*

Being supported by people in positions of power was comforting when assessing people of higher socio-economic and educational status. This status influenced the way some clinicians practised at the time. In John's case (Story 6, p. 197), there was a greater awareness of his performance being under scrutiny so greater caution was exercised in dealing with Beverly's assessment. Beverly and her defacto, Gordon, were familiar with the health system, and Gordon was able to seek assistance from health professionals high up within the ranks.

*[I was] worried. Apprehensive! Because I knew the details [of the case]! I knew it was going to be difficult. [Gordon] didn't want our involvement. We were more careful because he was a doctor. He was a well-known doctor who had already contacted the hierarchy. I was anxious to involve Dr. Berry rather than the registrar. I was glad to have the consultant psychiatrist with me. He has more responsibility in decision-making. More clout!*

Relatives and people who were scheduled viewed the desired elements of a schedule slightly differently.

#### For relatives

For relatives, the most important factor was being able to trust clinicians and the mental health service. Being believed, having their concerns validated, having ongoing support for



the person who was scheduled, and feeling a sense of familiarity between themselves and the clinicians involved was important. An ongoing relationship ensured subtle changes to the person's mental state were noticed and monitored. However, Sandra's examples of good support described later (p. 133 & p. 143) were exceptions and, unlike Sandra, most relatives felt very isolated by the event.

#### For people who are scheduled

For those being assessed and scheduled, having a known and trusted mental health clinician present provided some reassurance that they, or their actions, would not be misinterpreted and that the intervention would be motivated by a concern about their safety and well-being. Rosa's previous casemanager had left the service, and she had only just met Norelle. They had not yet established a relationship. Rosa believed that her previous casemanager would not have scheduled her this time.

*I didn't know any of the people involved. I had only met my casemanager that day as the previous one had left. With the other one we used to talk like a friend. She'd come and I'd make a cup of tea and we would talk. This one just comes and gives me the injection. She is too busy. If the other had been here! They made a bad decision because I didn't need to go to hospital.*

Susan expressed the same feelings as Rosa about the presence of known clinicians, and complained about how she was treated upon admission. Not knowing the two men who knocked on her door that Christmas Eve did not bother her and she welcomed them into her house. Yet, she felt threatened once admitted to hospital due to staff's requests that she take medication she did not think was necessary.

*I just knew they were from the centre. When I got to the hospital I refused medication and got a message from the psychiatrist through the registrar: "Tablet or needle!" I inquired about the need for medication but many patients get threatened and then we take it. I also felt misunderstood by the Extended Hours Team. I was not going to drown and if John had been there he would not have thought that.*

Teresa had both her brother and her casemanager with her at the time of her schedule and felt betrayed by both. She did not know Dr. Finley.

*There was loss in my brother and Olwyn no doubt, but the doctor meant nothing to me whatever. I felt betrayed and I felt hard done by, for want of a better word [tearful at this point].*

For Penny, as for Susan and Alex, it did not really matter who was there at the time. Eventually, admission to the psychiatric unit had become both familiar and indifferent (Morrison et al., 1999). McGorry (1992, p.6), in discussing recovery and secondary prevention, stated that the number of times the person has been scheduled influences how they experience support: "The first episode of psychosis and the first admission to a psychiatric hospital, which generally coincide, present an enormous adaptive task for the individual .... It produces a major crisis in the individual and in the family system and requires them to make great emotional and cognitive adjustments. Superimposed upon the stress and disruption of the psychosis in most cases is the secondary trauma of admission, frequently under distressing circumstances and on an involuntary basis."

He added that: "Subsequent episodes of psychosis differ from the initial one .... The experience is less novel and therefore involves a different kind of crisis for the individual and family, one which is not necessarily less severe" (McGorry, 1992, p.9). In cases such as Penny's, the admission process and the hospital ward become a familiar and integral part of life. Penny still remembered the words of an inpatient nurse:

*I had no one I knew with me, but it didn't worry me. I'd been in [the psychiatric unit] before; I was taken by police before. It was pretty much the same. It didn't worry me much. The first time I was scheduled I was 17 and I was very scared. I was dumped at the unit in the middle of the night and just kept there.... I was pretty scared! The male nurse on duty said to me: "You'll get used to it after the fifth time or so. It will be like coming home!" Somehow, this seems to have rung true.*

The level of support and sense of personal safety experienced by clinicians, relatives, and the people scheduled impacted on the feelings about each other at the time. These feelings, and the impact of the experience on relationships, are discussed next.

## **Feelings**

For clinicians, describing their feelings about clients and relatives appeared relatively easy, with candid disclosures made of their less positive feelings. For relatives and the people who were scheduled, the feelings and thoughts were broad, as the scheduling event was just "the end result" of living with mental illness. Powerlessness to do anything other than initiate the schedule, and fear about the safety and well-being of the person being scheduled, were the main feelings experienced by relatives. Those who were scheduled experienced anger and a sense of betrayal and lack of trust towards both their relatives and the mental health clinicians.

These feelings run parallel to acceptance that scheduling has to happen and its outcome is usually beneficial.

Most of the information about the feelings of those who were scheduled and their relatives was incorporated into Chapter IV – Power (p. 56) and Chapter V – Crime or Illness (p. 73), as these concepts overwhelmingly represented their experiences at the time.

#### Feelings between clinicians, relatives, and people who were scheduled

Clinicians described a variety of feelings about the people that they scheduled and their relatives. As a rule, they believed that the schedule could not be avoided. A sense of superiority, concerns about maintaining relationships and a sense of betrayal were some of the most common feelings described.

The actual process of the schedule was described as “straightforward.” Occasionally, clinicians admitted that scheduling was a painful task that they would rather avoid whenever possible. Generally, as in the work of Beveridge (1998), clinicians acknowledged that people who were scheduled would experience feelings such as anger because of the coercive nature of the intervention. This is supported by other literature on involuntary admission describing feelings of anger, sadness and loss of trust at the time of hospitalisation (Morrison et. al., 1999). Clinicians experienced strong and diverse feelings regarding their role.

Doug explained how he resented attending to people in acute psychosocial crisis who he described as “the worried well” (p. 61). He saw his role as most valuable in working with people affected by psychotic illness, like Margaret, where the choice of treatment and containment were more “straight forward.” He disclosed feeling a degree of “patronising” towards Margaret. To patronise is defined in the Collins Pocket English Dictionary (1981, p. 613) as “to treat kindly but as an inferior.” It involves condescension, or “descending voluntarily to a level regarded as lower” (Collins Pocket English Dictionary, 1981, p. 181). Doug appeared to enjoy the knowledge and power that he had over people who were “too unwell” to make decisions for their own care.

*It was fairly straightforward. The fact was Margaret was clearly so unwell that clearly she needed to go into hospital. I didn't think there was any other alternative. So I probably didn't have any particularly strong feelings either way. If anything [I felt] a bit patronising. I guess I was pleased that I had a student with me and [she] was seeing someone who was clearly as psychotic as you can see.*

Angela, on the other hand, was very concerned when the decision to schedule Liz was made. The decision was made to ensure Liz's treatment, in case she changed her mind on the way to hospital or once she got there. This is consistent with the practice based on the assumption that a person who is experiencing a severe mental illness is incompetent to give informed consent to voluntary hospitalisation as seen in Chapter IV – Power (p. 56).

*I was quite concerned at that point. And I was quite concerned about the whole thing of Liz having an involuntary admission. I was quite concerned the registrar decided that she had to be an involuntary patient! From this particular point in deciding it, I just didn't know how the client was going to feel about that. I think she was probably too unwell to think anything much at the time. There was a bit of that fear: "Oh God, I hope the EHT get here quite quickly and I hope Liz doesn't take off because it's going to become unpleasant if that happens." So we were quite concerned that it all went as smoothly as possible.*

Louise was very disappointed about Penny's unexpected relapse. She felt a sense of betrayal, on both parts, as though Penny's wellness depended entirely on their relationship and the work she (Louise) had put into it. The need for people with a mental illness to take responsibility for their own treatment was seen as a necessary condition to avoid re-hospitalisation. Penny's apparent inability to "take responsibility," and having to organise the schedule through deception, added to Louise's frustration.

*I felt dreadful because I felt like I was betraying Penny. I guess I had a lot of feelings! I felt like I was betraying her and I didn't want to do it. On the other hand, I was just so angry that I'd been put in that position! Because I was working with her! So she had some responsibility to look after herself. The deal is that you're working in partnership and she had the intelligence to understand what was going on. I guess she had the option if she didn't want to go to hospital. At some point, the people that I see have to make a choice to work with me or with whoever they are working with, and choose to trust and accept some advice. Penny wasn't prepared to do that at that point, even though on some levels she was saying "I know I'm not a hundred per cent."*

For Doug, disappointment and betrayal were more in the context of his expectations of Margaret's parents who, as he saw it, "did not have a mental illness" and "ought to have known better." He knew that they had been offered "psycho-education," a formal program offered by mental health services to people living with a mental illness and their families about what is mental illness, prognosis, psycho-pharmacology, prevention, etc. This includes identification of early warning signs and early intervention by mental health professionals in order to prevent relapse (Falloon et al., 1984; Leff & Vaughn, 1995). However, on this occasion Margaret's parents did not appear to "follow advice." This frustrated Doug who

decided that such disorganisation required “a firmer handling.” He decided to call the police to push Margaret’s parents to act more expediently and get Margaret to hospital. As we have seen, in this case police presence was not necessary from a safety point of view but rather as persuasion agents.

*When I was casemanaging Margaret I always said to the parents: “Make sure to contact me if you have any concerns.” So I wasn’t quite sure why that hadn’t happened. I guess I felt a bit let down. I guess words like “stupid” and “dumb” and things like that spring to mind but they are not quite the right words to use. When I spoke to the parents I certainly said to them: “You know it’s important that as soon as you think Margaret is becoming unwell you give us a ring. It’s important that we do intervene at the earliest possible signs of a manic episode.” The family nodded their heads and seemed to know what I was talking about. So certainly I was surprised that when their daughter was just so clearly unwell they hadn’t contacted us. If [Margaret’s parents] were reliable, we might not have rang the police so early to get them to come. We would have waited five minutes. But the father [was] fussing around and [Margaret was] getting dressed [and] getting undressed. [The parents were saying]: “You need winter clothes” and “No, you don’t need winter clothes.” Margaret was getting changed, having a shower, and we thought that we’ll be here all day if we don’t hurry up the family into the car. We need to get the police or we’ll be here tomorrow at this rate. [The parents were saying]: “She’ll go with you” [but] we did disregard that. Which was in a lot of ways based on the fact that it was their daughter who was florid and they hadn’t even contacted anyone. Or they hadn’t for whatever reason thought that was necessary.*

Ironically, just like the people who were scheduled, clinicians thought that having their own opinions validated and being in control was important. It was not only Doug who was openly irritated and frustrated by the behaviours of people experiencing mental illness and their families. These feelings were common amongst clinicians when people they were “supposed to be working with failed” to follow the advice given to them. Despite the current focus on regarding families as allies and partners (Lefley, 1996), some indications of the old style adversarial relationships remain (Kuipers & Bebbington, 1990).

As a result, the word “sabotage” is commonly used by clinicians as an indicator of their frustration with relatives “changing their minds” about treatment or follow-up, or when they suddenly decide against hospitalisation of their loved one after having requested urgent attention. Lefley (1996, p. 124) conceptualises this phenomenon in the context of the family’s “adaptive response to inept or potentially harmful interventions” on the part of mental health services. Louise felt trapped in such a situation, as though unable to meet her own expectation to please everyone, while also seemingly unable to view the experience from the family point of view.

*You do get the shits with the whole lot of them actually! In reality I was getting probably approximately ten phone calls a day from relatives, acquaintances, other services, etc. about Penny. Ten phone calls a day! Probably for two or three weeks before hand! When it actually happens they want you to do something and when you do something they are still really uncomfortable about that as well! I suppose you can't expect more, but it is difficult! Because you can't really do the right thing in anyone's eyes!*

Relatives interviewed used the same terms as those described by Rogers et al. (1993, p. 19) in their study on service users. Relatives used their limited power and knowledge to "bring to an end" their spouse, parent, or child's distress and put a stop to "the disruption in their lives." They felt powerless in the face of the illness, the prospect of hospitalisation, the potential for self-harm, the potential for violence, the complex issues relating to treatment adherence, and the way the events unfolded. The presence of police and the fear of complications to the schedule caused near panic for Maureen. She was horrified when she saw the policewoman running towards where Tony was hiding, with a gun in her hand.

*I was terrified because there had been a fellow with some psychosis down in Victoria who had been shot and it happened just the week before. When the [police] came, as soon as Tony saw them, he went underneath the house into the garage, and I knew he couldn't get out. It was quite dark under there and one police followed him and one came out the front because I said he could get out through the door. And as we were walking down I heard this person actually running. The policewoman. She had a gun! I saw it in her hand and I nearly died! And I screamed: "Oh, don't" and she said: "What do you mean?" I said: "Don't bring your gun out with you!" And she said: "No, I wasn't going to." And I said: "Because he's not violent, he would never be violent towards you.' So I was absolutely terrified! All I could think of was the one behind him and I thought: "What if Tony turns around?" That was really one of the worst experiences I had for that short time. Even now I still have a picture in my mind that if Tony turned around with a piece of wood or something that policeman would shoot him. And it was only when he opened that door it was: "Thanks heavens he's come out." But they were wonderful. And the policewoman straight away said to her friend: "He's not violent." So I think she saw what I was like. That was awful!*

People who were scheduled felt powerless, betrayed, and lacking control over their own lives. Tom's answer about feelings encapsulates the sense of hopelessness experienced by some people when they develop a severe mental illness. He acknowledged that his feelings changed from time to time, depending on his mood and current events. As with most people (see p. 54), his moods changed from day to day. Happy and sad events alternated to influence his moods, and his feelings often reflected these differences. He was unsure about how he felt towards his mother though, believing she could have dealt with the situation differently.

*I never really thought about it quite honestly! Because it depends on how I feel, I suppose! To answer that question you can ask me every different day and get a totally different answer. From "I don't care" to "Oh yeah, that was pretty good" to "I probably wished I had died." What other course was there [though]?*

He felt he had been "a dummy," unaware of the reality around him, too unwell to process the situation coherently. He "allowed" the situation to be controlled by others. His anger was obvious as he related the events, describing himself as "very unwell" and "not feeling very much at all."

*I didn't know what was going on. I mean, I have trouble finding [out] what's going on from day to day. Like now! I don't even get out of bed before twelve. That's if I get up before 6pm at all. Sometimes I'll just sleep all day, and other times I'll sleep half the day. It just depends. I was a dummy. I didn't know what was going on! And no one was telling me! And no one wanted to! So it's like I didn't have a choice. I was told what to do. That's about it. [I felt] nothing really. Nothing! Didn't have any thoughts about it really. I didn't even know who they were. There were two people. They just came into my house and they told me they wanted to talk to me. So I just talked to them. I wasn't given an opportunity to [feel anything]. To be quite honest with you, I couldn't tell you, but anyway.*

Those who were scheduled had mixed feelings about the experience and those who initiated it.

### **Clients' feelings about those who initiated the schedule**

Most people who were scheduled trusted and respected mental health professionals and their decisions. It was apparent that some relied on their paternalistic actions, feeling that their lives were somehow out of control and that hospitalisation was an opportunity for a much-needed break. Others, however, wanted to maintain a degree of choice, autonomy, and control. This influenced the way they felt about those who made the initial call to the mental health service or to the police. However, no matter how the events unfolded, the experience itself and the feelings it engendered impacted on the relationships between those involved.

### **Relationships between those involved**

#### Relationship between clinicians and their colleagues

No literature was found describing the feelings of clinicians at the time of a schedule and the impact of the intervention on relationships between one another. Some of the information collected is similar to that described by those who were scheduled and their families. As with

the people who were scheduled and relatives, much of what clinicians felt at the time of the schedule depended on their relationship with the colleagues they were working with on the day. Mental health clinicians acknowledged that the scheduling event affected their relationships — either positively or negatively, depending on a number of variables. These included the degree and quality of existing relationships and the individual clinician's ability to maintain a therapeutic stance and ensuring the best possible outcome for all. Internal factors included a sense of control over the sequence of events and the degree of empathy felt for the person being scheduled and other people involved. External factors included acknowledgement of their own judgement and skills by colleagues and the acceptance of hospitalisation by family members.

It was evident that good relationships between colleagues minimised the stress of the scheduling event. Respect for clinical practice and skills; ability to efficiently attend to other people involved; provision of another perspective; opportunity to share and discuss opinions and feelings; and ability to plan and co-ordinate the intervention efficiently were some of the qualities and benefits that enriched team work. Attending to an event with a colleague who already had a relationship with the person being scheduled facilitated engagement and provided background knowledge that expedited the assessment process. A thorough understanding of all the significant issues involved assisted in decision-making.

Lack of co-ordinated planning and conflict with colleagues affected clinicians' anxiety level and the degree of confidence experienced. The end of a shift was a time when conflict with other staff was likely to occur due to professional needs encroaching on personal schedules (see Stories 3 – Elinor, p. 194 & 4 – Dr. Swallow, p. 195).

Clinicians believed that having their line of work validated was important, especially when the public can misinterpret the activities undertaken, such as scheduling, as activities of social control. Efficient and skilful practice leads to increased confidence and the development of trust between health professionals. When the need for acute psychiatric intervention is clear due to the presence of florid psychotic symptoms and bizarre behaviours, practice and skills are further validated by the efficiency in negotiating medical attendance and admission. Doug was rewarded by the opportunity to take a student nurse to schedule Margaret. The situation encountered justified in his mind the coercive practices used. Doug again portrayed the social perception of psychiatry as an agent of social control ( see pp. 25 & 60).

*It was good for the student that she saw someone who was very unwell and really got the idea that we are not in a Nazi level or anything like that,*



*dragging off people who are just minding their own business. I don't think that any fair-minded person could have seen Margaret and not thought that she needed some sort of intervention. You'd need to be very extreme in your views. It made my relationship with the doctor better because they could obviously see that it hadn't been a waste of time. When we said: "I think you need to come around and see this person for an assessment as quite possibly she'll need to be scheduled or go to hospital voluntarily," it justified myself and the casemanager as efficient.*

#### Relationships between clinicians and relatives

Data from this study show that the effect of a schedule on the relationships between consumers and clinicians varies and is dependent on existing relationships. There were times when people who were scheduled and/or their families were angry and felt personally injured during or following the event, and avoided further contact with the mental health clinician, and often with mental health services in general. This is supported by existing literature on the families' views of mental health services and treatments provided (Rogers et al., 1991; Solomon, 1994). At other times, those who were scheduled and their families were grateful for, and relieved about, the intervention and its outcome, although acknowledging that the event is in itself always traumatic (see discussion on "Thank you" theory on p. 69).

#### Relationships between clinicians and people who were scheduled

Despite Angela's initial concerns regarding the impact of the event on her relationship with Liz, she believed their relationship was strengthened through clear explanations given at the time. Angela's genuine concern for Liz was expressed in the way support and reassurance were given, and Liz felt cared for and valued. This seemed to ease her transition to hospital and her settling into the inpatient unit.

For Louise it had not worked out quite so well. This could be due to the EHT co-ordinating the event without personal knowledge of Penny and with concerns about Louise's safety, while in Angela's case they followed her instructions. Nevertheless, Louise felt closer to the EHT members because she knew they had acted out of concern for her safety. Unfortunately, and to Louise's dismay, her relationship with Penny was damaged forever.

This event highlighted for Louise the anecdotal evidence that the involvement of the primary clinician in their client's schedule may at times be non-therapeutic and counter-productive (see Elena's experience p. 142). When developing or maintaining a therapeutic relationship, clinicians need to take special care in making decisions about involvement in scheduling. When Louise saw Penny at the hospital and attempted to discuss what had happened at the

coffee shop Penny moved away without acknowledging her presence. Since then, Penny has refused contact with both Louise and the mental health service.

In many circumstances, relationships are not affected. Dr. James believed that the event she was involved in with Peter and his family would have no bearing in their future relationship with her, or the service. John, on the other hand, did not acknowledge that relationships develop as soon as contact is made. He later acknowledged, however, that the way he and Dr. Berry interacted with Beverly would impact on future contacts between her and the mental health system. “[With] Beverly there was no relationship. I felt fairly sure we were making the right decision. I wouldn’t want to try to see her again though!”

Dr. Jones also felt that maintenance of relationships between those who are scheduled and clinicians, and acceptance of the event, was dependent on the quality of the relationships already established and the level of recovery achieved through hospitalisation. He said, “I haven’t seen Caroline since. I suppose she would be a bit put off initially. I had known her before. With the people I schedule, particularly if they get well,<sup>19</sup> very rarely it is an issue.”

This is consistent with the literature on living with mental illness. Wasow (1994a, p. 30) states that “the process of adaptation to mental illness never ends.” She notes that current research on coping with severe mental illness identifies a number of characteristics of families who cope well, and a great deal will depend on pre-illness relationships within the family as well as current relationships. Research is also available on patients’ attitudes toward commitment, showing that most patients who leave hospital following a positive treatment outcome believe that commitment was necessary (Kane et al., 1983; Toews et al., 1986).

On the other hand, Sandra felt very strongly that events such as the one she was involved in with Gwen when she had to have the police enter her home by force, permanently damage rapport and trust.

### Relationships between relatives and others

#### Relatives and clinicians

Hatfield (1994, p. 67) looked at the role of the family in service delivery and their relationships with mental health professionals and found “that there are still significant difficulties to overcome in this area.” Working fully in collaboration with relatives remains a gap in day to day practice. As Hatfield (1994, p. 68) states, collaboration “is based on the

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<sup>19</sup> The “Thank you” theory (Stone, 1976).

fundamental democratic principle that everyone affected by a decision should have a part in making it. Collaboration means shared problem definition, shared decision-making, and shared responsibility with final decisions reflecting a balance of the needs of all those involved. It means working with people rather than doing things to them.” However, the scheduling event does not appear to always allow for such a collaborative relationship, thus impacting on how those involved may feel.

The data show that the type of service offered, the interpersonal skills of the clinicians involved, and the amount of explanation provided helped relatives develop a positive attitude towards the clinicians and the mental health system. Most relatives of people who had an established, ongoing mental illness felt that mental health services provided them with little support, and they often relied on other parents and relatives for support and information.

Interestingly, the relatives of people with a first onset psychosis connected to the local EPOCH team clearly felt more informed and supported. They relied on the service rather than on other relatives during the initial stages of the illness, as well as for assistance in the decision making at times of crisis. It is worthy of note that this team was recently developed and their practice based on the latest knowledge and research in the field.

The EPOCH team applied the principles of cognitive theory and therapy to first episode psychosis as an adjunct of pharmacotherapy by gently challenging “the inferences and evaluations associated with delusional interpretations of events and stimuli and with distressing emotional and behavioural reactions.” Additionally, the independent use of “cognitively-based psychotherapeutic interventions” were applied “to help the recovering person to make meaning of the experience of psychosis while maintaining a sense of coherent self-identity, self-worth and competence” (Spencer, 1998, p. 38. Unpublished report).

Maureen explained:

*It's important to have back up, explain: "This is why we are doing it." I've heard those words echoed a few times: "We are doing this because you are a danger to yourself or somebody else." And I think the [person affected by mental illness] needs to hear it! And we need to hear it a lot! Because otherwise we think: "I can protect him!" But there are times that you can't! You can't take the risk! Because we'd die if anything happened to them and we hadn't sought help!*

Once relatives felt confident in their knowledge of mental illness and services available, they felt responsible and valuable in providing support to others in need. Sandra and Kerri had developed strong social supports and assisted others in need. However, unlike Sandra who

developed her role with EPOCH's support, Kerri's involvement was due to the mental health service's absence.

Relatives from the EPOCH team felt that relationships with mental health clinicians were strengthened through the support received: "I can't think how any of them could have been any better, they were all marvellous. Everybody was very helpful." However, others had their negative perceptions and experiences reinforced. While most felt safer knowing where to get help, some scepticism about the availability of adequate resources to provide such help was obvious. Responses included: "As long as help comes! It is good to know there is a place I can call" and "I feel safer knowing that there is help available, to the extent that there is!"

Eileen had no confidence whatsoever in the mental health system. She was at work when Grant was scheduled and she herself had to be involved in a pseudo-professional capacity because she worked in a GP's practice. Grant had been unwell for quite sometime, but due to his assumed potential for violence mental health services were refusing to be involved. As commonly practised (Rogers et al., 1993; Deveson, 1998), advice was given to Eileen to call the police, which she did not want to do.

Kerri was also at work at the time of the schedule but she described a more positive experience. She had been informed of what was going to happen and had already been through the experience of having Brian hospitalised. He also had a casemanager whom Kerri knew and trusted, and the staff members involved took the time to inform her of the outcome of their visit.

#### Relatives and family members

Often being the ones who initiate the scheduling event places great stress on the relative's relationship with the person being scheduled (Lefley, 1996). However, most relatives stated they were "beyond guilt," "past being desperate" and felt "too upset" at the time of contacting the mental health service to worry about consequences.

When relationships between family members broke down, the development of mental illness and changes in family members' behaviours, as well as the unfolding of the events and decisions to be made, were important factors. Family breakdown happened for a variety of reasons. There were often different explanations given for the illness behaviours and different interpretations of the stigma attached to the label once diagnosis was made (see also Bates, 1977). Kanter (1996, p. 800) noted the importance of identifying conflict between care-givers as "essential identifications ... with the person in their care." This conflict is evidence that

both parties care about the one affected by mental illness and, often, if mental health clinicians were involved in resolving these differences separation may not have needed to occur.

Wasow (1994a, p. 31), in her chapter on professional and parental perspectives on coping with mental illness, noted that catastrophic events, such as the development of mental illness, can have disastrous effects on the family unit and individuals within it. On the other hand, these events can foster "the emergence of strengthened lives," and some families feel stronger. Maureen encountered some losses. Amy, Tony's sister, reacted poorly to his illness and the attention he demanded from his mother. Her husband, Bill, could not understand the behavioural manifestations of the illness and was intolerant of Tony. Maureen believed that men and women had different expectations about their roles, with women more often taking the role of primary caregiver (see Cochrane, Goering & Rogers, 1997). Bill, however, seemed to ignore her need to fulfil this role and expected her to fulfil his wishes of a quiet retirement on their own. Having professionals around to support them during these times was important in ensuring a positive outcome to their relationships (Kanter, 1996).

*Fathers experience it differently. I think because they have all these hopes that their son, Australians think: "My son is going to follow after me and do this." I don't think they can cope with things like a woman does. I think it's within a woman to cope with caring. I think that's the way he looks at it, that he's been held back now. Whereas I see it as a lifetime thing! No matter what happens, I'll be there for Tony. He'll say: "Well, you can't keep him with you all the time. We have to move on with our own life." And I don't see that! I see that if he's sick like that, he's part of my life. I think we are [closer together] now because we worked it out. But that's why you need back up. That was good that Dylan was there all the time, and he was saying to Bill: "This can happen!" I think if we hadn't had that back up in the beginning it might have been different.*

The stigma attached to mental illness and the fear of having it within the family caused some distancing between relatives. Stigma "has been described as the most pervasive subjective burden experienced by families of persons with mental illness" (Judge, 1994, pp. 172-173). Although Violet's family and ethnic community were quite supportive and accepting of Alex, she felt that only herself and her daughters were working closely together in ensuring that Alex was well cared for in the future. Her husband remained at a distance, unwilling or unable to provide support. The fear of acknowledging the existence of mental illness in their midst distanced other relatives and friends. The burden of care for Violet was evident in her relief whenever Alex was hospitalised. She was never sure of whether he was safe as his disturbed

behaviours often placed him at risk, such as when he would stand in the middle of the road trying to stop moving traffic.

Those families who became closer disclosed that the sadness of mental illness was their catalyst. They had to work together and support one another not only through the crises but also on an ongoing basis. A deep sense of loss for their loved one, and being confronted by that loss potentially becoming greater through disability or suicide, motivated people to express to each other feelings they had not disclosed before.

A successful high school student with a responsible, mature personality, Elena did not appear affected by living with a parent experiencing mental illness. Although parental mental illness is seen as a risk factor for the stable development of children, no evidence has been found in empirical research and the phenomena of the resilient child remains mostly unexplained (Feldman, Stiffman & Jung, 1987; Lefley, 1996). Sharing the responsibility of caring for her mother with her grandfather was difficult due to grandpa's lack of knowledge of the English language. Moreover, she had a close bond with her mother, a nurturing bond that led her to take on a parenting role. This bond is recognised in the literature as being "less susceptible to disruption by mental illness than is the bond between father and child. In fact, mentally ill mothers seem as capable as healthy mothers of maintaining a positive relationship with their at-risk sons and daughters. Moreover, they are able to do so even when faced with the added burden of a mentally ill spouse or no spouse at all" (Feldman et. al., 1987, p. 237).

*My grandpa will only call for help at the last minute because he doesn't speak proper English. He'd probably wait for me to come around and call. He'd wait until she was really ill. I feel like I'm the one [with the main responsibility] because she is my mum and I'm here. And she looks up to me. Even though I'm her daughter she does look up to me. I look up to her too. I felt bad because I didn't know what to do to help her. I can't force her to take her tablets! Sometimes I tell her: "Have you taken your medication?" She says: "Yes." All I can do is believe her. I can't really check or anything!*

#### Siblings' experience

Tom and his brother, David, had a strained relationship while growing up. However, Tom's mental illness appeared to have brought the two brothers closer together. Their newly developed closeness touched their mother, Sandra. Judge (1994) discusses available literature focusing on the experience of children, siblings and spouses of people with severe mental illness and the implications of this knowledge for services and clinicians. She states that "the experience of siblings of persons with serious mental illness has, for the most part, been

overlooked by family research” (Judge, 1994, p. 162). Sibling relationships are more enduring than any other relationship and are of special significance in individual’s growth and development (Judge, 1994, p. 171).

On the other hand, Maureen disclosed the impact of Tony’s mental illness on his sister, Amy. Fear for her own safety, inability to continue studying, self blame for not identifying the signs of relapse sooner, concerns about a genetic loading in the family and fear of developing the illness were mentioned. As Deveson (1998, pp. 84-85) recounted in her personal story, in the accounts where the person experiencing mental illness had a sibling, the family was affected by difficulties in dealing with both the person’s behaviours and the sibling’s reactions.

Judge (1994, p. 173) describes a number of feelings experienced by siblings of people affected by mental illness. Grief, survivors’ guilt, fear, shame and anger are reported, as well as anxiety related to ongoing crisis experienced by the family. Resentment over the amount of attention received by the person experiencing the illness, being seen as responsible for some of their risk behaviours, and being unable to deal with their odd behaviours at home were some of the reasons for conflict. These findings are supported by some of the stories recounted in this study (Maureen & Kerri).

Pedro felt he had a responsibility to ensure that Jaime received the treatment he needed for a prompt recovery. As the older brother, he wanted to “fight for him” as he had done as a child. He wanted to protect him and make sure he was all right. However, he felt he was fighting a much harder “bully” than those encountered in schools, a bully — the mental health system — he had no power over.

*Jaime doesn't feel closer to me! But I do feel closer to him because I keep thinking that I have to make [decisions about him]. Suppose I go into [hospital] tomorrow [to visit] and I think he's not sick! What can I do to help him? Take him out of hospital, basically! I would fight for that but that wouldn't help him. I feel like he's only got me to look after him. But he's got the system against him in a way! Because he's sick! But the system keeps involving the police.*

#### Relationships between people who were scheduled and others

No studies have been found on the perspectives of the people who are scheduled about the effects of such an event on their relationships. In keeping with the findings previously described about the importance of existing relationships, people who were scheduled expressed feeling disappointed and betrayed by the mental health professionals involved at the time, especially those with whom they had developed close trusting relationships. With

those with whom relationships had not developed, for instance the doctors who wrote the schedule, indifference, and anger towards their actions, was common.

#### People who were scheduled and clinicians

Trust is an important concept throughout this study. A good trust relationship with the primary clinician assists in developing and maintaining trust in the mental health service. The availability of one valued relationship is enough to enable people to monitor their mental illness and work positively towards recovery. Paul had changed his primary clinician since his discharge due to the resignation of the initial one. He was much happier with Joanne, whom he had met as an inpatient nurse. That continuity of care suited their relationship and he trusted her judgement and knowledge as well as her focus on his best interest.

Confidentiality issues, such as mental health clinicians' sharing or obtaining information about a person, placed a strain on trust but did not alienate the person from the mental health service. It was confronting for Paul to know that, no matter where he moved to, information about his mental illness, his behaviour and hospitalisations could be shared between health professionals.

#### People who were scheduled and their families

Not surprisingly, this group also viewed the impact of the scheduling event on their relationships as depending on whether these relationships were good to begin with. While for some people family relationships had broken down following the development of mental illness, for others, support and understanding were sustained and valued. Occasionally, relatives were alienated from the relationship following unsolicited and unwelcome attempts to support the person (see Leff & Vaughn, 1985).

Several contributors to limited family involvement were mentioned. Forced separations through hospitalisation, relatives' lack of understanding of the effects of mental illness, stigma attached to the illness and to psychiatric hospitals, lack of knowledge about what to do when behaviours were out of control, and issues of privacy and confidentiality were common.

These findings are in keeping with studies investigating the social networks of people with severe mental disorders that found social networks shrinking around the time of the first episode of psychosis (Tolsdorf, 1976; Kuipers & Bebbington, 1990; also discussion on pp. 108-109). Although the concept of confidentiality in law is unclear and open to individual interpretations, there is evidence that it must be carefully considered where family



involvement is beneficial. The ultimate aim of well-being and recovery of the person experiencing mental illness must be considered (Furlong & Leggatt, 1996; Lefley, 1996; Szmukler & Block, 1997). Szmukler and Block (1997) in discussing confidentiality aimed at engaging individuals and families in treatment while avoiding possible ethical dilemmas, invoke the need for fairness and carer status in involving families.

Rogers et al. (1993, p.18) stated that “a psychiatric crisis and its resolution entails a negotiation between three different parties: professionals, prospective patients, and those connected with them in their immediate social network.” Despite the obvious nature of this statement, as noted later (p. 141), the principle of consumerism and collaboration does not apply in acute psychiatry. In this case “the patient has little obvious say in the matter about their involuntary removal from civil society as it is the actions of others which decide the outcome” (Rogers et al., 1993, p.19). This lack of involvement leads to the development of feelings of anger, resentment and lack of trust.

As noted throughout this study, deception is a commonly used tool to achieve safe outcomes. This is a conscious practice, often described as legitimate by clinicians (see Lopez, 1996). Alfred (Story 24, p. 223) was hospitalised only once before. His father had initiated that first experience and Alfred had not been able to forgive him. This time, although his psychiatrist initiated the schedule, he blamed his mother and sister, as they were involved on the day. It took Alfred a long time to understand their concerns and agree that he needed help. Alfred found it difficult to accept that mental health clinicians can turn up accompanied by police and invade his private space without warning.

Paul was also shocked by his family's involvement. Once he had time to think about the events, his anger began to surface. Like Teresa, he would rather have been deceived into hospital with some likely story, like Amanda used with Wagner, than undergo an experience that showed him how little control he had over his life.

A sense of betrayal was a common theme throughout the interviews. Goffman (1961) first described a “betrayal funnel,” whereby others conspire with mental health clinicians against the person, but although this betrayal funnel may well exist, the greatest betrayal is not about conspiracy but about breach of trust. Teresa was very angry with her brother for a while. She blamed him for calling the police and initiating the whole event. She knew very well he was driven by genuine concerns about her well-being but she remained adamant that she could have been treated at home. She would have agreed to it if she had been aware of the consequences of refusing treatment.

Penny stated she had contacted the service on several occasions for assistance before being scheduled. She was not very happy with the way she ended up being refused treatment when she wanted it and forced to accept it when she did not.

*I was not very impressed! No one had rung up and then three [mental health staff] turned up without a warning. They said they were worried about my health. I had rang on several occasions trying to get them to arrange for me to see a social worker and they never sent anyone out. It is an impossible situation.*

People felt anger if they were not involved in the decision-making process. Not being validated and heard as a person, and having decisions about their lives made by people who did not know them and saw the illness rather than the individual, was resented. These interactions, and the feelings they aroused, seemed to affect the chances of the person's future involvement with the mental health system.

Staff attitudes and practices appear to be based not on set principles and values but rather on the personal disposition of the clinician. This can have a positive or negative impact on the outcome of the intervention for those who experience it first hand. The following data provides a window of understanding into the impact this event has on relationships with mental health services and treatment follow-up.

### **Future contacts with the mental health system**

The importance of a therapeutic relationship in adherence to treatment, in being able to identify and effectively act on early warning signs, and in providing the support required to effect change within the context of the person's life has been documented (Marland, 1999). Scheduling impacts on this relationship, whether established, developing or not yet begun. Comments by most clinicians support the findings of a study by Repper, Ford and Cooke (1994) whereby they found that being scheduled affected the person's future contact with mental health services. Statements in this study such as: "Why expose yourself to the experience again?" and "It is not surprising! Sometimes it's not the case, but they are usually reluctant and avoidant" were common.

As part of the original interview guide there was a selection of questions about the impact of schedules on future contacts with the mental health service. Each of these questions asked informants to respond according to a five point Likert scale, ranging from strongly agree to strongly disagree. Clinicians were asked about both relatives and people who had been scheduled and the likelihood of them contacting mental health services again following a

scheduling event. Relatives and people who were scheduled were asked from their own perspective (Table 5). The responses follow the interview pattern whereby the clinicians are described first, followed by relatives, and then the people who were scheduled.

**Table 5.**  
**Less Likely to Contact Mental Health Staff when in Crisis**

Group	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
Clinicians*1					
Clients	2	4	1	3	0
Clinicians*2					
Relatives	0	1	2	6	1
Relatives	5	3	2	0	0
Clients	0	7	2	1	0

Note. \*1 Clinicians' response about clients; \*2 Clinicians' response about relatives.

Clinicians believed that future contacts depended on the relationships previously established with mental health professionals, the mental health diagnosis of the person, their level of insight and understanding of the illness, and the treatment outcome. The concept of insight, frequently cited as a basis for establishing individual levels of competency, remains unchallenged as a feature of mental illness. This is despite the growing evidence that there is no difference between the level of insight among people who experience mental illness, those with other medical diagnoses and non-patients (Applebaum & Grisso, 1995; Hoyer, 2000).

Dr. Swallow believed that many people seen by mental health services would continue contact due to their own perceived need for support. She believed that the effects of institutionalisation, including the more disabling and chronic course of the illness (see Goffman, 1960), caused people to rely on mental health clinicians to assist them in meeting needs such as companionship, protection and/or support.

Other clinicians felt that people experiencing mental illness would contact the mental health service because they knew they were unwell and that they would benefit from hospitalisation. Others would not contact the service in an attempt to actively avoid being hospitalised, unaware or not having experienced the service's main aim of treating them at home in the least restrictive environment.

When asked the same question about relatives, clinicians had quite different beliefs. They thought that many relatives felt guilty about the outcome of a contact with mental health

services, but the need for care and support of their mentally ill relative would always lead to contact, albeit in desperation. Kuipers and Bebbington (1990, p. 150) acknowledge this guilt and the reluctance of relatives in initiating a process they know all too well. The authors are of the opinion that mental health teams need to develop good relationships with police in order to reassure and support relatives effectively.

Clinicians believed that at times lack of contact from relatives was indicative of pressure exerted by those experiencing a mental illness, through pleading or threatening not to contact mental health services again. The quality of the service received influenced subsequent requests. Provision of adequate information and a good attitude from clinicians were identified as key factors to facilitate engagement and the development of future relationships.

The majority of relatives stated that, despite the painful experience of having their loved one scheduled, they would consider contacting the mental health service again should another crisis arise. Some had already done so. This supports the clinicians' beliefs about relatives maintaining contact with the service following a schedule. Several barriers to effectively referring a relative to, or receiving support from mental health services were mentioned. These included the mental health services' requirement that the person experiencing mental illness is aware of the referral (consent to contact); poor assertiveness skills to demand services when their own assessment of need was discordant with the clinicians' assessment; and previous negative experiences with services provided.

Relatives were distressed by the amount of responsibility they carried in ensuring the safety of their family member. Handing this responsibility over to mental health clinicians was, in many cases, a relief. As seen in the literature (Lupton, 1996) and supported by this study, many people still believe and trust medical knowledge and authority. Maureen was glad of the current legislation that allows for people who are a danger to themselves or others to be committed for treatment and containment against their wishes. This provided her with reassurance that everyone involved would remain safe and that Tony would receive timely treatment.

*I am grateful the law is there because I know when they are psychotic they don't think straight. As I said, my biggest concern last time was that Tony may commit suicide. Even though he only said it once: "That's a good time to die." And he had written a letter: "I wish I had died, I wouldn't have to go through this pain now". And that was all within these few days before! So when that happens you think: "Thank heavens there is someone there who'll come out and just say: "We'll take it out of your hands." But as I said, there's the other side of it that's hurtful as well because you think: "OOPS! [Am I doing the*

*right thing?] I was pleased when they arrived. I thought: "We can't have the responsibility for this forever. This is your bag." They came in and saw what was happening. They were calm, listening.*

Sandra was very happy with the intervention received. She had no previous experience of events such as this and was not sure of what to expect. What she witnessed was a high quality assessment, coupled with excellent interpersonal skills and provision of useful information, and an outcome that ensured everyone's safety.

*[I was] relieved that I'd found somebody who was happy to at least listen and tell me what was wrong with him. So that gave me some sense of relief. I was actually surprised! I really have no complaint about the public health system even though I'm privately insured. I guess I don't know what my expectation was when I called. I guess I'd have been satisfied if they just said: "Take him here or there. Call in to the local doctor" or something. But in fact I got better than that! And they were here within time and they were very good. I knew I couldn't do it by myself because I didn't know what I was doing with him. By that stage I knew I had a problem! I didn't know what it was so I didn't know what to do about it. And I knew I couldn't just leave him. I knew I had to do something. I couldn't walk out of here and gone to work on Monday with him the way he was.*

Sandra and her son, Tom, were some of the people seen by EPOCH clinicians. This team's practice was based on an innovative program developed to address the needs of adolescents and young adults experiencing their first episode of psychosis (Edwards, Francey, McGorry & Jackson, 1994; Jackson et al., 1996). In following Jackson's (1996) model of cognitively oriented psychotherapy for people with first-onset psychosis, EPOCH clinicians focused on assessment and forming a therapeutic alliance followed by facilitation of adaptation to the psychosis while focusing on the treatment of secondary morbidity. This practice included working very closely in partnership with family members (Stewart, 2000). The difference in feelings with the EPOCH group is noticeable and worthy of further research.

Davidson and Strauss (1992), on which some of the EPOCH clinical practices are based, reports on research conducted with people struggling to recover from mental illness. Their study shows how an enhanced sense of self, like the concepts of self-efficacy, locus of control and self-esteem, enables people to recover from their disorders. Of interest are the questions born from the use of this model in the areas of clinicians' control and responsibility (Davidson & Strauss, 1992, p. 143):

*How can you treat patients as responsible and self-directed agents and at the same time act to ensure their safety and well-being? How can you avoid demanding simple compliance from patients and at the same time help them to*

*avoid relapse by managing their medications? Who does know best, at what times and concerning what areas? Such questions raise many unsettling and difficult issues which require additional thought and clarification....*  
*Maintaining too much control as a clinician would seem to deprive patients of [a] very human and very important opportunity for learning, while also possibly impacting negatively on their efforts to develop a functional sense of self.*

People who were scheduled were given the same belief statement. The experience of being scheduled was described as traumatic and by the majority as necessary. Despite the trauma, there was recognition in hindsight of the benefits gained from hospitalisation, and from the new or ongoing contact with the mental health service. Surprisingly, this was not acknowledged by clinicians. They believed that the trauma would be enough to deter people who experienced severe mental illness from contacting services again.

Steve disclosed having a poor experience both prior and during his admission to hospital. He believed that he could have been treated at home, considering that the hospital treatment was mainly pharmacological. His post-discharge period was difficult because he was left without supports for nearly two weeks. He described being isolated, scared, and suicidal during this period. Eventually he was contacted by EPOCH. His negative feelings were shifted to a better understanding of the service resource issues, and his comments denoted a degree of protectiveness of the service and a solid feeling of support, involvement, and responsibility in his own ongoing care.

*My trust is pretty large, I guess because I received a lot of support since I came out, so I do trust mental health services. Probably not initially, not in the first couple of weeks. Because I got such a run around in hospital! I was waiting there for a long time. I saw different nurses during the time that I was there. I only saw a doctor once, or twice actually, and it was annoying. I spent two weeks out of hospital before I got to see a doctor up here [at the centre], so it all fell apart during hospital and after I came out. But now a bit of time has gone by. I've seen a casemanager regularly and I'm involved in the early intervention program. That helped quite a bit to restore my trust in the mental health services. But the actual services that I received, or the treatment that I received while I was there and immediately after hospital, wasn't very good.*

When making the decision to contact the service again, previous experiences and the current need for support and treatment sometimes conflicted. Some people developed good relationships with clinicians despite previous experiences, and contact was easy. For others, the relationship was non-existent or had deteriorated dramatically, posing some doubt in their minds as to whether they would contact the service before a crisis escalated past the

possibility of community care. Alfred felt more confident now he had a primary clinician with whom he had developed a good relationship.

Mike remained quite confident in his dealings with the mental health service and had contacted them at times of need following his schedule. He believed that the degree of helpfulness provided at those times depended on the clinician answering the initial telephone call, showing again an inconsistency in clinical practice as evidenced throughout the data.

*I've had a few little episodes where I needed help. I got high and didn't like it, and rang up. Or couldn't sleep, so I rang the number here and it has been transferred to the psychiatric unit. Sometimes it's been helpful; sometimes it's not. Depending on the answer you get, or how you're feeling at the time.*

#### Involvement with mental health results in future schedules

A statement was made to the three groups about the belief that involvement with community mental health services would lead to further schedules. Most clinicians agreed that people who were scheduled believed that involvement with mental health services would increase their chances of being scheduled again. Most relatives, in answering the same statement, were clear about the role of mental health services in attempting to provide treatment in the community. The people who were scheduled gave mixed responses, depending on experience (Table 6).

**Table 6.**

#### Involvement with Mental Health Staff May Increase the Chance of Being Scheduled

Group	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
Clinicians*1 Clients	1	7	2	0	0
Clinicians*2 Relatives	0	7	1	2	0
Relatives	4	0	0	5	1
Client	1	2	3	3	1

Note. \*1 Clinicians' response about clients; \*2 Clinicians' response about relatives.

Fear of further hospitalisations and subjection to coercive measures such as use of police officers and paddy wagons, were identified by clinicians as causing people to avoid contact with the service and a preference for invisibility (see also Repper et al., 1994, p.36). Hoyer (2000, p. 5 [cited from html. version]) stated in his discussion on the concept of insight and its

impact on refusing psychiatric treatment (see the discussion on p. 131) that: "It is important to remember that not wanting to be treated within the mental health care system may sometimes be based on experience *and* insight, rather than the opposite" (my emphasis).

Dr. James believed that continued relationships with the service depended on the amount of information received following a schedule. Sensitive information giving, she believes, may result in increased compliance with medication and treatment follow-up and lead to a decrease in concerns about coercive treatments or interventions.

Mental health clinicians were of the opinion that relatives believed the increased chance of being scheduled depended on individual circumstances. Clinicians thought that relatives would see involvement as having a detrimental effect in fostering dependency on the system and that, additionally, the person would be given a label and experience the unwanted side-effects of medication.

Clinicians thought that current resource restrictions caused undue frustration for relatives because mental health clinicians were unable to maintain ongoing, supportive involvement. They responded to relatives' and individuals' needs when the crisis was an acute phase of psychosis, whereby further deterioration in the person's condition could no longer be prevented without hospitalisation. Lack of resources caused clinicians to become a means of safe transport to hospital rather than having the intended purpose of prevention and early intervention in first onset or relapse.

Relatives believed that if the situation deteriorated beyond the possibility of community intervention, ongoing contact with services would provide a prompt response and safe outcome. Their responses reflected not so much a difference in opinion but whether at the time of their answer they were focusing on their need for respite or on the treatment needs of the person experiencing mental illness.

Sandra was very happy with the ongoing contact between Tom and the EPOCH clinicians. She felt that he saw himself very much as part of the treatment team and carried the responsibility for his own care and well-being. Kerri, however, despite her good relationship with Brian's casemanager, still felt that the care provided was inadequate and that often people would not be scheduled even when relatives felt that was the only option. The burden on the family was, in her view, seldom considered.

The answers of those who were scheduled depended on the relationships maintained with mental health clinicians. Some people believed that admission depended solely on their



mental health status, while others believed experience had shown that contact with services in itself increases their chance of being scheduled. As Good (1988, p. 45) stated: "Within any human society, the context in which a communicative act is offered is critical to its interpretation .... The beliefs which are held about another person at the time of communication, are a significant part of what that context amounts to." Thus, previous experiences and the interview context influence the opinions expressed by those interviewed.

Rogers et al. (1993) identified a disregard of patients' view and a preference for professional or family opinions in studies looking at various aspects of psychiatric care and legislation. This is still prevalent today, as Rosa reminds us.

*Because they always believe the family or the friends! They don't listen one word of the person who is sick. [We] could stay at home if they explained and gave tablets.*

#### Schedules as necessary

A third statement was given to the three groups about whether involuntary hospitalisation is necessary when acutely ill. Clinicians were asked about what they believed to be the opinions of relatives and people who were scheduled. They believed that people who were scheduled and relatives generally agree that involuntary admissions are necessary. This is supported by the answers of the other two groups (Table 7).

**Table 7.**  
**Involuntary Admission is Sometimes Necessary**

Group	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
Clinicians*1 Clients	1	8	0	1	0
Clinicians*2 Relatives	5	5	0	0	0
Relatives	7	3	0	0	0
Clients	4	6	0	0	0

Note. \*1 Clinicians' response about clients; \*2 Clinicians' response about relatives.

This again demonstrates the implications of recovery in what is described as the "Thank you theory." This acceptance depends on the level of insight and degree of recovery achieved once treatment is started. The diagnosis of the person influences the belief clinicians have about his

or her capacity to understand what is happening and to acknowledge the benefits of the intervention.

Clinicians believe that relatives will always agree to involuntary admission being necessary and see the legislation as a helpful tool. Some clinicians believe that relatives are more likely to contact mental health services and to attempt to use the relative's diagnosis to have the person removed from their home. Some believe that this is "used inappropriately" at times, showing a degree of misunderstanding of the burden of care on relatives who have primary responsibility for the care and control of the person experiencing mental illness (Kuipers & Bebbington, 1990).

*Once a client has been scheduled there is more of a chance that the relatives, friends, neighbours get on the blower and say that they are mad. They often use the label as an excuse to have the relative removed, or for an intervention to happen, [especially] if there are any behavioural problems.*

Relatives agree that involuntary hospitalisation is sometimes necessary when people are acutely unwell. However, this knowledge does not make the intervention any easier to deal with. Pedro was at work at the time his brother Jaime was scheduled. His anger towards mental health staff who failed to notify him of the schedule was evident throughout the interview. He felt cheated out of involvement and consultation and felt that his brother was treated like an object.

Despite the clinicians' belief about those who were scheduled, this group also agreed that involuntary hospitalisation is sometimes necessary when acutely ill. However, having the option of receiving treatment at home and of not involving the police remained high on their agenda. Being believed and listened to was a common theme. People who were scheduled felt that their opinion and knowledge of themselves were not validated nor considered, and doubting their own judgement and competence remained with them. Teresa dwelled on this point for quite a while, trying to see herself with an outsider's eyes.

*Everyone is saying around me: "You don't realise how sick you are." And I was quite aware! I thought it was so clear! I was quite aware of how sick I was, and I do think I remembered my whole life, and I just went into a daze and I couldn't respond to anything. I just couldn't cope, I found. So yes I was [unwell. But] it's defining what exactly is "ill." Is someone at that stage where they should be involuntarily taken or are they not? That's the tricky part. But I do think there are cases and causes for it to be necessary, yes.*

Teresa's disconcerted answer encapsulates the results from a study by Melamed, Kimchi, Shnit, Moldavski and Elizur (1997). Their study examined the relationship between competence to consent to psychiatric hospitalisation and insight in 113 psychotic patients admitted voluntarily. The results indicated that roughly 50% had insight into their illness and 60% thought they needed hospital treatment. The study highlighted a contradiction between level of insight and agreement with hospitalisation, indicating that insight does not necessarily mean competence. The authors stated that "this contradiction needs reconciliation. One possible way to reconcile the problem is to separate the issue of the patient's illness, which causes his psychosis and occasional irrational actions, from that of his *right to voluntary admission despite* the possible interference of his illness with his competence to consent" (Melamed et al, 1997, p. 725, my emphasis). In Teresa's case, as in others, it is possible that a discussion of the least restrictive choices available would have led to an informed decision about voluntary hospitalisation that would have benefited her without the trauma and humiliation experienced.

Penny recognised that at times she was too sick to stay at home, whether supervised or not. Her illness had a very rapid onset and she quickly became unable to make decisions about her own need for treatment and containment.

*Sometimes I've been so off the air! If I'd had the option of being at home, at times I think I'd still be better off in hospital. No one on the outside would have the energy, or the patience, to look after me.*

Elena felt both relieved and anxious at the presence of mental health clinicians. Relieved because she trusted their skills and ability to deal with the sensitive and unexpected situations that arose. Anxious because she realised the limitations of hospital treatment and knew that her mother could become angry with her for contacting the mental health service, as she had done before. Like other relatives, however, she felt she was powerless to do anything else at the time.

*They know how to react if something is to happen while mum's sick. Sometimes the way they talk calms her down a bit. But not always. They might agitate; they might cause a few more problems. Like when they left I noticed that my mum had more anger towards me for calling them. [That made me] feel useless. Because that's really the only thing I can do: call for help. My mum is always the same. It's only when she gets ill I don't talk to her much. I get a bit: "What's happening to her? She's going into her little world again!" We sometimes have our little arguments but we are really good friends. She tries not to scare me when she's sick. She tries to act like she's fine. But she doesn't*

*realise that people can tell. She tries to reassure me that everything is going to be all right. She hates me [calling for help].*

As we have seen, scheduling impacts on relationships and trust between clinicians, people who experience mental illness, and relatives of people experiencing mental illness. The belief that contact with mental health services will increase the possibility of being scheduled impacts on the ability to call for assistance when in crisis. Relatives and people who were scheduled differed within their own groups as to whether they believed that increased contact with mental health services could lead to a schedule. Clinicians were of the opinion that this was the case, reinforcing the notion that lack of resources will lead to more acute interventions and less options of acute care in people's homes. This impacts largely on families with a primary care role with the person who experiences mental illness, and the trust they may or may not develop and maintain with mental health services.

### **Trust**

Schedules are undoubtedly events that affect the level of trust experienced by those involved. Trust in family and friends, trust in colleagues and professionals, trust in oneself and one's judgement, trust that it will not happen again, trust that it will all be okay. Beliefs about basic values such as self-determination, control over one's life, being treated with respect and dignity, and being heard and acknowledged are strongly held. Those involved in the scheduling event need to be able to trust that the mental health service will do what is best for the person being scheduled as well as their relatives and friends through high standards of practice.

For the person, the fact that at times they experienced an altered reality created relational disturbances, and being able to trust their environment and the individuals in it was very important (Jackson et al. 1996). Simon Champ (1998, p. 59), a mental health consumer and activist, described the importance of relationships for those who experience psychosis and how these have an effect on the development of hope and sense of self. He stated that "the best professionals involved in my care have, like me, opened themselves to the mystery that is schizophrenia. They have gained my trust, sharing and supporting my inner search for meaning and for an understanding of the relationship between myself and my illness." However, as we have seen, in acute mental health work there is seldom time for clinicians to "connect" with the experience of the other.

The involuntary removal of a person from their own home for containment and treatment is one area of health care where the principles of consumerism do not seem to apply (p. 129). Rarely are people asked their opinion and given a choice as to whom they see and what services they receive. As we have read, not only does the person being scheduled have “no rights,” but their relatives also lose their rights to participate in the decision-making, albeit often willingly. At that point in time, just as a child must trust her or his parents to make decisions that are in his or her best interest, so adults must trust mental health law and the clinicians’ judgement and decisions (paternalism).

Lupton (1996, p. 161) conducted a study on the emotional dimensions of the doctor–patient relationship. The results of this study draw attention to communication as a notion that influences how individuals classify good or bad doctors. A doctor’s — and I believe equally so all mental health clinicians’ — ability to listen, provide explanations, and look beyond the symptoms were qualities leading to the development of trust. Trust is seen as based on openness and mutual disclosure and neither of these qualities appears to be present in the scheduling event. Good (1988, p. 33) defines trust as “an individual’s theory as to how another person will perform on some future occasion, as a function of that target person’s current and previous claims, either implicit or explicit, as to how they will behave.” In this section, the added information given by relatives on this topic is presented. The feelings of clinicians and of people who experienced mental illness were described in other chapters, where they appeared more in context.

#### Trust and relatives

For Pedro it was all a matter of being able to trust the clinicians to look after people in a professional manner. However, that had not been his experience, as he witnessed behaviours indicative of what he defined as “very low” standards of care both in the community and in the hospital settings. His sense of personal safety was shaken as he recounted an event witnessed in the psychiatric inpatient unit.

*I've got no confidence [I won't be] taken away if I'm there at the wrong [time]. And that is the only feeling that I've got. This is all about trust basically. It's about trust! That's it! I try to understand people. But I'm not a nurse because I wouldn't be able to give what I think a nurse should give. But when I go to a psychiatric hospital and I see somebody for example telling a patient: "Don't do that!" And the patient does it, and the nurse or whatever taking the cigarette and throwing it to the floor really enraged [mimics taking the cigarette out of his mouth and throws it on the ground] and [shouting loudly]: "Get up! That's it! Don't do that again!" And things like that! I don't think that those people should be carers for these people. Even my brother said:*

*"Disgusting!" This is the only profession that I could say should be more standard to me. It feels to me that anybody does this kind of job!*

Eileen had no trust in mental health staff. She believed that there was strong collusion within the system to protect health professionals. In so doing, high quality care was compromised and both those experiencing mental illness and their families were affected. Previous data support Eileen's view.

*I have no trust in the psychiatric system as they lack organisation and have a so-called professional attitude of defence. I feel that doctors have this attitude whereby they have to constantly defend the psychiatric system and their actions. Doctors often alienate the families because families constantly ask for information, feedback, explanations, reasons, etc. Professionals don't want to know anything that may make their life difficult. I was branded as an emotional woman. Over the past twelve months my trust in the mental health service has decreased due to response of the crisis team who were not there the only time I ever requested their help. This was late at night and I was desperate and they advised me to contact the police.*

On the other hand, Terry's faith in the mental health system remained strong as he believed that they would always support him in hospitalising Vincent, who remained unwell.

*My trust in the mental health system has increased where the need for hospitalisation is concerned. I feel that in the end, I will be listened to. And I believe that the mental health service should continue to be involved if they can get to see Vincent.*

There is ample anecdotal evidence within mental health services that clinicians are ambivalent and often discordant as to whether the schedule ought to be co-ordinated by the primary clinician or not. The data presented support the idea that this is a clinical decision that needs to be made in each individual case, taking into consideration the impact of the intervention on the relationship and treatment adherence. Elena saw trust as an essential component of a good therapeutic relationship. This meant, in her opinion, that sometimes it would be better not to have the known clinician attending, but rather someone who will not mean much to the person.

*I think sometimes people feel they can trust [the mental health staff] more if they've seen them before. But other times [they] might feel they are back to take [them] to hospital. So maybe it is better [to have] a change.*

Maureen also mentioned trust as essential for good working relationships between families and clinicians. Her relationship with Dylan, from the EPOCH team, extended to meeting her

own need for support, thus assisting her in providing support for Tony. Eventually, the whole family was involved in Tony's care. Together they were able to identify periods of added stress and anticipate relapse. Those who had positive experiences described a sound level of trust in the mental health service. An increased awareness of mental illness, a feeling of mutual co-operation, and support for both the relatives and the people experiencing the mental illness were valued. Maureen stated:

*It's increased my trust because I know they really care. It's been a very good service from the early intervention team [EPOCH]. I've got no complaints at all. Because every time I rang up they've listened to everything I said and they've come out when I've asked them to. My only complaint is for the people who can't get [this help] in some areas, or don't know about it.*

And Sandra added:

*I don't know if [everybody else] had the some sort of experience as I did, but I have to tell you that I couldn't have been helped much more. I still felt rotten! But nobody was going to make that go away. So I don't know that there was any more that could have been done for me. They were very helpful. I asked a lot of questions too! And I'm sure at times that wasn't useful because they have a lot to do and clearly they could probably do with some more staff. There are times when they are absolutely run off their feet and you can see that! So, I guess I try to be selfless and do as much for Tom as I could to avoid putting more pressure on them. Relatives need to understand what is wrong with their [family member]. They must need more support then than at any other time in their life.*

Some relatives, however, felt that they had lost trust in others. There was a sense of uncertainty in life. A reticence in talking to anyone who did not have an understanding of mental illness. Suspiciousness about how well the person with the mental illness might be at any time. There was loss of trust in individual clinicians who were not as supportive as expected. Responses denoted different feelings, such as:

A sense of nostalgia: "I think it's an individual thing. But you miss more, worry about taking things for granted, which I tend to do normally."

A sense of betrayal: "I don't think I lost trust in people. I lost trust in talking to people who don't know how to deal with it, and so I felt I had let Tom down."

And a sense of parental concern: "The need to always know where he is, always know to be wary and to stay with my gut instinct; and a feeling of being unsupported."

All this information confirms that this event is traumatic. Interestingly, relatives appeared to be the ones who had endured the greatest losses. Most people who had experienced a schedule, despite being clear about how painful the intervention was and how angry they felt, described having developed relationships that assisted them in living more stable lives and develop supportive networks. For relatives, the development of mental illness and the perceived loss of the person as they knew them had a catastrophic impact on their lives and their sense of fulfilment as parents. Lefley and Wasow (1994a, p. 28) have no doubts that severe mental illness "is a catastrophic event for families." McCubbin and Figley (1983, cited in Lefley & Wasow, 1994, p. 28) described catastrophic stress as "sudden, unexpected, and frightening experiences that are often accompanied by a sense of helplessness, destruction, disruption, and loss" and this is evidenced in this data.

In the next chapter I present the opinions of clinicians, relatives of people who were scheduled, and people who were scheduled as to how the process of scheduling could be improved. This will provide a basis on which to build services that are responsive to needs by creating mechanisms that link individual practice to collective outcomes (Bolman & Deal, 1991).



## Chapter VIII – Can Scheduling Be Improved?

*Thought is not what inhabits a certain conduct and gives it its meaning; rather, it is what allows one to step back from this way of acting or reacting, to present it to oneself as an object of thought and to question it as to its meaning, its condition, and its goals. Thought is freedom in relation to what one does, the motion by which one detaches oneself from it, establishes it as an object, and reflects on it as a problem.*

Michel Foucault (1994, p. xxxv)

As we have read so far, the scheduling event is a complex experience. Clinicians adapt to this intervention by justifying it as minimising risk to the person experiencing mental illness and others and providing timely treatment. Clinicians also practice in an ad hoc fashion, based not on evidence but rather on how it has always been done, how they are taught on the job, and what they believe is required. Relatives of people who are scheduled see the event as both distressing and relieving, a way to bring an end to pain and distress, of achieving either treatment or respite for their loved one. Those who were scheduled see the benefit of this “final action” and accept its results, albeit not its means.

A number of concepts are identified as important in the experience of scheduling. These are: the use of power and how this is experienced; the criminalization of the behaviours exhibited by those being scheduled; the lack of information and education about legislation, including the challenging concepts of insight, competence and informed consent; and the impact all of the above have on relationships and future contact with mental health services.

To gain further understanding of the impact of this event, participants were asked to think about the last schedule they were involved in and describe what was done particularly well, what was the worst part, and whether they thought the event could be improved. Some prompts were used, including whether they believed that families need to be more involved, either at the time or in prevention; whether a debriefing or discussion forum would be useful; and whether information about scheduling ought to be provided and to whom. The responses to provision of information were incorporated into Chapter VI — Information and Education (p. 108).

## What was done particularly well

### Clinicians' view

As evidenced in the stories and feelings noted, mental health clinicians face a diverse range of situations and experience a variety of feelings before, during, and after a schedule. A number of factors influence how clinicians feel at the time and how they describe good processes and outcomes.

When the person experiencing a mental illness is disturbed and resists hospitalisation, mental health clinicians appreciate expediency, the opportunity to take therapeutic risks, the time to provide support, the gentleness of those involved in containing the person, the provision of thorough information, and good communication between all. Being available outside normal business hours provided clinicians with a sense of worth and an opportunity for achievement that enhanced their job satisfaction.

In replying to the question about what was done particularly well, Sandra stated that her experience with Gwen was difficult because they had not developed a relationship, and Sandra had to resort to intrusive and coercive measures. She was comforted, however, by the expediency of the admission process.

*It happened very rapidly, not one of those where you go buggering around for days. It went very smooth, according to plan. Gwen was handled gently by myself and the doctor. And the neighbour was fantastic in giving me crucial information I needed.*

John, albeit partly due to Beverley's socio-economic status, offered Gordon, her defacto, personal escort and support. This provided him with the opportunity to explain the mental health system and the processes of admission and acknowledge Gordon's distress. Although John felt good about being able to provide a service of this calibre, as we will see later, he did not make himself equally available to Steve, or his mother.

*The support given to the defacto [was good], talking to him, taking him to the hospital, introducing him to staff. He was tearful and distressed, worried about his actions. Time was taken to explain that it was a medical decision [to schedule]. I go through that with a referrer generally anyway. The close relative is more affected, they assume the person will never forgive them. Also [it was good] that we were very quick. The job was efficient.*

Dr. James' memory of what was done well in Peter's schedule focused on the empathy and kindness in supporting this family through a difficult period. The sensitivity she and her

colleagues expressed to family concerns, such as previous experiences, led her to spend adequate amounts of time working collaboratively. This enhanced her sense of personal reward about the outcome of the intervention.

On the other hand, Dr. Penford found this question a good opportunity to make a joke about the professional attitudes of mental health clinicians with a comic scenario that, in part, reflects the stereotypical perceptions of psychiatric crisis work.

*It was good that the mother was there with Caroline. Also the police were very professional and responded quite promptly. Oh, of course [laughs] we were efficient and professional. [Then, straightening himself up with a joking tone he smacked his left fist into his open right hand and said:] Well, actually we had just drowned five beers at the pub and we couldn't wait for some action! [Laughed again]*

#### Relatives' view

Five relatives thought that nothing that was done was helpful and the event would remain in their memory as the worst day of their lives. The other five thought the event brought them comfort, reassurance, support, and the likelihood of being able to assist the person experiencing mental illness in their recovery, and in the event of future crises.

Mental health clinicians' genuine interest for relatives' needs rated the highest. This interest was shown both organisationally and professionally. Organisationally, through being available twenty-four hours a day, being receptive as a first point of contact, and providing an outreach service. Professionally, through a prompt response; not being hurried; asking questions that clarified immediate issues and provided a diagnostic basis; supporting the person experiencing mental illness; following up on requests for assistance; providing reassurance about the decisions made; and talking to people experiencing psychosis with respect. Sandra stated:

*The person who answered the telephone was interested in what I had to say. And interested in what my concerns were and willing to help me. And they did that without question. Not like: "I'm not the right person and I'll transfer you to other people, another government department!" It was like this person obviously knew what they were all about and asked a lot of questions that were obviously relevant. That gave them a clue as to what the situation was. To the point where he knew I needed a doctor. And someone being on duty 24hrs a day and being able to turn up and help somebody like me who clearly knew they were in trouble and wasn't going to be able to sleep through another night. I started to feel a bit better then: "Hang on! I've done the right thing getting some help here." Same as getting to the hospital! I think that was done*

*as best as possibly could have been for someone in Tom's condition. They didn't try and rush and hustle him and hurry him up.*

Elena followed the paddy wagon with the mental health clinician in the service car. She was reassured and comforted by the explanations and support given, and her reply supports the evidence that children of people affected by mental illness benefit from clear explanations about what is happening and why (Judge, 1994, p. 165).

Violet was touched by how mental health clinicians showed respect for Alex. Despite his chronic thought disorder, clinicians always seemed to understand what he was saying and responded with the kindness and consideration owed to any valued human being. Jan, although unhappy with both the process and outcome of the intervention, was able to identify one positive aspect of the event by saying that the best thing was: "That they came down at all. She [Nora] wasn't herself."

#### The view of people who were scheduled

Despite the painful experience of being scheduled, transported by police, and having her or his rights taken away, people who were scheduled identified actions, words or events as positive. Being provided with support after discharge, experiencing a service they described as "personalised," being acknowledged through a friendly attitude, and hearing words from others that expressed care and concern were some of the positive aspects described. Penny, despite believing that nothing was done particularly well added that she was pleased with having a clinician allocated who would provide her with support to prevent future admissions.

Mike had no supports at the time. However, he thought that the police officers attending to transport him to hospital were friendly. Steve, on the other hand, burst out laughing at my proposition that anything could have been done well. Nevertheless, he did acknowledge a personal touch, a concern for his well-being, in senior clinicians attending to him in his own home to ensure his safety.

*Ahemm, (laughs) probably John and Peter coming down to talk to me, coming to my house, coming in to have a chat, that was probably pretty helpful. Looking back on it was a pretty thing for them to do. And Dr. Berry came down as well, so that was pretty good. So that sort of personalised service was pretty good*

This care and concern was also experienced by Teresa who, despite being quite adamant that nothing was done well at the time, managed to think of something: a few repeated words from Olwyn that she remembered with warmth.

*No, absolutely nothing [vehemently]! Not one thing you can think of! There was absolutely nothing. As far as I'm concerned I was seeing Olwyn and my brother outside the paddy wagon and between the two of them I couldn't stand them! They were disgusting! How they ever allowed me to come to this! The only good or helpful thing would be, I'd say, [that] Olwyn kept reiterating: "Teresa, this is for your own good." Now I understand that. And maybe I wasn't as lucid as I thought. So that's the good thing. But there wasn't a good thing for me at the time because as I said it was a shock! I woke up at twenty-five to four and I came up here for my appointment only to find [pause] I was terrified of what would happen!*

Alex and Paul saw the event as an "average, middle of the road" intervention. However, Alfred, Rosa, Susan and Tom were adamant that nothing whatsoever was done well. Susan, despite strongly believing that psychiatry has a role in treating people against their will, and feeling protected by this benevolent paternalism, added that nothing was done particularly well. On the other hand, Tom could not come up with an answer at all. Instead, he replied by saying what he thought was quite inappropriate to have happened: he felt that his mother had left him alone in a dangerous situation. Unsafe, and alone.

*I think the dumbest thing that they did, my mum and my brother and this dude who mum worked with, who was just helping us out, they all went to lunch and left me in the apartment with however much money I had, and I could have gone anywhere. I mean they were only gone for half an hour but [pause]! It's just common sense. Like sure they didn't know what to do and they had to think about it. So they didn't know quite how dangerous I was until they got the doctors around but they could have [sigh], they could have still been there or something, I don't know. Yeah, my own parents did it wrong. My own mum did it wrong. Leaving me there!*

## **The worst part of the event**

### Clinicians' view

A number of issues were directly related to unpleasant feelings. Being in the presence of people experiencing mental illness or family members expressing distress about the event; the negative attitudes of some colleagues; their own inability to provide adequate community care; and the use of deception and sense of betrayal were mentioned as causing the greatest impact.

Sandra and John felt that the worst was the distress experienced by the people being scheduled. This distress was seen as caused by the coercive measures used. Elinor, whose anxiety was high due to the risks taken in her intervention with Eva, felt burdened by the psychiatrist's reaction that invalidated both her clinical and therapeutic skills. For Louise and Amanda, lack of resources to provide least restrictive care caused frustration.

Feelings of betrayal and disappointment with the person being scheduled, their relatives, and the mental health system were discussed earlier. These feelings were difficult for clinicians because they legitimised deception and "lying" as part of the skills required to achieve a therapeutic end. Being part of a powerful system, dealing with its inadequacies and its lack of resources, and needing to involve the police, added to their frustration. As we have seen, the sense of betrayal and the use of deception had the most impact on Louise's emotional reaction to the schedule.

*The betrayal. What I perceived as a huge betrayal of a client who I'd worked really constructively with. I suppose there was betrayal all round really. I certainly felt like I betrayed Penny in the end. I set up a situation where she was going to be scheduled and I couldn't tell her about it. I don't think that lying to clients is a great thing for a therapeutic relationship. I threw out the line, wheeled her in, and she was scheduled. That's not the best thing I've ever done. I'm not working in mental health to be a mechanism of social control, but there I am!*

Doug was disappointed with – even betrayed by – Margaret's apparent inability to adhere to the prescribed treatment and her parents' "failure" to follow advice. He acknowledged the parents' concerns regarding police involvement, as though partly aware that he had used "persuasive power" by calling them in unnecessarily.

#### Relatives' view

As previously stated, some relatives could not think of anything that was done particularly well or was helpful, while others stated the event could not have been better. However, they were all able to identify a particular action or behaviour that they defined as "the worst" part of the event. The breakdown of relationships, the admission process, the use of deception, the police involvement, and the absence of supports were their main concerns.

The admission process was the worst part of the event for some relatives. When accompanying the person being scheduled to hospital they witnessed them being restrained and forcefully sedated. This caused distress and a deep sense of aloneness. Exhaustion at the

end of the day did not help maintain healthy contact with available supports. Sandra described her experience:

*The [worst was] the way people had to try and hold him down and sedate him. And while everything in my head tells me that absolutely had to happen, it just had to happen — he couldn't go on, he was throwing himself at the wall, he was going to hurt himself, so it had to happen — but it was certainly distressing. Very distressing! And being on my own. That was awful. They were all so busy! They had to do what they had to do! They had to be looking after him, not looking after me. I'm a big girl. I can look after myself. But that was really tough! I couldn't stop crying. I couldn't stop! [And] the other thing that's hard [is to] come home of a night and you're really tired, and you've been there for twelve or fourteen or sixteen hours and you just want to fall in the bath and fall into bed. You don't eat properly, you can't be bothered, and then the phone starts. The grandmother, the uncles and aunts, and then the friends rang and it's like, it's very good that people are concerned but you try and spend two hours a night on the phone! It's the last thing you're going to feel like! I got to the stage where I wanted to record a message, Tom's update for the day: this is what we did today and this is the progress we made! See you later!*

Just as clinicians sometimes had to resort to deception to ensure a safe admission to hospital, so relatives, at times, had to deal with the ongoing demands for reassurance and support from the person experiencing mental illness through lying. Lying protected them from the person's anger and maintained a good relationship. However, it was never done easily, particularly in Elena's case, as lying meant knowingly breaking the values learned from her own mother, the same person now "making her" break the rules. This is one of the greatest challenges for children of people who experience mental illness. As Elena attempted to maintain an objective stance, her mother attempted to incorporate her in her delusional system. This resistance stance is seen as "essential for resilience" (Judge, 1994, p. 165) and, fortunately, Elena had a good enough relationship with her mother to withstand the pressure.

*It was a bit scary! My mum not knowing what she was doing, not knowing what she was saying! Talking a lot of crap, which I found a bit scary because she wanted me to believe it! She would say: "Don't you believe me?" until I would say: "Yes, I believe you." And then she'd stop asking me. But until I said: "Yes, it's true!" Like I would have to lie to her, otherwise! That was bad! I shouldn't have to lie! I should be able to say: "No mum, it's delusional. It's not true!" But you just have to shove it aside and say: "Yeah mum, it's true. You are the Virgin Mary! You are having a baby."*

Police involvement and transport in the paddy wagon rated high as the worst part of the experience. Police officers brought finality to the event (see Chapter V — Crime or Illness, p. 73). Being unable to help and protect their loved one was confronting.

*[The worst part was] probably standing at the door when the police were there and John was there. And Steve absolutely not believing that this could happen to him. Seeing the disbelief in your son and to know that you were part of it. I was part of the cause of it! I didn't have a choice! I was quite grateful to Dr. Berry for taking it out of my hands.*

Relatives' dissatisfaction with mental health services has been documented (Hatfield, 1987a; Rogers et al., 1993; Solomon, 1994). Some relatives noted the absence of support from mental health clinicians during and following the event with anger and resentment. Jan was not informed of what happened to Nora. Later she found out that Nora was sent home without follow-up. Jan was distressed about this: "The total neglect that followed! Pretending that Nora doesn't exist anymore. No one sees her! She doesn't even remember what she did!"

Grant, on the other hand, was considered too dangerous to be attended to at all. Eileen was distressed by the lack of support and by having to resort to police officers to ensure her son's safety. The deterioration of her relationship with Grant that followed was painful.

*Everything was horrific. Grant was very disturbed! It was night time and very cold. I was desperate to get him safe. Then two great burly policemen arrived. Two great burly police and a defenceless child! No one there to protect him! [Tears well up in her eyes] And the mental health people wouldn't go!*

Other relatives who had poor experiences with mental health services were distressed that they were unable to negotiate appropriate treatment and ongoing follow-up. The person experiencing mental illness eventually became so unwell that involuntary hospitalisation was the only option. For many relatives, difficulty negotiating the mental health system and hospital environment when visiting was the worst part.

Pedro could not get over the way the scheduling event had developed that day. He did not understand the *NSWMHA 1990*, was not sure of the criteria or process for admission, and believed that the clinicians involved lacked the high quality interpersonal skills they ought to have. He worried about other people having the same experience as he did.

*It should be more difficult to put somebody in hospital than that! I don't know the process! I don't know the Act! If I read it, if I try to read it it's too difficult for me anyway! But what I can't conceive is the work of some people, the way that did happen! There is no way! Sure there must be another explanation! Always excusing; excusing somebody else! And then we don't get any quality! I mean, with this work you have to give the biggest quality that [you] can. I hope that she [Norelle] improves her life because I wouldn't like it to happen to another person!*



### View of people who were scheduled

For those who were scheduled the worst part of the event included the use of coercion; lack of support; their own passivity and resignation; the fact that they had a mental illness; and not being included in the discussions about admission and treatment planning. Coercion included the presence of police and attending the magistrate's hearing, the use of force, and the feelings of powerlessness. For Penny the worst thing was:

*Not having any say. Being taken by force. I said: "I'm only hitchhiking, I'm not hurting anybody." [She added]: "I agreed that I needed to be in hospital, but I didn't need a Court to decide for how long."*

For Teresa, the worst part was being transported in the paddy wagon and having her rights taken away.

*The worst part of the whole thing was definitely the lock up and the actual certification. Taking my rights. Particularly when my brother was informed of our rights and stressed: "I have rights to organise these sort of things," and I thought: "Great!"*

Paul was shocked that it could all happen without any warning. He felt ambivalent as to whether this warning should be given or not, denoting values held by society about the potential risk of certain groups, such as people affected by mental illness, versus the individuality of each case, namely himself. He believed that the simple existence of mental illness is the forewarning that schedules can happen.

*[The worst was] being removed out of the blue [Interviewer: From your house? Nods in assent]. If you give people forewarning they sort of begrudge you, put up a barricade, get the machine guns and all that sort of stuff! So you can't really forewarn them! Depends on the individual. For some you can forewarn. Some you can say: "Look, these are the problems." Basically they have to forewarn anyway!*

For Alfred, his family's "betrayal," being left out of the negotiations and the element of surprise of the event, left a sour taste. He felt vulnerable in his home and has kept his gate locked ever since.

*They talked to my mother and sister outside and left me out. That was very annoying, they should have included me. Also the police van. I had been to hospital before in the mental health car but I was much better then. I would have gone with my mother. Also the way the police acted. I was sitting in the lounge-room and suddenly saw them running in through the back gate. They just barged in! The gate is now locked so they can't just come in. They would*

*have to jump the fence. But it frightened me that they could just come in and get me.*

Steve did not receive the same care and attention given to Beverley's husband by John. The worst thing for him was the way he was "dumped" at the hospital.

*Being dumped there. Just being dumped. [At home it] was pretty laissez faire because even though the police were there I just thought I'd be there for a night. They said: "You might only be there for a night." So I thought I was just going for a night. I didn't realise it would end up being three weeks, so I felt pretty calm about it.*

On the other hand, Susan recognised her own passivity and resignation to the whole event as the worst. Despite the accepted paternalistic role of the mental health system, she felt alone and objectified.

*The resignation. Knowing I'm going back to the hospital. I just walked up to the police and was taken without resistance or question. And the paddy wagon. You get bounced around a lot and you're left alone to think [tearful]. The police are in their own little world in the sense that they've done their job and that's it.*

### **Can the scheduling event be improved?**

All three groups were asked their opinion about how to improve the process of scheduling. Some clinicians and people who were scheduled described schedules as "just part of the bigger picture" of the overall effects of living and/or working with mental illness. Others described it as a separate and compounding event that added to the burden of mental illness.

#### Discharge planning

Improvement is described as a process that works in hindsight, as a preventative measure to be carefully explored upon admission, in the planning for discharge. McGorry (1992, pp. 11-12) stated that:

*While the admission experience is often traumatic, discharge involves a major transition for many patients who have been able to achieve a definite but still fragile state of recovery in a protected milieu. Preparing for and negotiating the anxiety-laden process of discharge consumes a lot of staff and patient energy, particularly where there is poor continuity of care between hospital and community.*

Overall, clinicians and those who were scheduled believed that prior to the person coming to the attention of the health or police services a schedule could not be planned any better. Surprisingly, no relatives raised the issue of discharge despite their poor record of involvement in discharge planning and their stated need for education and information about all relevant matters. It makes sense that "the provision of an aftercare plan that includes the family's recommendations, capabilities and resources ... needs to be considered if the discharge plan is to be viable" (McElroy, 1987, p. 227). Doug stated:

*I think scheduling is the end result. That if you want to look at improvement you'd have to look further back and possibly you'd have to start with discharge from hospital.*

Better resources would allow clinicians to provide better follow-up and acute community care to prevent relapse. Louise said:

*Most people who are scheduled have had previous admissions, certainly a significant percentage, so I think it needs better follow-up, better community facilities, so that the person doesn't become so unwell that they need scheduling. When you are actually at that stage, when they are getting unwell, I don't see what else could be done.*

Steve was quite distressed about his discharge and stated that this process should be improved. He was sent home with no immediate follow-up and as a result had become suicidal.

*The discharge was disgraceful. It was a case of seeing someone and that was it! "Okay, you can go home." I didn't fill out any papers or see any papers. I knew I had a Schedule II but I didn't think it had passed. I didn't sign anything when I went in and then I didn't sign anything when I came out! There was just a case of "Okay, you can go now," and that was it. If mum hadn't been there to drive me, I would just have to get in a taxi and come home. If John had come along and said: "Okay, we are going to take you back to the community health centre. Hook you up with a casemanager. Make an appointment for you to see the casemanager. Get you involved in the rehabilitation team," that would have been a lot better, you know! And given me an "exit pack." You just get nothing, you know! That's it: "You're free to go now. We've held you here against your will for the last three weeks but now you can go, see you later!"*

Mike also believed that the process of scheduling and involuntary admission could be improved by ensuring follow-up and early intervention after discharge. Otherwise, like Louise and Tom, he believed that once in an acute phase of the illness little can be done to prevent a schedule re-occurring.

*If you are acutely unwell you can't prevent going to hospital. Part of my experience was that I was unwell, I was in Accident & Emergency, things happened and I was just put back into the community. Nobody followed me up so I went another six months or so and then I had an acute episode. That's when my father got some attention. That shouldn't have happened. [We need to] make sure that those sorts of things don't happen. People slip through the cracks! My family knew something was wrong but I guess they didn't know who to call. My mum spoke to a GP but nothing happened. So I got acutely ill and picked up by the police.*

### Family involvement

The importance of family involvement in the care of people living with severe mental illness has been documented (Feldman et al., 1977; Hatfield & Lefley, 1987; Kuipers & Bebbington, 1990; Lefley & Wasow, 1994; Lefley, 1996). Families are often described as support for the person through the hospitalisation and through encouraging and monitoring their adherence to medication regimens, assisting in identifying early warning signs, and providing much needed support upon discharge. Surveys to determine what families want from mental health professionals have come to similar conclusions regarding the need for respite, support, and information (e.g., Riesser & Schorske, 1994).

Angela was very aware of the impact mental illness has not only on the person who experiences it but also on significant others. She included flatmates in the "significant other" group requiring support and explanations and she believed that keeping significant others informed and involved before, after, and during a schedule is essential. In a study of assertive community treatment for schizophrenia, McFarlane, Dushay and Stastny (1997) compared people whose families were involved either intensively or episodically in their care and found that "even modest levels of family involvement improve the patient and family outcomes."

Louise believed that families were not involved in the care of the person affected by mental illness due to the effects of stigma and the burden of care. She saw her role as primarily working with the person experiencing mental illness, bringing the family in only at times when additional monitoring and control were necessary. This statement somehow contradicts her previous concerns about working as an agent of social control (p. 150) and her preference for a partnership model.

*Families don't know what is going on because of the stigma of mental illness. Families don't say anything, don't talk to anybody, and often it may be too late when somebody is scheduled. Certainly I would think that if anyone was working with someone on an ongoing basis then part of their role would be to educate both family and the client about the Mental Health Act, about their*

*responsibilities. I'm a mental health worker. I'm here to support [the client] but, if at some point [the client is] unable to guarantee their safety or the safety of the community, or other people in the community start fearing that they might assault them, then it's my responsibility to make sure that doesn't happen.*

The importance of providing information to relatives cannot be overestimated. Hatfield (1987b, p. 77), in discussing the process of coping with and adapting to severe mental illness, stressed the importance of knowledge and information that "is provided in a straightforward and unconfused manner." Relatives need "practical information and know-how" rather than help with psychological problems (Hatfield, 1987b, p. 63).

Furlong and Leggatt (1996, p. 621) reviewed the international literature and policies on confidentiality and concluded that "making confidentiality an absolute principle ... will act against the development of partnership between relatives and service providers and will in many circumstances directly disadvantage or even endanger the patient." To balance confidentiality with the family's need to know and be involved in the treatment and care plans some clinicians suggested the use of written agreements made jointly when the person is well.

The "Ulysses contract" (Rosenson & Kasten, 1991) has been described in the literature as a way of maintaining the autonomy of people who experience mental illness by arranging for consent to interventions prior to becoming acutely psychotic. Rosenson and Kasten (1991, p. 1) believe that "the most authentic expression of autonomy may be the decision by a patient whose psychiatric symptoms are in remission to plan for treatment in the event of a crisis." However, this contract has been rejected by other consumers who advocate John Stuart Mill's philosophy that "individuals do not have the right to relinquish their liberties" (Lefley, 1996, p. 202).

Sutherby et al. (1999) conducted a study on developing "crisis cards" in a community service based in the Camberwell sector of the Maudsley Hospital in South London. All patients resident in that sector who met specific criteria (n. 106) were offered a crisis card or joint crisis plan. The purpose of this card was to "record a set of statements made by a patient independently of any agreement with the treatment provider about what should happen in a crisis" (Sutherby et al., 1999, p. 2, [cited from html. version]). In total, 40 users completed a joint crisis plan, with a 30% reduction of admissions the year following the development of the card. Concerns about the possible use of coercion in developing these plans were allayed by the collaborative partnerships that developed and the enhanced sense of autonomy, mastery, and control over the illness experienced by the participants.

The right to privacy and confidentiality is an argument that arises when considering the extent of involvement of families and significant others in the care and treatment of people experiencing mental illness. As discussed earlier, each case is unique and clinicians need to keep an open mind and exercise good judgement in making decisions regarding family involvement while “thinking of the family as part of the treatment and rehabilitation team” (Furlong & Leggatt, 1996, p. 621). Additionally, to be able to work effectively with family members information needs to be shared. As Hatfield (1994, p. 67) stated: “If rules of confidentiality get in the way of families being properly informed, families may have an untenable situation and may be encouraged to consider having the person move to other quarters.” Sandra had this to say:

*The family's involvement depends on the level of contact with the client, how involved they are in their lives, how much they are wanting involvement. We need to use our own judgement because of families who are interfering and with bugging boundaries. A sister constantly rang up to say that her relative, who has schizophrenia, was getting married and she didn't approve of that. She wanted staff to intervene. Staff need to listen but keep boundaries.*

Terry brought to my attention that psychiatric institutions are viewed by society, of which relatives are an integral part, as frightening places where all sorts of madness and violence are witnessed (i.e., Maureen, Sandra, and Alex). Mental health professionals are familiar with inpatient environments, and every day they go home to the safety of their families. For relatives, having a loved one locked up in an inpatient unit is a frightening experience, to which they, as those who are hospitalised (i.e., Penny, Alex and Susan), might get desensitised as it becomes more familiar.

*Involving the family initially and making them feel it's all right! Because we are frightened at the time! It's Terrible when you see people who are worse than your child. And even though he's twenty-two, which I suppose in the law's eyes he's not a child, you think: "What if he gets hurt there?" That was my major concern, if he got hurt by someone.*

Family involvement in treatment, as with most issues relating to people affected by mental illness, needs considering individually. Overall, the role of relatives is described as essential for a good outcome and experience of those involved. Through being involved in the assessment process, decision-making, treatment planning, and monitoring of symptoms of their loved one, relatives increase their understanding of mental illness, its symptoms and available treatment options. They develop the ability to show empathy and support the needs

of the person, and are able to identify early warning signs and assist at an early stage, thus preventing deterioration. For Sandra, keeping Tom well was of primary importance.

*[Family involvement leads to] understanding, being able to help him in the future if he's unwell again. And Tom spent a lot of time hoping he wouldn't get another episode but there's nothing to say he won't. I guess understanding, trying to understand as best I can what he was going through and what support he needed when he came home. Because I had my own little theory that said: "Well, all of those people go back[into hospital], they are on first name terms [with staff] when the police bring them in, and that's because they have been in there so many times!" And I think a lot of that is due to the fact that many of those people have got no one to support them when they go home. No one to encourage them to take medication and encourage them to get on with their life. And I really believe that's why so many of them fall backwards, because there isn't enough support for them when they get out.*

Lefley (1996, pp. 77-78) briefly discussed the role of mental health systems as a stress for families. Ambiguous communication, failure to provide training or involvement in treatment, increased financial drain, difficulty finding alternatives to hospitalisation, and stress in dealing with the legal and criminal justice systems were reported. Not being informed and involved in the care of their loved one was described as distressing. Relatives felt that they had a better knowledge of the person who had been scheduled than the mental health staff who had either only just met them or knew them only during hospitalisation, when they were at their worst. Unless family members were informed of all the decisions being made, they were unable to advocate and plead for what they saw as the person's best interest.

Some comments were suggestive that families could take the role of co-casemanagers. There were instances when people affected by mental illness refused to see a member of the mental health service, although both clinicians and family had identified the need to do so. By working closely in partnership with the family (see Kuipers & Bebbington, 1990) adherence to medication regimens, comprehensive knowledge of the home situation, and monitoring of mental state would be made easier.

Kerri's son, Brian, had not had the opportunity to develop a relationship with a primary clinician. For a long time, the service this family received was minimal, and Kerri carried the burden of care. She strongly believed in case-management "by proxy," whereby mental health clinicians would support the family members in caring for the unwell relative. However, as Brian was unwilling (or unable) to develop a rapport with a clinician, no follow-up was offered. The provision of clinical care through the primary caregiver was identified as a way of improving the outcome of the event. Identifying family needs and strengths needs to be

given more attention, as “not only must family members learn how to cope with their disabled family member, they must also learn how to cope with mental health professionals” (Spaniol, Jung, Zipple & Fitzgerald, 1987, p. 169). Families are important resources in the recovery process of the person who experiences mental illness, and support from mental health professionals should be available on an ongoing basis, as well as at times of crisis. Kerri stated:

*In this case it is the mental health service that needs more involving. A casemanager is needed even when the primary client refuses casemanagement. To assess the situation, assist and advise the family on the options and best ways of dealing with certain difficult situations. The unwell relatives can be managed via the parent. And through supporting the parents the client receives better care. In my case, I have had ongoing difficulties with casemanagers, as there has been no follow-up and no contact. Adequate ongoing counselling also should be provided to the families of people with a serious mental illness as they have great mental health problems in dealing with all the related issues: loss, grief, acceptance, guilt, the sense of betrayal! The families are carrying the burden of looking after a loved one who does not make rational and responsible decisions. And they continue to behave as children within the family, so we need to be involved. We know better what their needs are.*

Rosa agreed that “it is good to talk about the feelings and what happened” but, because of her previous experiences, she wanted less family involvement.

*No! The family less. They say you're sick! One word wrong! And the doctor is supposed to believe more the patient and listen to background of what happens.*

Tom believed that families should be more involved and able to understand the person separately from the illness. Lefley (1987, p. 111) discussed this idea – the perception that the person is the illness. She states that “despite apparent apathy and self-absorption, mentally ill persons are typically extremely sensitive to the environment and to the perceptions of others. One of the most devastating sequelae is the reaction to one’s own deviance.” Tom encapsulated these feelings in his answers throughout the interview. He also believed that the genetics of the illness cause particular personality types that create intolerance and lack of understanding.

*I think families need to be more understanding, because they just don't! It's like you can give them all the textbooks in the world they still are not going to understand! They're not. It's like today. I'm watching TV. They are talking about how people who have got bipolar disorder are naturally sarcastic. So for twenty-one years I've been in trouble because I've had a big mouth! Because I always shouted my mouth off to people because there was always*



*something wrong! And I always had to put it down first. Because that's what the disease defines me to be, sarcastic, a little asshole. That's me. I was defined by this disease!*

Teresa was cautious about the need for confidentiality when involving the family. Her concerns, however, were limited to personal information that her brother would not have needed to know, such as the personal details of her life. This might support an argument for conditional confidentiality, such as sharing general information that can assist those involved, leaving out sensitive personal details. Paul also believed it was a good idea to involve the family if they were available, and acknowledged the impact of mental illness on family relationships and the alienation that often follows.

*If the family is around! That's a big if because quite often people with mental illness manage to drive away their family. Yes and no. Depends on the individual case I couldn't say this or that. [Interviewer: depends on the relationship?] Yeah! You see it's the biggest insult you can do to someone, is to claim them mentally ill and to take them away. Just bear in mind that is the most crucial thing.*

#### Discussion and debriefing

Considering the traumatic nature of this event, individually tailored debriefing sessions ranging from formal debriefing to defusing were suggested as possible strategies to improve outcomes. Use of independent debriefers was mentioned, as well as the need to tailor sessions to individual needs and situations. Creamer (1994, p. 47) said that "crises should always be managed actively and there is no substitute for good preparation." However, in mental health there is still among clinicians an ethos (often referred to as a "culture") of toughness and having to cope with challenging situations. Clinicians saw debriefing as more useful for those who were scheduled and family members than for themselves.

Two scenarios were described to support both the "for" and "against" positions. In the first one, Dr. Penford gives an example of where debriefing did not happen but could have been useful. In the second, Angela describes informal debriefing held some time after an incident as a response to an identified need. Together, the scenarios suggest that debriefing may be useful and could be an important part of the post-schedule therapeutic process, but that individual consideration must be given as to whether it is done and how.

1. *If formal debriefing is necessary that should happen in some cases where there has been a particularly traumatic event for whatever reason. I can think of a young girl who was scheduled when she was only about sixteen and that happened where a number of teenagers were involved. They could see it*

*was very bad. The police taking her away in the paddy wagon. She was really embarrassed about that and the parents felt that it was very appropriate that the action had been taken because she was very much over the top at that point in time. I don't think she was acutely unwell. I think that she was very disturbed at the time and the police had disclosed she was quite aggressive too. And in situations like that, it's appropriate for her to get some counselling, maybe a couple of sessions afterwards for her to be able to describe how she felt at the time and how it can be avoided in the future.*

2 *I did that with one of my clients actually, after she was admitted. This was an older woman and she was quite unwell. It was very helpful just to review the whole scheduling procedure. It was, I think, just a week after she was admitted to hospital. I just went and sat and talked to her about the whole process and that. She'd actually started to respond to some medication at that stage. She found it helpful just to talk about it. We just talked about how the experience was, what was it like with the police officers coming and getting her. Were they okay to her? I think we neglect [relatives and other people] and we shouldn't. Because afterwards, months later, when they tell you: "Oh when that happened it was awful," it's just so far away and [we] have to go over this when you could have allocated an hour and just talked about it [then] and asked them how it went.*

Among relatives, disappointment that the quality of the service provided was below standard, as fluently described by Pedro, was evident. When working closely and intimately with human beings the service ought to be always of the highest quality. Pedro felt this would make the need for debriefing or discussion redundant because people would have had all the explanations, information, and support they needed as the events unfolded.

*I should not have to notice that something, somebody has done something wrong! It's as simple as that. Shouldn't be left up to the families, or to anybody else, to see that the way the police [involvement had] been handled is beyond mishandling basically! Or very unprofessional if that's the word you want to use. What I mean is that the people who were dealing with my problem were very careless, basically! That's what I am saying. In this case, the way people behave affects the job. I wouldn't call it a "job" because I don't like that as a "job." It shouldn't be a "job" to begin with! [Interviewer: Because it involves human beings?] Definitely!*

Discussing the event afterwards, rather than having a more formal debriefing, was identified as a good strategy. Although some relatives identified schedules as events beyond anyone's control requiring no further discussion, others acknowledged this need by saying: "The process of being scheduled can be improved by acknowledging that it is a bad but necessary experience. Patients are never spoken to about it, even when they are well enough!" Some relatives described having the opportunity to discuss the event as "an indulgence," a term that underlies the difficulties encountered in requesting or accepting support. Betty stated:

“Probably I don’t indulge in that enough. Like any traumatic experience, I think that you probably should talk about it. I don’t do it myself but I think we should.” For some others, it is just a matter of wanting to forget a very traumatic experience: “If it’s a bad situation, you maybe just want to forget about it.”

As Pedro hoped, relatives that had a positive experience felt they did not require any further discussion. When clinicians approached the event with empathy, willingness to help, and genuine interest, relatives’ questions were answered satisfactorily and anxieties were contained as they arose.

*We didn’t discuss [it afterwards]. It might be [useful] for some people, I guess. Because I asked a lot of questions some of the information was forthcoming anyway! And that led me to ask further questions if I didn’t understand. I don’t know by what means all of those people get in [hospital] but clearly no one goes to see them after they are there! Certainly they volunteered information too to start with. And no one seemed to be too busy to answer my questions. I never felt like I was being a nuisance really! I was always made to feel that my questions were welcomed and the answers were forthcoming quite readily. I don’t know that any more could have been done for him.*

Some relatives suggested that discussing the event could be used as an educational tool. Involving the person who was scheduled was viewed as a way to increase her or his understanding of the illness and how it affected their behaviour, their environment, and their social relationships. These discussions would lead to developing responsibility for their own care.

*I know the first time the doctor explained to Tony: "Do you understand we will call in the magistrate if you keep going on like this?" But at the same time he’s saying: "This is his first psychosis, we are trying to go really easy on him." But they were worried and I think they wanted to [take him before the magistrate] last time. It was only when I went to a few of those lectures<sup>20</sup> [at the hospital] that I thought: "Maybe that’s not a good thing now." But I understand the other side of it! What they were saying about that is: "If they don’t get help at the right time they can become forensic because they end up in the jail system." Which has happened to people. That’s why they need to understand it! That someone is going to stop them in the end! It’s either going to be the hospital or the Courts. They need to sit down when they are well. And when they leave hospital they are well enough to [tell them that] all these things will happen. And that’s when they need regular contact with people like Dylan and social workers! Anything! Just to say: "We can see he’s slipping back and this could happen again." And they kept reminding Tony that: "We can take you against your will."*

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<sup>20</sup> Psycho-education programs for families and friends of people affected by mental illness.

Tom did not think that the scheduling event could be improved in any way. However, he believed that discussions would be useful to lead people who experienced mental illness to an understanding of what had gone wrong and how to “fix it,” like with car maintenance.

*Well that's the thing. It's like anything. It's got to be fixed, right? And it's another human being. You've got to make them understand why they are fixing it for a start, how they are fixing it, how long it would take to fix it, maintenance of it so that it never comes back, and so forth!*

Like some clinicians and relatives, he did not see that the schedule itself could be avoided at any stage. He believed that the illness would take its course, no matter what, and would do so differently for different people. If someone had the kind of illness that requires frequent hospitalisations, that would happen, no matter what, unless the person her or himself took full responsibility for its management. Tom doubted that most people would have that degree of willpower, or willingness to conform.

*That's not doable because it's like, just to give an example, just take five people. We'll take two people from group [EPOCH group], two people from hospital, and me. There's five of us and we are all different. We've all got different conditions. But whether we are scheduled or not again is only up to us really! Ultimately! Because we've got to put on this smiley face and pretend [his tone of voice rising] and flat out lie and pretend that we are completely sane or we've got to keep taking drugs and keep doing the things that they convince us are the right things to do! The right drugs, da-da-da so forth and stay out of it! Funnily enough, some people just don't have the ability to stay on a drug or to follow a certain change in their life! I mean sure we've been fucked over and we've probably eaten crappy tasting tablets like twice a day for the rest of our lives! But you've got to do it! Some people don't and go back. One of the guys, I'm still a pretty good friend of his, had been in three times and some people, they go more than three times. Some people go less, some people stay longer and you go in, not as many times but stay in longer every time, whatever. Different circumstances for different people. Different strokes for different folks, whatever. [His voice getting lower, more despondent]*

That the psychiatric system has remained mostly unchanged in its practices is evident, despite the changes in focus, philosophy, and policies. In reply to the suggestion of debriefing, Teresa stated:

*Yeah, I mean that's an option too. I mean to be honest with you I don't think we'll ever change the system. I don't think much of it as it was and I don't think I want to be part of it again! But I certainly think that, for other people, it is pretty scary! And if you are in such a bad way anyway, and they will say I was in a very drastic state of health, it's more stressful again to be pulled away*

*and put into a paddy wagon that is bloody uncomfortable. I mean thrown around! It's demoralising!*

Paul believed that discussing the schedule would be useful before the situation gets to the point where it is going to happen. Providing information in an attempt to avoid the magistrate's hearing is important, again evidencing a preference for persuasion rather than coercion into treatment.

### Clinical knowledge and skills

The need to respond to changes in practice and policy in mental health work has been identified throughout the literature discussed in this study. In order to do this effectively, clinicians and managers alike have to maintain their knowledge and skills up-to-date and develop services and practices that incorporate working fully in partnership.

Bernheim (1987, pp. 254-255) identified a number of important elements that need incorporating into professional training. Sensitisation to the plight, burden, and tasks of the family; development of a sound, evidence-based body of knowledge regarding the aetiology of mental illness; training in didactic skills; training in related areas such as problem-solving and stress management; and the provision of supervised practicum experiences are mentioned.

The data collected here show that there is an awareness of training needs among both clinicians and consumers. However, as evidenced in previous studies (e.g., McElroy, 1987), the identification of these needs do not match between the two groups. In addition to the need for greater availability of resources, the need for the development of theoretically based skills required for the effective provision of acute community care was mentioned. This includes risk assessments, negotiation, developing systems of safety and co-ordinating care plans, and provision of informal debriefing, support and education to the person scheduled and their families.

Louise had worked in other health services where the practices of acute community care strongly supported a focus on treatment in the least restrictive environment. She saw lack of theoretical knowledge and management support systems as accounting for the practices in her current area health service.

*A proper acute care service so people can be offered an alternative to hospitalisation would be a start. A system where the staff understand the support that's required, the negotiating that's required with clients to be able to support them in the community. Issues like medication. A system of clients guaranteeing their own safety and guaranteeing that they are not going to*

*harm other people. To develop acute short-term management plans in the community. The ability to negotiate with families and look at all the factors that are needed if people are to be supported in the community. Negotiating with other agencies that are also able to offer support.*

She was under considerable pressure, however, to perform within a partnership program, and found it hard to practice efficiently with the current pressures and expectations. As is often the case in under-resourced services, the families were left out of the service loop.

*I think everybody tries to involve families as much as possible, but it is really difficult. To be educating clients, supporting clients, educating families, supporting clients working with families, protecting confidentiality, not creating a situation where the client feels alienated, feels like there is no confidentiality, liaising with other agencies, etc., etc., etc. I mean how do you do it all in a week with a full caseload?*

Doug acknowledged the importance of providing support to families who care for people experiencing mental illness. Again, resources were considered a problem, including the effect of staff turnover on continuity of care.

*While schizophrenia is supposed to be a biological disorder, there's absolutely no doubt that the people who do well have support from their family and their community, and the people I think who do badly are the people who are very isolated and haven't that support. The problem is though that would take a lot of time and effort. It's often your colleagues! It can be difficult with people always leaving, coming and going. To involve the client is obviously important. I don't think it happens to a certain extent. To involve the family depends on circumstances, depends on the client, their relationship. In some cases, I think that it works very well and it does happen but, I guess in the majority of cases, I wouldn't think about it.*

Relatives suggested a number of strategies to improve the outcome of schedules. High on their agenda, as seen throughout the study, was the commitment of mental health clinicians to the work they did. It was important to employ and train mental health professionals with a high level of interpersonal skills that enabled them to work effectively with other human beings and ensure high quality care. McElroy (1987), in her chapter on the different perspectives of families and professionals about the needs and concerns of caring for people experiencing mental illness, stressed the importance of a therapeutic alliance between the two groups. She stated that "professionals do not always view families as collaborators dealing with the common goals of caring for the patient and reducing distressing aspects of the illness among all members through dissemination of information or involvement in treatment" (McElroy, 1987, pp. 237-8).

Pedro had a poor experience of mental health professionals and felt very strongly about those who work with special-needs groups:

*I think [we need] honesty in the people who work in this area! Let's get rid of the people who are not committed to it! To me caring for other people is very important! It's not just a nine to five job! They need to look at the individual! I'm not talking about working long hours! What I am talking about is that the rewards should be there but also the quality of care should be the best. To me there's a special person to do that! As simple as that! I don't think everybody in [the mental health service] is equipped to do that. [Interviewer: It requires special skills to look after human beings? Different from looking after things?] Yes, definitely! Definitely!*

On the other hand, Sandra had a very good experience with mental health professionals and was quite happy with the schedule's outcome, and it was good for precisely the reason raised by Pedro (p. 162).

*I don't know [what needs improving]. Tom and I talked about that the other night. I don't know! And I don't know whether that's because, as I said, I had a good experience, in inverted commas. Because I happened to be there at a time when people who clearly care about what they are doing, are very committed to what they do, happened to be on duty. I didn't find all the staff in the hospital as supportive, I can tell you! I'm not sure how the process can be improved.*

For those who were scheduled, the issues were slightly different. Part of Paul's distress was his awareness of how others viewed his strong beliefs as delusions, symptoms of mental illness. Like Paul, Champ (1998) noted that this feeling shakes the individual's trust in his or her own ability to interpret the world. Paul felt that schedules can be improved by listening to the person experiencing the psychotic symptoms and attempting to reality base them, without invalidating them.

*Okay! Listen to people's delusions. And have somebody say: "Look it is delusional it is not true!" Having the shrink or the nurse say, preferably the shrink say: "Look, I'm terribly sorry but it's not true!" No one actually said it at the time! It's not everything you think, it's not true, it's just that particular thought is not true! That particular thought is not true and to fix that we would like to give you some medicine that would make those thoughts disappear. As simple as that! It's like the explaining about swimming. That's all you got to do!*

Alfred on the other hand was concerned not so much about why the schedule had happened, but the way it had. The event shook his sense of personal safety: "I was too sick but I have a problem about *how* they did it. It was not necessary" (emphasis in the answer).

Wasow (1994b, pp. 277-281), in her chapter on training clinicians to work with families, describes compassion, respect and knowledge as the most important components of effective work. She further breaks down these components into generic skills that all clinicians should possess, including knowledge, attitudes, clinical skills, and advocacy skills. Obstacles to training identified are still current today: current educational curricula that are not comprehensive and up-to-date; lack of interest on the part of students and clinicians in working with this population; and the claim that lack of resources, funding and time limit clinicians and academics to develop expertise in this area. Working with families means working with all the individuals within that system. To do that, clinicians need to develop a framework and perspective that considers all clinical work as a partnership, at all times.

### Partnership

Working in partnership with consumers, both those experiencing mental illness and their families, has been a focus of mental health services policy in the past five years in Australia (*National Standards for Mental Health Services*, 1996; *Caring for Mental Health*, 1998; *Second National Mental Plan*, 1998; *Mental Health Promotion and Prevention National Action Plan*, 1999). Nevertheless, involvement of the person who has experienced mental illness in the negotiations and decision-making process was the least mentioned strategy in this study.

There are differences of opinion as to whether information and negotiation should take place between clinicians and those assessed for hospitalisation. Angela felt strongly that decisions such as whether to admit someone need to be discussed with the person, and they need to be aware of all the options, including that they can be admitted against their wishes.

*I think it's really important before making that decision that it's discussed with the client. Even if they are unwell, they are provided with those options. That they can still be a voluntary patient, but being quite clear where you do meet the criteria and that you can be involuntarily admitted. But give the client some time to discuss that.*

Doug realised that there may have been different options to ensure Margaret's well-being, and that previous solutions needed to be re-assessed. Apportioning blame to Margaret's parents did not present new ways of working to prevent relapse in the future. As stated earlier, Doug believed that poor resources lead to lack of time to provide quality service.

*It probably could have been a good strategy, rather than to have spoken to the parents on the phone and emphasised that if the daughter became unwell to give me a ring, to actually have had a family meeting. And to have the parents*



*and the daughter [together] and to really talk things out. That probably would have been very effective. The problem with that though is it's much more involved, much more time consuming, in most of the cases it's a lot more effort, and I guess that's just that simple.*

The need for supportive involvement of mental health services was seen as the greatest need, particularly for families with less satisfactory experiences. Support and counselling, participation in family psycho-education programs, and sharing the burden of care were important. Parents identified the person experiencing mental illness as their "child" despite their adult age and disclosed that they would always have deep concerns for their well-being.

Eileen's son received little follow-up during the first years of his illness. Grant's behaviour was described as violent, and his determination to have nothing to do with the mental health system led mental health clinicians to not provide active follow-up until he seriously endangered his life, causing him to become physically disabled. Eileen was distressed and angered by this, and relationships with clinicians had been tense ever since.

*I feel left out by the mental health service. They will not give me, or Grant's father, any information about Grant's condition or treatment. The issue of confidentiality, of Grant being an adult living on his own, the need to maintain a therapeutic relationship with his psychiatrist, all keep me out of the picture and of a role as carer that I want so much. It's like once one is an adult they don't belong to anyone any more. What has happened to the family as part of the treatment of schizophrenia? I feel cut off and this is very painful for me. We need to get these people off their bottoms and get them doing what they are supposed to do! Information must be available to give people access to their rights and knowledge about where to go for help. You must give people a feeling that they are worthwhile, for both patients and families, or the battle will never be won.*

Teresa felt that if there had been no other option but to be scheduled, she should have been given more information and convincing reasons as to why this had to happen and why treatment could not be provided at home.

*I think maybe a little bit more time should have been taken to say: "Teresa, you're in a bad way." Try and avoid the police issue at all times! Rather than the police, I think if you can get one of the cars from community health. And this means that you sit in the back and you lock the door, if you have central locking in case you're afraid they are gonna jump. I think that would be a nicer way to go. But I think it's very scary! It certainly was for me to be pulled by the throat, to be taken by police.*

The role of families in maintaining the person experiencing mental illness at home has been discussed. Collaborative work can help families keep the person experiencing mental illness at home.

*Yeah, that's great if they can, you know! But not everyone will! I am just myself on my own. I don't have family. But [if] you notice when the person is going down hill that is the time to get involved with the family. And maybe before it gets to the stage where something occurs like it occurred with me something maybe can be done. Something like outpatients or whatever, at various stages*

Mental health policy needs to prioritise “voluntariness” and support increased housing, employment and social supports. Rogers et al. (1993, p. 190) questioned whose interest is being served and whose opinions are being considered in the current trend of working in partnership. They suggest that mental health consumers and professionals need to work in partnership in persuading governments “that users’ needs are best framed broadly in personal and social rather than medical terms, and they will also have to convince the wider public that people with mental health problems have a right to ask for peaceful co-existence in society.”

Cahill (1996) saw an important consequence of the partnership principle as a narrowing of the gap between service provider and consumer, with consequent transfer of power and control. As we have seen, however, scheduling and involuntary admission are not areas of health care where consumer participation is sought. Participation means “getting involved or being allowed to become involved in a decision making process or the delivery of a service or the evaluation of a service, or even simply become one of a number of people consulted on an issue” (Brownlea, 1987, p. 605). We are still a long way from real participation in this area of mental health care.

### Support

Stigma often leads people who experience mental illness and their families to feel the impact of social isolation and lack of community supports (Kuipers & Bebbington, 1990; Lefley, 1994). The time of admission of a loved one, particularly when involuntary, is seen as a particularly important time for added support. To have someone, such as a nurse or other clinician, supporting relatives in hospital while waiting for their loved one to be settled in is important. The realisation that the focus of attention and care must be on the person experiencing mental illness does not decrease the reality of the emotional needs of relatives who feel guilty, frightened and, as Sandra stated, very alone:

*Somebody listening to me would have been great, but the nurses had to look after Tom and I had no problem with them doing that. In an ideal situation, someone there to sit and talk to me would have been all right because I had to wait a long time. I know they had to do what they had to do for him, and he was there because he was sick. They weren't worried about me but it felt like it was hours, and hours and hours. It felt like time just took forever to get him settled. I know they are very busy in hospital and unfortunately that is just the way it is. But you feel that once your child is in there it's always out of your hands. There's not a lot of time to actually sit down and say: "This is going to happen nicely." It's always: "This is happening! That's happening!"*

Steve thought that the schedule could be improved by providing him, and others in his situation, with support throughout the admission process and after discharge. Unlike Beverley's husband, John took Steve to hospital and left him there on his own. This was frightening for Steve, especially as he was forcefully sedated without been given information on treatment options and possible consequences of his refusal to consent. He felt he was denied the opportunity to fully consider his choices and the necessary information on which to base these choices, bringing into question the dialectics of informed consent (persuasion) versus coercion in psychiatry.

*Well, it would be nice to have support there when I went in. What happened was John took me to the hospital, the police and he left, and then I was waiting in a room to have a consultation with Dr. Finley. But after Dr. Finley left I was there for another forty minutes for the nurse to check me in. So I was kind of dropped off and that was it! I was left on my own. It would have been nice if John had stayed and explained what was going on. If he had given me my rights, [or] said: "This is what is going to happen, we want you to take [medication]" [pause]. They [the nurses] said: "Would you be willing to take medication?" And I said no! And then there wasn't an explanation [such as:] "Look you're gonna have to take medication, we want you to take medication!" So I was actually forcefully injected with medication because I wasn't prepared to take it! But it wasn't explained that could happen until later! And it would have been nice to have John there as someone who I'd seen that day. To have someone there to explain things to you.*

#### Availability of resources

The consequences of economic rationalism and shrinking resources have a serious impact on clinicians' ability (real and perceived) to provide high quality services that include both the person experiencing mental illness and their family. Kanter (1996) discussed the ways in which mental health clinicians are challenged today by the need to engage significant others in the care of people experiencing mental illness when time and resources are so scarce. Reduction of admissions and improved treatment outcomes are some of the known benefits of this "Tom Sawyer" approach" (Kanter, 1996, p. 799). According to the clinicians interviewed,

lack of resources affect such things as planning, monitoring, information gathering and giving, educational sessions with relatives and significant others including police officers, consultation with clients, relatives, and colleagues, and the measurement and evaluation of outcomes.

Provision of high quality care is difficult when clinicians are overloaded and need to manage time more efficiently within current resource constraints. Involvement of families in the treatment and discharge planning and discussions about behaviour management, communication, and access to services are seen as necessary but time consuming strategies. However, the possibility of effective use of time by providing family group-education and support as evidenced in the literature (Kuipers & Bebbington, 1990, p. 56) were not mentioned.

*As a casemanager it is really difficult to provide all that [information and support] to everyone, especially when you're feeling traumatised yourself and you have a full caseload. If somebody is being really sick for a while and you spend days putting time in to make sure they are in a safe place then you know that's often to the detriment of a whole lot of other clients. So you reconcile [those needs] and manage your time. I guess [we work] in a system where we don't necessarily have the resources to work with families as much as some of us would like to [it can all seem very difficult].*

Alex, after years of institutional care, thought he had no opinion about how to improve the schedule. However, he obviously preferred the community care option as he disclosed his fears by muttering in a monosyllabic tone: "Getting used to the old patients in there. The other patients get nervous in there." He admitted, despite his large size and history of potential violence, to be frightened when in the inpatient unit: "That they are going to attack. I should have stayed here at home."

Alfred had nothing to say.

A number of strategies to improve scheduling were brought forth by clinicians, relatives and people who were scheduled. These are: Discharge planning; Family involvement; Discussion and debriefing; Clinical knowledge and skills; Partnership; Support; and Availability of resources. None seem outrageous or insurmountable. All aspects of care have potential applicability in everyday practice that is of high quality and are customer focused. However, the issues raised here and throughout the study have serious implications for future practice in the care of people who experience acute mental illness or disorder and their relatives. These implications are discussed in the next and final chapter.

## Chapter IX – Conclusion

*It is sad to note that major obstacles in the mental illness movement are conflicts and disagreements between groups.... Because of these disagreements, the emphasis should be on making the effort to stand in the shoes of the other. If we cannot agree on some big issues, let's at least aim for a respectful understanding that will enable us to stay focused on our common agenda – the best possible care for persons with severe mental illness.*

Wasow, M. (1994, p. 282)

In the preceding chapters, several important aspects of the human experience of the compulsory removal and transportation of a person deemed to be mentally ill or disordered to a psychiatric facility for further assessment and possible involuntary admission were explored. The mental health service's practices in relations to such experience have been highlighted, as were some of the issues that seem to provide a focus for understanding this event better. This attempt to "stand in the shoes of the other" provides a base for developing a better understanding of this very human event and, through this understanding, develop and refine approaches that may allow us to better address the needs of all involved.

The specific objectives of this study were to describe the experience of a scheduling event for clinicians involved in schedules, relatives of people who are scheduled, and the people who are scheduled themselves. Information was sought as to whether information about rights, the *NSW Mental Health Act 1990* and the reasons for involuntary admission were given at the time. Areas of good practice and areas for improvement were explored and important information has been gathered.

The study's methodology evolved naturally and easily to best suit the sensitive information collected. In doing so, it demonstrates that the assumptions about consumers' willingness to participate in research on a sensitive topic and the possible effects of such participation on their psychological well-being and relationships were unfounded. The people with mental illness and the family members who became involved welcomed the opportunity to talk about these significant events in their lives. Their narratives bear witness to the way schedules are enacted and to the memory of stressful events as recounted by those who experience them. If we choose to doubt the memories of people who are scheduled and their significant others we need to doubt our own stories and experiences as clinicians directly involved in these events. And, yet, all this "rings true" for me and for those with whom I have shared the analyses over the course of the research. All these stories are my experience: seen, heard and lived through many years of acute mental health work in the community.

Several important factors and concepts are identified of which power is the predominant one. Clinicians use their power to ensure minimum risk and maximum safety for all, at times without considering the consequence of these actions on the dignity and self-respect of others. Relatives experience the event as betrayal or relinquishment of responsibility and confront the dichotomy of power and powerlessness: power to initiate the event and powerlessness to provide help without involving external agencies. In the struggle with, or adjustment to, mental illness the focus of mental health services is the person who experiences the mental illness. People who are scheduled are aware of their own powerlessness vis-à-vis mental illness, their relatives and significant others, and the mental health service. The role of police officers collaborating with mental health services and the use of paddy wagons is resented, not because assistance is provided, but because of how it is done — through deception, coercion and without negotiation. This engenders feelings of humiliation, fear and betrayal, and causes disturbed behaviours that reinforce the belief that people experiencing psychotic symptoms are unpredictable and incompetent to make decisions about their own care. Illness and crime connect in this context, affecting relationships with mental health services and future treatment adherence.

The people involved in this study, health professionals, people who had been scheduled and families alike, said that important information is often not provided. Their answers demonstrate the need for community education — about mental illness and scheduling, family involvement, and debriefing. As they talked about these topics they identified, and helped me to identify, not only areas that need improvement, but also those that demonstrate “best practice.” It is clear that information giving at the time of a schedule is based on the values, practising style, experience and relationships of individual clinicians. The decision about what information to provide, however, must depend on a skilled assessment of the level of coercion needed, not on assumptions about competence and insight. Competence is individual and situational.

Mental health professionals are concerned with validation of their knowledge, recognition of their skills, and avoidance of legal and professional liability. The findings of this study suggest this occurs when people practice within services that advocate care provision in the least restrictive environment, but lack the necessary resources to do so. Emphasis is on following documented policies and procedures rather than on addressing and adapting to the needs of the people involved. At times, there is an almost formulaic approach to providing services, creating a large chasm between local area health strategic plans and the reality of

everyday clinical practice. Clearly, lack of resources helps explain this approach, but other factors are also important.

The informants connected to the EPOCH team described their experiences as more empowering, expressed a greater degree of understanding of the illness and its consequences, and valued their own responsibility and involvement in the recovery process. Family members' worked in partnership and were acknowledged by both the clinicians and the people who experienced psychosis as valued members of the treatment team. Their involvement as primary carers and partners in treatment and recovery must be acknowledged and supported in mainstream clinical practice.

A number of strategies to improve the way schedules impact on those involved have been suggested by the participants. Education and information about mental health legislation and the powers of the mental health system must target specific populations including high school children, parents and teachers. Clear, sensitive and honest information that includes *how* and *what* might happen enhances the understanding of the intervention and its possible outcomes, i.e., treatment and recovery.

There is an identified need for university curricula to include mental health/psychiatric specialisation. In NSW *general* health clinicians practice in this specialised field, graduating with little understanding of what it means to live with a severe mental illness or what is required to work effectively with people who experience it and their families. Their knowledge is obtained "in the field," as it happens, with virtually no clinical or educational support.

Mechanisms need to be in place to examine the sensitive practice of scheduling before and/or after the event from both clinical and ethical perspectives. Practices must not be based on the personal beliefs, values or inclinations of the health professional, but rather on what is good practice as shown by empirical research. Evidence-based practice that considers both the bio-medical and the psycho-social-cultural aspects of a person must be incorporated in the training, professional development, and appraisal of all clinicians working in mental health.

Teaching about interpersonal skills and the therapeutic use of self needs to be re-introduced and interpersonal practices observed and evaluated throughout a clinician's career. The current reductionist medical model and the structure of medical systems could be seen as responsible for the practices described and the impersonal distancing between clinicians and consumers. The clinicians' concern with their own performance, skill validation and sense of

belonging and their focus on doing what they see as the “right” way, the way they “have always done it,” clashes with the need to be present as therapeutic agents. Clinicians’ level of knowledge and skill in interpersonal practice and the therapeutic-use-of-self needs identifying and enhancing to ensure that people who use mental health services feel validated.

Discharge planning and integrated continuity of care are areas needing attention to ensure that clinical practices enhance the recognition of individual needs and the establishment of recovery goals that are based on sound knowledge of available resources and realistic expectations. Unrealistic expectations about the way consumers function and what they can achieve are based on the clinicians’ fear of failure as treatment providers. This leads to feelings of betrayal – that the client or relative are not “taking responsibility” – or feelings of frustration that nothing can be done because of lack of insight, incompetence or resistance to treatment on the part of the client and, sometimes, the family.

The need for debriefing after the schedule is clarified with fluency and insight. There is a need for such a process in most, but not all, cases. The impersonal, bureaucratic formality of the scheduling event and the power maintained throughout by the mental health service providers justify the need for debriefing as a more informal, supportive, consumer-driven process. The development of trust relationships is vital to such a process.

People who were scheduled advocate for a review of the current process of scheduling. The most traumatic aspect identified is the fact that there is “no warning.” Persuasion and coercion, and the element of surprise rather than negotiation, contradict current belief and current practice in consumer collaboration. The NSW legislation states that service providers are not to use coercion (threat) to achieve a voluntary admission. This is interpreted by many as “explanation and information cannot be provided” as they are both, inherently, of a coercive nature – or can be interpreted as such. This makes the concept of informed consent in psychiatry null and void – an impossible proposition, even if it seems from the data and my experience that it could be used to raise awareness and insight (Fiorillo, 1999, March).

The experience of hospitalisation is both frightening and traumatic for those who are scheduled and their relatives, and there have been pleas to use it as a last resort. The resulting familiarity with the ward environment and the behaviours witnessed as inpatients add to the powerlessness of this already disadvantaged group. We owe it to future generations to strive for a mental health system that supports treatment in the least restrictive environment and has the necessary resources to provide it in the most humane and therapeutic way.



This study supports previous research on the effects of involuntary admission and treatment of people experiencing an acute episode of mental illness and builds on that knowledge. It provides information on which to build healthy public policy, create supportive environments, strengthen community action, develop personal skills and re-orient health services so they are more in line with the World Health Organisation *Ottawa Charter, 1986*. In the meantime, as mental health clinicians we must look at what motivates us and believe that practice changes do develop from increased knowledge and understanding. Scheduling is an event that has meaning as a lived experience. It is not a sequence of prescribed actions leading to a safe outcome: hospitalisation. The voices in this study tell the same story. They recount anxiety, fear, concern, need for validation and support, and lack of options. Throughout, however, there is a common voice that says that working in partnership is rewarding – and possible – in this acute event, as it enhances everyone's sense of autonomy, mastery and control over mental illness. In partnership the person ceases to be the illness.

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## Appendix A

### Interchangeable Terms

Casemanager	Clinician/Primary clinician	Health Professional	Service provider
Person affected by/experiencing mental illness	Client	Consumer/Service user	Patient
Relative	Family member	Consumer/service user	Significant other
Mental Health	Mental Illness/disorder	Psychiatry	
Schedule	Section	Civil commitment	Regulation
Informants	Participants	People interviewed	Respondents
NSW Mental Health Act 1990	NSWMHA 1990	The Act	
Police van	Paddy wagon		

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## Appendix B

### Abbreviations

ARAFMI	Association of Relatives and Friends of the Mentally Ill
CMT	Casemanagement Team
DSM IV	Diagnostic and Statistical Manual
ED	Emergency Department
EHT	Extended Hours Team
EPOCH	Early Psychosis
EWS	Early Warning Signs
GP	General Practitioner
NESB	Non-English speaking background
NSW	New South Wales
NSWMHA 1990	New South Wales Mental Health Act 1990
PTSD	Post-traumatic Stress Disorder

## Appendix C

### Stories

To provide the reader with the context within which the scheduling events unfolded, a narrative description of the schedules is presented. The thirty stories are told. Fifteen are recounted in their entirety, as told by the participants. Some editorial license was used to enable the story to read well while still reflecting the communication style of the storyteller. Three are the same event, described separately by both the person who was scheduled and his mother. These are stories 17 and 26; 19 and 28; and 20 and 30. As you will read, there are no differences in the practices described or the feelings experienced amongst the three groups. Each group validates the other in its veracity, or its memory.

#### Story 1 – Sandra

Sandra was Gwen's casemanager. Gwen had been deteriorating over a few months and there had been concerned reports from other clinicians, as well as neighbours' complaints. While becoming unwell, Gwen refused to allow any mental health professionals in her home. A neighbour had reported seeing her going down the street with faeces running down her legs. Sandra arranged for a visit with the psychiatric registrar who wrote a Schedule II. Sandra returned to Gwen's home accompanied with police officers, but Gwen still would not allow them in, shouting verbal abuse. Ultimately, the police officers had to remove the bars off the windows to gain access into Gwen's home, and she was removed amongst much screaming and fighting. She was transported by ambulance with police escort.

#### Story 2 - Doug

Doug had previously worked in the Inpatient unit. He had moved to community health to the Casemanagement Team (CMT) and then to the Extended Hours Team (EHT) a few weeks before the interview. His client was workload transferred to other casemanagers, as the EHT only did crisis work. Margaret was one of his previous clients. She was in her mid-twenties. He knew her and her family very well, and had worked with them for several years in the inpatient unit, and later in the community.

One morning Sherrie, one of the casemanagers, approached him about Margaret. She was recently nominated as Margaret's casemanager, but they had not met. There had been many telephone calls from Margaret's family and from the hospital about Margaret. Sherrie wanted



to know what Doug thought. Margaret was not seen by anyone from the mental health service for about six weeks, because the casemanager allocated before Sherrie had resigned.

Doug was disappointed to hear that Margaret's continuity of care had failed, and that someone with such a long history of severe mental illness had not been followed up. He told Sherrie that if there were many calls about Margaret, than she was sure to be unwell, and needed seeing as soon as possible. He was also disappointed with Margaret's parents for not having contacted them much earlier. He thought that they would know better; her father had to fly interstate to bring Margaret home only a few weeks earlier. Doug put this lack of communication down to poor understanding of mental illness, and probably pressure from Margaret for her parents not to contact the mental health services.

When he was the casemanager, Doug saw Margaret regularly at the local mental health centre. She came by herself or with her parents, and her mental state and medication were assessed. Doug offered to ring them up to ask them to come to the centre where he would introduce them to Sherrie. He spoke to Margaret's mother who was quite pleased to hear from him. She reported that Margaret was unwell, doing all sorts of bizarre things and had not been sleeping. Doug asked to speak to Margaret, but she refused to go to the centre to see him. Doug left it at that.

Within a few hours, telephone calls started coming in from the hospital. Margaret presented there the day before, unwell, saying bizarre things and being sexually inappropriate. Doug spoke to Sherrie again, and together they decided they needed to go and see her. They rang Margaret's mother and arranged a visit. Doug, Sherrie, the psychiatric registrar, Dr. Walton, and Emma, a student nurse, set out to see Margaret.

When they arrived at Margaret's house the situation was quite bizarre. Margaret was as "florid as she could be." She had put on a Papua New Guinea mask that she believed was a trick she could play with her own skin. She kept pacing up and down incessantly, very pressured in speech, claiming to have vaginal thrush, with the mask on her face. There was no doubt she was floridly psychotic. She had put cream on her face, powdered dry on, caked on, and had make-up on top of that over her eyes and lips, so she looked very white. She also had her hair done in long spirals, which made her look more bizarre. They decided that involuntary admission was necessary and Dr. Walton explained to Margaret and her family about this decision.

Getting Margaret to accompany them was difficult. She was disorganised and took a long time to gather her belongings. Doug worried a little, as he was not sure whether she would change her mind about going with them. Doug and Dr. Walton discussed the need to call the police.

Margaret's parents were concerned about the potential police presence, asking Doug not to call them. Initially, Doug agreed, but he then started to feel frustrated with Margaret's inability to organise herself. Doug decided that the help of police officers was necessary. He contacted them, and explained what was happening. The police officer who answered the call said a car would arrive within 15 minutes. Margaret's parents continued to beg Doug not to have the police involved. "Well to do" people, living in a nice residential area, they were concerned about neighbours witnessing Margaret being "dragged away."

They saw the police arrive. Doug went out to ask them to wait in the car in front of the house. He did not want to use them unless it was necessary. Margaret's parents continued to beg them to send the police away. Margaret, however, was no closer to being ready to leave, and Doug's frustration was mounting. Her parents could not decide on which clothes to take, they wanted Margaret to have a shower, she kept getting dressed and undressed. Doug told her parents that he would send the police away once Margaret got in their car and told Margaret that she could either come with them or the police would have to take her. Eventually Margaret got into the EHT car. Doug waved thank you and goodbye to the police, and drove off. Margaret's parents followed in their car, a look of relief on their faces.

### Story 3- Elinor

Elinor was on duty over the weekend. Eva's husband, Bill, rang saying that his wife was displaying some bizarre behaviours. Elinor could hear her over the telephone, screaming and shouting threats at her husband. He stated he wanted to let them know what was happening in case he needed them later. They were not known to the service. At 6.30 that evening, Bill rang back and requested a visit. Elinor went, accompanied by Carol, and they assessed Eva as being clearly psychotic and in need of treatment and containment. They contacted the psychiatrist on call, Dr. Bates, who, after some negotiation, came to write a schedule.

#### Story 4 – Dr. Swallow

The telephone rang. Dr. Swallow answered. It was Dr. Watts, a local GP. She was concerned about a patient of hers, Anne, who was seen by the EHT the previous day. At the time, there did not seem to be enough evidence that Anne was a risk to herself or others, and the team took no action.

Since the visit from EHT, however, Anne's mental state appeared to have deteriorated, and she fled her home due to hearing persecutory voices. She contacted Dr. Watts upon arrival at a distant country town. Anne always had a very good relationship with her GP and thought of informing her of her whereabouts and reasons for leaving. Dr. Watts was worried. She had known Anne for many years, had developed and maintained a good therapeutic relationship, and was aware that Anne was capable of presenting well to people she did not know and trust. Dr. Watts spoke to Anne at great length about the voices she reported hearing, how they were threatening to kill her should she return to the unit where she lived.

In time, Dr. Watts managed to persuade Anne to get on the next train and return to Sydney. She promised to meet her at the train station and that they would then talk about what to do. Dr. Watts rang Dr. Swallow, requesting urgent support and assistance in meeting Anne at the train station for an assessment and possible admission. Dr. Watts was also concerned that the EHT would refuse to attend for a second assessment, because of the strong possibility that Anne would "deny any fears" or "hearing voices" to them.

The train was due in the evening, around the time the EHT shift ended. Dr. Swallow felt anxious about approaching the team to accompany her to the station. Luckily, she had a good relationship with both mental health clinicians on duty that night. She explained the situation and apologised for the time of day, sensing their annoyance, and hoping it would not reflect on their interaction with either Dr. Watts or Anne. She hoped that Anne required hospitalisation so that her request to the EHT would be validated and the effort organising the schedule would not be in vain.

When they arrived at the train station, the train had arrived ten minutes early, Dr. Watts was nowhere to be seen, and they had no idea what Anne looked like. Looking around, there was a magic moment when Dr. Watts arrived, the mental health clinicians were there, and Anne seeing Dr. Watts walked towards her. It worked like clockwork.

As feared by Dr. Swallow there was a degree of conflict between the mental health clinicians and Dr. Watts. They were dismissive of her opinion, and Dr. Swallow had to intervene and

reassure them that she had known Dr. Watts for a long time and trusted her judgement. To make things difficult, Anne appeared relatively normal in her mental state. She was not disturbed or agitated, but told Dr. Swallow how she was petrified, felt she was not safe at home, had nowhere to go with no plans other than to escape the “voices” that persecuted her. She fled her home in a state of total mental disorganisation placing her at risk to her personal safety.

Dr. Swallow discussed with Anne the need for hospitalisation. Emphasis was placed on persuading Anne that the hospital environment would be safe, she would be out of danger there. Although Anne agreed to go to the hospital, Dr. Swallow wrote a Schedule II. In doing this, Dr Swallow explained to Anne that it was her own need to protect Anne and ensure her safety that led her to decide to schedule.

The EHT clinicians were not happy about the schedule. Both Dr. Swallow and Dr. Watts were concerned that Anne might change her mind, flee from the car at traffic lights or while the car was in motion. If Anne became agitated and fled, the mental health clinicians would have no “power” to try to stop her, giving Anne the opportunity to disappear and again place herself at personal risk. Anne got in the car with the mental health clinicians without arguing, and was transported to hospital without further incident.

#### Story 5 - Amanda

Wagner came for regular sessions. This time, however, he was clearly depressed and expressing suicidal ideation. He talked about going to the “gap” – a high cliff with a sharp drop into the sea — to jump off. Amanda knew that Wagner was in possession of guns at home and he was a capable shooter. Although Wagner had not mentioned the guns, Amanda was worried. She decided to talk to the psychiatric registrar and ask him to assess Wagner. Following the assessment, Wagner went home for a couple of days, with daily follow-up, and on a higher dose of medication, but there was no improvement.

Amanda believed that there was no way Wagner would agree to hospitalisation, and his parents were away at the time, so Amanda arranged for a visit with a psychiatrist. Wagner was unwell, and kept asking for tests because “his brain was hyperventilating.” He had ongoing delusions about his brain not working properly to write philosophy.

It was about 2 or 3 in the afternoon when the doctor saw Wagner. The doctor decided to write the schedule, although Amanda felt that he could have been maintained in the community with the assistance of the EHT if they could see him everyday and give him medication.

Wagner was given the alternative of taking medication but he would not take it, and was very depressed. There were concerns that he would just walk out of the hospital if he were not scheduled. Amanda drove him in, thinking that Wagner "went like a lamb," believing he was going for a physical examination pertinent to his mental state. He was only concerned with his cognitive functioning.

#### Story 6 - John

John sat at his desk. He was rostered first on call for that shift. He and his colleagues had finished handover from the previous evening. Nothing much had happened, some routine jobs to be done, ringing people to remind them to take medication or to ask how they were. The telephone rang. John answered promptly. It was the Intake Officer. There was an urgent call about a woman, Beverly, who had just arrived from overseas. She was in her late forties and had a known history of bipolar disorder. Her defacto husband, Gordon, had rung requesting assistance.

John took the details and prepared to ring Gordon back. More details were needed to ensure the best possible outcome, and a time for a visit needed to be arranged. Gordon answered the telephone. He sounded agitated, spoke hurriedly and softly as though he did not want to be heard. He was unsure whether the travel and jetlag had affected Beverley, but she appeared very elevated in mood, unable to sleep, irritable, and interfering with everything Gordon tried to do. He was concerned about her reaction if she heard him on the telephone talking about her.

Gordon was a doctor and, apparently, there was a lot of money involved in their trip overseas. They were coming into town on business and it was important for this crisis to be managed with extreme care. In Gordon's opinion, Beverley needed urgent treatment, as their reputation was at stake due to her irritable and disinhibited behaviour.

Gordon did not want the public mental health services involved, but he realised there was no other choice. He was a well-known public figure, with contacts within the health system, and had already contacted the mental health directors. He had been advised to call a local general practitioner, who in turn advised him to contact the local community mental health service, as the situation seemed to be serious and volatile.

At this point, John was a little cautious, because of the status of those involved and their relationship with the local medical directors. He felt that greater care was needed not to upset anybody. He was compelled, however, to call the police before leaving the mental health

centre requesting their assistance at the scene. Experience told him that this situation had potential for violence and he had a responsibility to ensure the safety and well being of all involved.

John was worried and apprehensive about going to do the assessment. Knowing the details increased his concerns about his performance: this was going to be a difficult task. He first discussed the call with a colleague; they both felt it might be easier to ask a doctor to attend as it would probably be necessary to write a Schedule II. It would be more efficient to take a doctor.

Dr. Berry was a senior Consultant Psychiatrist, fortunately available on that day to accompany John. John was more reassured now, as Dr. Berry would be able to make the necessary decisions and explain to Gordon what was going on. If there were any problems or concerns raised, John would not have to deal with them himself.

It was eleven o'clock in the morning. John and Dr. Berry arrived at the house where Gordon and Beverley resided. The police were already waiting outside. Dr. Berry and John approached them to brief them about the situation. There were serious concerns about Beverley's safety and well-being. She was reported to be unwell and would need admission.

John and Dr. Berry went to the house. Gordon allowed them in. Beverley was angry, ready to fight. She started screaming and shouting when she saw John and Dr. Berry, realising their intent to hospitalise her. John was anxious. He did not like these confrontational situations; worried she would attack him he avoided eye contact, saying nothing. Police officers followed closely. John moved aside to let them through.

Beverley stood her ground, very angry. A police officer approached her, talking quietly yet firmly. He said: "Beverly, we would like you to accompany us to the hospital." She moved swiftly towards him and kicked him, then turned toward John and Dr. Berry. The police officers moved quickly, uncertain of what her next move would be. They got hold of her arms and legs, a tight grip around her neck. She screamed in pain. John looked over. There was nothing for him to do. Dr. Berry filled in the forms.

Beverley continued to fight all the way to the police van. Down the stairs through the patio. Screaming for help, to be set free. Neighbours looked out of windows, passers-by stopped on the pavement across the road. Gordon looked devastated. His face was drawn, near tears. He looked over, clutching himself as in a comforting embrace. Beverley had her legs spread open against the door of the paddy wagon into which they were trying to put her. How humiliating.

How undignified she looked. John was saddened by the circumstances, but felt powerless to do anything. After all, she was unwell. Hospitalisation was the last resort. The police officers were lifting her up and throwing her into the police van. They quickly closed the door. It shut with a metal clang. The bolts were pulled across. Beverly was locked up, on her own, banging against the sides of the van.

John remained with Gordon. He felt his duty was accomplished, but he could not leave Gordon to find his own way. Not in the state he was in. Together, they drove to the hospital. John decided to stay to provide support and reassurance. Gordon was very tearful and distressed, worried about his actions and the consequences for their relationship. John took time to sit with Gordon. He waited until the admission procedures were complete and then left.

John was shaken by Beverley's reaction and the amount of physical force required in restraining her and putting her in the paddy wagon. He felt her distress, and the neighbours' who witnessed the event. However, he knew this was only another day's work.

#### Story 7 – Angela

Angela was at the mental health centre waiting for Liz to arrive for her regular appointment. When Liz arrived, Angela became concerned. She did not look her usual self, was clearly depressed, and Angela could not help feeling that she was dangerously unwell. Angela had not expected Liz to present like this, and had not anticipated the possibility of an admission. She knew that Liz regularly attended her appointments with her psychiatrist at the centre, and she was seen the previous week. Although aware that Liz was not as well as she seemed to be when they last spoke, her mental state came as quite a shock to Angela.

Liz had previous involuntary admissions, but these had happened before Angela's time. On only one occasion since their relationship began did Liz attend the centre unexpectedly, asking to see Angela who was on holidays at the time. That time she was scheduled by the clinicians on duty.

After spending some time talking to Liz, Angela became increasingly concerned about her motor retardation and suicidal ideation. She decided to ask the duty registrar, Dr. James, whether she would be available to see Liz there and then. Angela was worried that Liz was a high suicide risk and did not want to send her back home without being seen. Dr. James agreed to assess Liz immediately. Angela introduced them to each other, and accompanied Liz into Dr. James's office. Liz was pleasantly mannered, but answered all the questions in

monosyllables. Her eye contact was poor, she felt worthless and that life was not worth living. She had been living in supported accommodation for several months now, and had very few social supports. She had lost contact with her family due to their difficulty in dealing with her illness, and the housing support worker was the only stable and reliable relationship she had. However, even this relationship was sometimes trying, as Liz's condition was quite unstable at the best of times, requiring intense support.

Dr. James completed her assessment and decided that Liz needed to go to hospital. Liz was asked to leave the room briefly, while Angela and Dr. James discussed these concerns amongst themselves. Would Liz present at the hospital if they agreed to let her find her own way? Liz was ambivalent about going to hospital, and was suicidal. This was the basis for the decision to schedule her, because Liz might not stay in hospital voluntarily long enough to receive adequate treatment. The need for a Schedule II was discussed, and both Angela and Dr. James decided to disclose these concerns to Liz. Angela worried about how Liz would react, but thought that maybe she was too unwell to think much about anything at that time.

They discussed with Liz the possibility of hospitalisation. Liz's motor retardation was worrying. This increased their concerns about her ability to understand what they were discussing and to consent to an admission despite her apparent agreement. Dr. James told Liz about their concerns: "We are worried about you, and I feel that I need to admit you as an informal patient because I'm quite concerned that you might otherwise leave once you get to hospital." Liz agreed.

Angela wanted to take Liz to hospital herself, but she had other commitments to keep. She contacted the EHT and discussed the situation. The EHT clinicians agreed to escort Liz to hospital, making plans to collect her from the centre. An exact time of arrival could not be given, which concerned Angela, who felt that if the EHT members did not get to the centre promptly Liz would leave. She did not want the police involved.

Angela asked Liz to wait in the waiting room while she completed her telephone calls and Dr. James arranged the admission. Luckily, a bed was available. Angela made Liz a cup of coffee and sat next to her. She told her that arrangements had been made to take her to hospital as soon as possible, giving her the names of the clinicians who were coming to pick her up. She explained the reasons why she could not take her herself, and assured her that she would contact the staff of the supported accommodation where Liz lived, to let them know what was happening and for personal belongings to be delivered to the hospital. She was concerned



about Liz and wanted to reassure her that they were looking after her best interests, and she would soon be well again.

Angela introduced Liz to her colleagues when they arrived, and Liz followed them into the car, giving Angela a little wave as the car drove off.

#### Story 8 - Louise

Penny was becoming unwell and Louise had taken the doctor out a number of times to see her. She had decided not to take medication but at that stage a schedule was not seen as necessary. In the meantime, Penny was evicted from her last place of residence and was now homeless. She could not be contacted anywhere, and Louise was desperately trying to find out where she was, ringing up different people, leaving messages. Eventually she located Penny, but Penny would not come to the health centre to talk. She chose instead to meet Louise in a coffee shop in the middle of town.

Louise felt incredibly compromised. She had a feeling that Louise was very sick. They had an agreement that if Penny become unwell she would take medication. Instead, she would not re-start it. Penny thought she was fine and believed the problem was accommodation needs not her mental health. At that stage, she had dropped a terracotta plant from the first floor on one of her flatmates' head. She had also been working as a sex worker, which was quite out of character for her, and Louise was worried. She could assault somebody and was putting herself at risk. She had been in fights and was covered in bruises. She had black eyes and had lost a lot of weight, and she had nowhere to live.

Louise arranged to see Penny with the psychiatric registrar on the day of the schedule, and the EHT clinicians offered to be involved in her place, as they were concerned for Louise's safety if she were involved. Louise was a bit worried that Penny would assault her. Nevertheless, she arranged to go down and meet Penny. The plan was that Louise and Penny would go into the coffee shop and have coffee. Louise had also organised the police and planned that when she and Penny came out of the coffee shop everyone would grab Penny. What ended up happening, however, was that as they were having a drink, two clinicians from the EHT and a doctor came in and introduced themselves. When she saw them, Penny stood up and became hostile. She then took off down the street and one of the EHT clinicians chased her, followed by the police officers. They caught up with Penny, put her into the paddy wagon, and took her to hospital.

## Story 9 – Dr. James

It had been a busy week at the centre. Dr. James, a young registrar in psychiatry, was trying to catch up with writing notes. On busy days, it could be quite a nightmare to try to stay on top of it all. In addition, she had to be on call for the hospital. It could be days before registrars got a proper break. Dr. James had gone into work early for these reasons. Luke, from the EHT, knocked on the door and put his head in, with a grimace and a raising of the eyebrows. “Here we go,” thought Dr. James.

Luke told her that he and Lisa had been to see Peter the night before. His family had called, very distressed, as Peter had not slept for a few nights now, pacing around the house, looking out of the window, and not eating. They were worried because Peter’s mother had been mentally unwell several times and was hospitalised in the past; they thought the same was happening to Peter now. When Luke and Lisa saw him the night before, they suggested to him that he go to hospital. Peter, however, refused to talk to them. He sat in a corner, or walked in and out of the room. His family said he had lost weight and was very moody and irritable. He also appeared to be responding to threatening voices and behaving in a fearful way.

Both his family and the mental health clinicians were worried Peter would do something serious, like attack someone or disappear from the house. His uncle told the clinicians that Peter had a compass and a bottle of tea-tree oil in his pocket. He took them out every so often to reassure himself he still had them. It looked like he intended to use them as some kind of weapons, to protect himself. Dr. James was not sure. What would he want a compass for? He was unwell, but he refused adamantly to go to hospital and said there was no way Luke and Lisa were going to take him.

Luke asked Dr. James whether she had the time to “pop in” and see Peter with him and Lisa that morning. It sounded urgent. It was important not to allow Peter to deteriorate further, as his behaviour could become unpredictable. Dr. James decided to go and assess Peter straight away. The outstanding clients’ notes would have to wait. She felt anxious as she needed them ready for her supervision session with the Consultant Psychiatrist the following day, but she could try to finish them at home that evening.

When they arrived at Peter’s home his uncle and other family members anxiously welcomed them. Peter’s mother had gone to the next door neighbour’s house as she was quite distressed by the prospect that her son would be scheduled. She had herself been sent to hospital many

times under *The Mental Health Act*, accompanied by police. Additionally, there were two cousins, one of Peter's siblings and an auntie.

Peter's auntie started to talk with Lisa. She wanted to know what was going to happen and needed some comforting. The other relatives sat in the room while Dr. James spoke to Peter. Luke also participated in the interview. Peter's uncle informed them that Peter had sat in the corner of the lounge-room with a knife for most of yesterday after seeing Lisa and Luke, waiting for one of the community mental health clinicians to return. By evening time, however, he was sitting around with his family again. Apart from having the compass and tea-tree oil still in his pocket, he did not seem distressed.

Dr. James thought it was clear that Peter was psychotic and he needed to go to hospital. She informed him that she thought he should be taking some medication and asked whether there was anything they could do to help him. Did he feel it might be of benefit to go to hospital? How about at least to be further assessed? If he agreed to that at least they would have him in hospital if they decided to schedule him. However, Peter was adamant that he was not going to do that. His relatives stepped in and said: "Well, it might be a good idea. Why don't you think about that?" It was obvious that he was not going to go voluntarily, and it was at that point that it was decided that the police needed to be called.

Luke went outside to make the call on his mobile phone. The police van arrived about fifteen minutes later. They arrived in a surreptitious manner and waited outside until Dr. James came out to speak with them. She discussed what she hoped they would be doing and they waited further, until Dr. James indicated to Peter that he needed to go to hospital. She was conscious of the fact that hospitalisation would be an issue for Peter, and that he was likely to become upset. She was moving cautiously, concerned about how he would respond and hoping, if possible, to be able to coerce him to go in without having to use the police.

Peter was clearly not willing to go, and the police stepped in. Dr. James brought them in and said: "Look, the police are here to help us because we are so concerned." One of the officers approached Peter and said: "We feel that you need to go to hospital." Dr. James thought they were encouraging and gentle, but also quite firm. Initially Peter refused to go. The other officer said: "You really have to go," explaining to him why. It was with the support of the family that he eventually decided: "Well, I don't have a lot of options."

The police and his uncle accompanied him to the paddy wagon. Peter was distressed, tearful, as were several of his family members. Having the police involved possibly brought back all

those memories of Peter's mother being taken to hospital before, and made them realise that this could be something that happens again and again. Dr. James thought that was why they were all gathered there, it was quite a momentous occasion, the first time Peter was taken to hospital, repeating his mother's history.

As Peter entered the police van, he turned around, and as the door was being shut, he hit his head against it giving himself a small cut to the forehead. Dr. James thought this was because he was distressed. She did not think he meant to incur any severe damage to himself, but he was obviously frustrated with his lack of options and choice. She felt sorry for him. She could see that although he was psychotic he was aware of what was going on. Dr. James thought Peter probably had "insight into the fact that he basically had the same pathology [sic] as his mother," and having lived with someone with a mental illness for a number of years he probably had a greater idea than many of what that would entail. "This" Dr. James thought, "probably contributed to his fearfulness." Her main concern was for his safety and for him to get some treatment and get better, and he was taken directly to the hospital, family in tow.

#### Story 10 – Dr Penford

Dr Penford accompanied the EHT clinician to Caroline's house, a woman well known to the mental health service. She had a manic illness and her mother had rung the service because she was out of control, smashing the furniture and screaming in the house. Her neighbours had called the police, and Caroline was at risk of being evicted by the Department of Housing due to her behaviour and ongoing complaints by neighbours. Caroline lived on her own. Once the initial assessment was completed, Dr Penford felt that Caroline needed to be in hospital as her violent behaviour was difficult to contain at home. He decided to write the Schedule II and went to the police station to drop it off, as was common practice. However, the police officers would not go without mental health support, so Dr Penford and the EHT clinician went back with the police.

Dr Penford made the decision to schedule Caroline, but at no stage did he inform her of either his intent or his action. He was positive that Caroline would just leave the unit if she were told. She was unwell and needed hospitalisation and she disagreed with it. Once they returned with the police Caroline was escorted into the back of the paddy wagon and taken into hospital.

### Story 11 – Eileen

Eileen's son, Grant, was scheduled at 10 p.m. at night. Grant turned up at the surgery where Eileen worked and was agitated and threatening. One of the surgery GP's contacted the EHT and they refused to attend because of Grant's history of violence. Grant was about to walk away into the night, possibly not to be seen again, Eileen feared. Grant was very angry with her, seemed to hate her, moved away from her screaming.

She felt lucky in that she had been working in a GP surgery for many years and was aware of the *Mental Health Act* and legislation. There were only two Schedule II forms in the surgery, she knew what they were for, and one was used on her own son. The crisis team did not respond due to the potential for violence. This sounded like a contradiction to Eileen who believed that mental health clinicians would be trained to deal with exactly that kind of situation. Her son was walking away threatening to kill her and anyone else who tried to stop him from walking all the way overseas. The police were called and Eileen was glad Grant did not resist them. He was scared, she could see that. It was his first time. Eileen felt that Grant reacted badly to the event and it "turned his attitude from wild to savage! Great hate came over him! The police scared him, what could he do? He knew not to resist."

Eileen felt "guilt, relief and anxiety, wondering what would happen now." There was no contact from the mental health staff and no follow-up at that time. They just advised her to contact the police if there were any further concerns. She was devastated by the police involvement, Grant having to go in that undignified way, just thrown in the back of the paddy wagon. She could not help him, reassure him.

### Story 12 – Jan

Jan had known Nora for a few months. Nora had been residing in the supportive accommodation Jan managed and had recently moved out to private accommodation, sharing with her partner, Mary, and Mary's child. Nora had led an itinerant life, moving frequently between Queensland and NSW. She was scheduled many times; Jan was not sure as to the reasons. She knew that Nora had been distressed, sad, needing support.

Jan tried to comfort and support Nora on numerous occasions, believing they had a good relationship. Nora was challenging and regularly fought with the other residents. She appeared disturbed lately, easily getting into fights, bursting into rages, cutting herself. Jan was relieved when Nora moved out, but felt obliged to continue providing some support. Jan

was deeply religious and committed to Christian values of love for, and assistance to, the needy.

On this day, Jan was at Nora's house for a support visit. Nora looked strange. She intermittently gazed at Jan, as though wondering about her presence. She had fresh cigarette burn marks on her forearms and legs. She had not brushed her hair and her make-up was more pronounced than usual. Jan asked whether she was feeling well. Nora grimaced and grunted with a yes, she was fine. Mary looked concerned, staring helplessly across to Jan. She could not talk in front of Nora. She could not tell Jan that Nora had been drinking a lot more, every day and night. She had also been taking drugs, Mary was not sure what. Her behaviour was bizarre, highly volatile, suspicious. She was often sullen, quiet, muttering to herself, deep in thought.

At the end of the visit, Nora asked Jan for a lift to the local shops. They were not very far, but Nora always preferred to be driven if she could have a choice. Jan wanted to help. She wanted Nora to know that she was her friend. As they drove to the shops Nora turned towards Jan and said: "Isn't it funny! You're here to help me and I have to kill you." Jan felt a shiver of fear going through her body. She had known Nora's behaviour as "sometimes good, sometimes bad" but this time she did not feel safe. She dropped Nora off at the shops and returned to the Support Centre.

A short time later Nora turned up. Mary and the baby were with her. Jan welcomed them and they entered the day room. There were many women in the house on that day. Probably thirty. Some were in their bedrooms. Others were busy downstairs, talking, looking after their children. Jan was feeling anxious. There was something about Nora she disliked. She picked up the telephone and contacted the mental health service. She explained Nora's behaviour and her threatening comment that morning, and they came. It was around midday.

Jan thought that Nora had "a spiritual problem." She believed Nora to be a survivor of ritual abuse. Nora had not told her that, but Jan had seen this kind of behaviour before, survivors coming to her church looking for solace and acceptance. Other people had helped them recover with dramatic effect. The church was helpful. Jan believed Nora to be demon possessed. She laughed, saying that others would think she was mad herself if they heard her say that. She would not tell the mental health clinicians that! She would be too embarrassed.

The mental health clinicians arrived and they all went into a room with some privacy to talk. Nora could not sit still, pacing up and down, refusing to give any answers to the questions

asked. She suddenly left the room. She stormed out and then stormed back in, telling everyone to leave, that she was fine. The clinicians got up. They told Jan that Nora would need to be scheduled if she were to be hospitalised, and told Nora she could go home whenever she wanted to. Jan was stunned. She did not realise that the clinicians were concerned. Concerned about Nora. Concerned about Jan and the other residents. She did not know they found Nora too volatile to try to negotiate treatment with. She did not understand they were telling her Nora *would* be scheduled.

After the clinicians left Nora's behaviour worsened. Jan looked at her and thought "this is not Nora talking." She could tell when the "demons took over." Nora changed! Nora believed she had killed her previous partner, that she had bashed her to death. She was very disturbed and unpredictable. She was pacing, saying she "had killed her family, had lost everything, was going insane." She was angry, furious about the mental health clinicians, who had "put her in a straight jacket and forced her on a chemical dance" in the past. Jan was troubled. Nora was now brandishing a carving knife at Jan and at the other women. Mary had disappeared with the baby.

Jan felt a sense of responsibility for her community. She felt she had a good enough relationship with Nora to be able to intervene safely. Nora paced. Up and down, up and down. Screaming. Brandishing the knife. Jan gently walked up to her and said, in a firm tone of voice: "I know you are in there. I know you have possessed Nora. I command you to put that knife down!"

Nora stopped. She looked at Jan. She saw the firmness and the determination in Jan's face. She saw the woman who had helped her in the past, at times of need. Slowly, gaze fixed on Jan, Nora placed the knife on the table and collapsed on her knees, sobbing.

Then suddenly, the mental health clinicians were at the door again. They were back with police officers: many officers. They held Nora down in tight headlocks and threw her in the back of the paddy wagon. Jan was shocked. She thought this was totally inappropriate. There were thirty women in the house watching. Mary was around. Her perception of dangerousness was different from that of the clinicians, and the police officers would not take any risks. Nora went into the paddy wagon quietly as though realising she was acting dangerously. Jan wondered "had the evil spirit left?"

### Story 13 - Elena

Elena stood in the dark corridor watching Paula, her mother. She thought: “This has happened so many times before! Why does it have to be so? Why can she not just take her medication and stay well?” Elena needed her mother to stay well. How was she going to pass her high school exams if she had to worry about her all the time? Grandpa was not much help. He did not understand much English and did not know when or who to call for help.

Paula had stopped taking her medication. Elena had tried to convince her to keep taking it but Paula got angry, telling Elena to “mind her own business or she would hit her across the face! How dare she, her own daughter, tell her what to do? How dare she open her mouth in defiance of Paula’s choices?” Paula thought she knew that she did not need the medication now. Medication stopped her from feeling and she was pregnant now; she was the Virgin Mary and about to give birth. Elena tried pleading with her, reminding her of her previous admissions to hospital – always scheduled, always with police. Paula was indignant! After all, she had the gift of healing and she deserved respected.

The nights became troublesome. Elena stayed up late, studying. She was not allowed to stay with friends so she had no respite from her mother’s behaviour. Her grandpa would eat his dinner, have a couple of drinks, and retire early. Paula was up in the middle of the night. Elena saw her on numerous occasions going up to the front door around three o’clock in the morning. She would just stand there, staring at the door, for long periods. Sometimes she would look through the keyhole, checking if the sounds and voices she had heard were just outside.

Elena was scared. “What was wrong with her mum? Who was at the door? Were they burglars? Home invaders? Were they horrible freaky things? How could she just stand there looking through the keyhole for all that time? Why did she keep so many water bottles and so much food in her bedroom? Why did she lock herself in there so often? What was going on?” Elena decided to call for help. There was no one else to turn to and she was tired.

She dialled the number for the EHT. A voice answered: “Extended hours team. How can I help you?” Elena explained the situation. She told the clinician of how disturbed Paula was. She described what Paula was saying and doing and how she herself felt. They would come and help. She was sure of that. Instead, the voice on the other side of the telephone line stated: “I’m sorry but we can’t do anything at the moment. Not until she is a danger to herself or society.”



Elena knew Paula was no danger. Yes, she screamed and shouted, but only because Elena insisted on pushing her to take those awful tablets. And after all that carrying on she would just go back into her room, without talking to anyone, close the door, and go back to sleep. Elena could not sleep all night. She was going to have to miss school again tomorrow. She wondered: "How was she going to stay awake in class? And what if her mother got worse, as she had done before, running half dressed into the streets?" Elena needed to be home to look after her.

The next morning Elena rang the mental health service again. She could no longer cope. She said: "My mum's not better. She's obviously a threat to herself if she doesn't know what she's doing. I think she should be admitted. I know her. She's my mum!" The nurse eventually arrived. Elena wanted to let her in, but Paula forbid her to open the door. She got very angry and slammed the door on the nurse's face and shouted at her to "F... off and don't come back!"

Elena knew what would happen next. The police arrived. There were four of them and they grabbed Paula. They wanted to bring her out into the van outside but Paula would not go, putting up a fight and holding on to furniture and doorways. Eventually she was "dragged out and thrown into the paddy wagon." Elena shuddered as the door slammed and the locks were closed. She laughed lightly, embarrassed at the sight of her mother's hands holding the bars of the paddy wagon's window. Then a sudden sadness overcame her. Paula did not deserve that. She was a good mother and had always loved her. A deep feeling of love rose through Elena's body. She wanted to protect her mother. She knew Paula did not know what she was doing when she became unwell. "To her it's just like a dream," Elena said.

#### Story 14 - Kerri

Kerri was 59 years old and lived at home with her husband, Bill, and their son, Brian. Brian was scheduled approximately five years before the interview and had a dual diagnosis of schizophrenia and developmental disability. He was previously admitted voluntarily and Kerri described the schedule as "a much more traumatic experience."

This time Brian was already unwell, refusing to go to hospital. Kerri called the treating psychiatrist from her workplace, and mental health staff called at the house around 9am scheduling Brian following a brief assessment. This time Kerri was relieved that treatment and containment was provided and that her son did not know of her involvement in his hospitalisation. His casemanager and another staff member talked to him and he agreed to go

to hospital for an assessment. They then rang Kerri at work to inform her of the outcome. She felt supported by the mental health staff because she knew they were going to see him on her request, but was worried about what was going to happen.

#### Story 15 - Terry

Terry was a 62-year-old man. His wife had left him because of relationship difficulties. Their eldest son, Vincent, remained with Terry, while their younger son had left with his mother, believing that she would not be able to cope on her own. They could not agree on Vincent's psychiatric care needs. She would not give Vincent his psychiatric medication, and she and Terry fought all the time. Their daughter had left months before, unable to cope with the family dynamics.

Dr. Smart, the Consultant Psychiatrist who had known them for many years, visited them a number of times at home, at Terry's request, but there was little he could do. Vincent could not be scheduled, he said. He was "quietly mad living locked up in his own room, sleeping on six inches of newspaper, broken glass and junk. He would not let anyone near him. He was filthy, would not wash, and refused to eat most meals. He left his meals and food scraps all over his bedroom. Would not allow anyone to clean." Terry was worried about vermin, and about Vincent's health. Vincent was very thin, but was not a danger to himself or others within the strict criteria of the *Mental Health Act*.

Terry was confused and troubled, feeling powerless, helpless. He decided he needed some help. If not for Vincent, then maybe someone would care about him and would help him. He went to the local psychiatric unit where Vincent had been so many times. He asked to see a social worker, wanting to know if anything else could be done. His son desperately needed help and he, Terry, could not cope anymore. He was tearful, felt weak and despondent. He could not care for Vincent like this! The social worker expressed concern about Terry. She told him she would try to find some help.

The situation had become hopeless. Vincent was confused and angry about the break-up of the family, and Terry had lost his ability to cope. He wanted to run away and leave Vincent. Terry was desperate. He said: "I have never been suicidal, never contemplated the act, but I feel that life is not worth much. It's just that I always have been one for running away instead."

He was at home that day, with Vincent. Neither of them was feeling very well. Terry could not remember exactly what time it was when, unannounced, Dr. Smart called in saying: "I

have decided to schedule Vincent.” He proceeded to write the Schedule II, then called the police and the ambulance, and waited with Terry. Dr. Smart realised how desperate Terry was but could not do anything because of the legislation. “Or did the social worker talk to him?” wondered Terry. Vincent remained in his room, refusing to talk to Dr. Smart. Terry sat silently. He felt nothing but numbness.

The police officers arrived, shortly followed by an ambulance. They joined Dr. Smart and entered the house, proceeding up the stairs to Vincent's room. The door was unlocked. Vincent lay on the filthy floor. There was no floor to be seen, just thick rubbish covering every square inch. The smell of garbage hit the visitors' nostrils. They could also smell urine. The curtains were drawn and the vents blocked with newspaper. The bed was broken, the mattress lying on its side against it. The only pillow was filthy black.

The scene was heart breaking. Confronting. How much longer could they leave him like that? Did he really have the right to choose how he lived? Could he really decide? Dr. Smart had known him a long time and knew Vincent was very ill, unmedicated probably for many months. Vincent saw them and jumped up, swearing: “What the f... are they doing here? Why the hell are they in my bedroom?” He recognised Dr. Smart. He saw the police officers. He looked beyond and saw his father: “That creep! That bastard! How dare he? I have done nothing wrong! I have the right to stay in my bedroom, do what I want.”

Dr. Smart tried talking to Vincent and assess how he was, how capable he was of making decisions about his life. Was he behaving like this because he was experiencing an acute phase of mental illness? He had been this way for several years. Yes, he had responded well to medication in the past, and he had been more communicative and sociable, thought Dr. Smart. Vincent's illness had taken a rather chronic course, and it was obvious Dr. Smart could not leave Vincent in that filth. He had a duty of care towards him and towards Terry. Vincent looked physically unwell, thin and emaciated. Dr. Smart said: “Vincent, I believe that you need to be in hospital for a while. We need to look after you and ensure you get better. You can get better.”

Vincent was adamant he was not moving. He was angry with his father. Terry remembered Dr. Smart saying to Vincent: “You either come in a dignified way or we have to take you.” He convinced him he had no choice. The police officers approached him. They were courteous, kind and gentle. They did not touch him. Although undressed with only underpants on Vincent got up, moved towards the door and down the stairs, into the waiting ambulance. Dr. Smart said goodbye to Terry and climbed into the back of the ambulance with Vincent.

Terry went back into the house to do a little packing. He kept busy collecting things for his son: clothes, art materials, etc. He did not think of going with Vincent. Not until later and then felt he would have a lifelong regret that he did not. He did not think of it and he was not asked. It must have been so terrifying for Vincent!

#### Story 16 - Pedro

Pedro had been looking forward to seeing his brother, Jaime, again. They grew up in Europe and, apart from a brief holiday five years ago, it had been eighteen years since they'd spent some time together. Pedro daydreamed about taking Jaime around the city. None of his family had ever come out here. This was his chance to show them where and how he lived, how he'd made a life for himself running his own business. He had not managed to buy himself a home, but he enjoyed sharing with flatmates. Owning property was not one of his priorities.

It was good to see Jaime again and see him well after his recent hospitalisation overseas. Jaime talked a lot about his life in Europe and the problems he had with his business and personal relationships. Pedro found it all a little boring at times and would then either not listen or move away.

He knew his brother had a nervous breakdown of some sort at home. He had been under a lot of pressure and his partner had "back-stabbed him" causing him to lose his part of the business. He knew about Jaime's hospitalisation and the strong medication he took. Now Pedro blamed himself for not paying enough attention, not being there to ease Jaime's burden. He should have listened to him more, should have believed his stories. They may have been true.

It all came to a peak one day when Jaime was assaulted on the streets. He went to Pedro's office distressed and bruised, complaining that his shoulder was broken. Pedro took him to a doctor. The X-rays showed no fractures but he was covered in bruises. Over the next few days, Jaime became increasingly irritable, stating that his attackers had come from overseas to get him. He began to mistake Pedro's friends for gang members and eventually withdrew into himself, avoiding everybody, not looking after himself. One day he stayed out all night and returned home dishevelled and dirty in the morning. Pedro had contacted his family overseas for some information about Jaime's behaviour and was told that he had been like that before. That was when he had required admission and long-acting anti-psychotics. It looked like he needed something now, too.

Pedro spoke to a friend who advised him to ring the Schizophrenia Fellowship number for advice. He desperately needed to find out the best possible way to deal with this situation. He needed to help his brother. A man answered the telephone. He told Pedro he had a son with schizophrenia himself and he believed that Jaime needed to see a doctor urgently. He gave him the number for the crisis team. Pedro hoped a doctor would restart him on the medication he had taken previously, although Jaime had suffered terribly with side effects.

Pedro was torn with the idea of bringing in mental health professionals. He knew Jaime did not trust any members of the family back home because of his belief that they had all been involved in causing his losses. They had not helped him anyway! He desperately wanted to remain on Jaime's good side. Jaime had no one else he could trust, and Pedro was his big brother. His role was to look out for him and protect him. Jaime's behaviour, however, was getting worse. Pedro could not take anymore so he called the mental health professionals and asked them to come and see Jaime.

John and a colleague turned up within the hour. They spoke to both Pedro and Jaime and tried to convince Jaime to take some medication. Jaime was co-operative with the interview but refused to go to hospital or take any medication. He said: "No way I'll go to hospital! Now I have my brain! If I go to hospital and they give me medication, I will be a vegetable. I am very angry now, but only because I'm looking for some answers. How would you feel if you had lost your family and your business?" He presented well. His reasoning made sense. John said that they would continue seeing him as they did not think he was well enough. At that point, they had no evidence to support an involuntary hospitalisation. Pedro felt reassured by this. It exonerated him from any blame by his brother for calling the team. It was good to also hear them say to Jaime that they were there due to Pedro's concerns about his well-being. Pedro needed Jaime to know this, that he had not just called the team because he was "sick of him or betraying him."

A few days passed and Jaime was getting worse. He stayed out nights, was not washing himself, had his arm in a sling and refused to go back to see a doctor. He told Pedro he did not trust anyone. Pedro was very concerned that Jaime's paranoia was getting worse and he would be unable to control him. He called the team again and they arranged for a visit while Pedro was at work, with a doctor this time. Jaime would almost certainly need to go to hospital. John explained to Pedro what the procedure would be. That a doctor and another health professional would go and see Jaime and then they would give him a call if the

decision to admit him was made. Pedro went to work that day reassured that Jaime's hospitalisation would be uneventful.

At eleven am Pedro received a telephone call at work from a very distressed flatmate saying that their unit was stormed by six police officers demanding to know whether there were guns in the house. Jaime handcuffed and taken. His belt, lighter, shoes and other loose belongings were removed from him as he was dragged down the stairs into the police van. The flatmate was very distressed for Jaime as well, as "it looked like he was some kind of murderer."

Pedro was beside himself. He rang the mobile number he was given and demanded to know what had happened and why he had not been informed of the visit. He was told: "We didn't have the time to ring you. We were very busy." He insisted but still could not get any satisfactory information. When the line dropped, he did not receive a call back. He felt hurt because he was not given the opportunity to support his brother during that difficult time. He felt guilty because his brother would probably think (and quite rightly!) that he had something to do with the events. He felt angry because he was left out of this family situation and because they were both treated like objects, their feelings not considered. Moreover, he was troubled because he would now have to try to repair his relationship with Jaime.

#### Story 17 – Betty

Betty was a 41 years old single mum. Steve first got into serious trouble in October 1996. At that time he was prescribed medication but he refused to take it. He refused to believe he was psychotic. At Christmas, they were at a relative's house in the country. Betty had realised for some time that Steve really needed help, as he was verbally aggressive. He had become totally vegetarian, scared of meat. He would not eat any meat, would not eat many foods and had lost a lot of weight. Over Christmas, he part-took in no conversation. He simply stood while every one else sat in the lounge room having a conversation. He stood. Betty knew it was time to do something serious. They came back home that weekend and Betty decided to see her GP, whom she had great faith in. Steve was very unsettled and would not sleep. He was becoming increasingly verbally aggressive.

Betty asked Steve to accompany her to see the GP. She told him that if he did not want to she would have no option but to call the police. She was just bluffing. They started out to walk to their GP, taking several hours with Steve walking ten paces behind his mother, at slow pace. Betty would stop at a bus stop and hail buses and he would not get on.

After speaking to Steve, the GP decided to contact the EHT. After they got home, it was a while before John and Peter arrived. Steve would not let them in and John talked to him for a little while through the screen door while Betty made herself scarce. When she came back, the clinicians said they would come back later with Dr Berry. Dr Berry went down to the house and Steve would not talk to him, would not let him in the house. So Dr Berry said to Betty "come up to the centre and talk to me."

Steve followed his mother all the way up the street trying to physically stop her, holding her hand, saying: "Mum, you can't go! I don't want you to go." He had never been physically violent, so he followed her right up to the corner pleading for her not to talk to the doctor. Betty spoke at length with Dr. Berry and told him that it was not easy to have one's son committed. Dr Berry replied: "Well, it isn't your choice. Your son is a man now. We don't need anything from you, and you are completely exonerated." Betty was worried that Steve would never talk to her again. However, Dr Berry reassured her she had no choice, it was out of her hands.

#### Story 18 - Maureen

Maureen, a 52 years old mother of two had a history of mental illness in the family. Her son, mother, sister, and two nephews had a mental illness. She and her husband were away when her son, Tony, became unwell for the second time. Tony had stopped his medication in November and the doctor said to him that if he did not take it he would just get worse. When they came back he was worse. He was smoking marijuana more than usual and becoming unreasonable again.

At the time of Tony's first schedule the family was building at the back of the house, putting a room and a bathroom in, and Tony started writing things on the wall to the builders, threatening them. Mrs Evan would try to explain and say: "Look, my son had a party and his silly friends wrote on the wall." She then started to realise that there was something wrong. With his HSC, she thought that it was nerves and he was under strain. He also got into trouble with the neighbours, thinking they were watching the house, saying: "Mum, you've got to lock the windows 'cause they'll be watching!" Then he started to hear a voice calling out to him from town.

That time he ended up throwing a brick through his sister's window. His best friend and Amy were sitting on her bed and the brick nearly hit her. He had just meant to break the window,

not to hurt her. However, he then broke another window the night he actually went to hospital.

This time his sister called the crisis team. Tony threw a cigarette lighter at her and she thought he was going to become violent again. She was scared. Maureen was pleased in a way, because it did not involve her. The first time Tony was scheduled she had rung the doctor and he had blamed her ever since.

Dylan and his colleagues said they were coming early and Maureen was trying to keep Tony in bed. However, they were held up and Maureen was having difficulty distracting Tony who wanted to go for a drive. She had to call a neighbour, one of Tony's friends, to keep Tony busy for a while. Maureen believed he knew that there was something happening and he was trying his hardest to get out of the house.

Tony already had a casemanager, since that first time. Dylan had been seeing him regularly and had talked him into recommencing his medication, but Tony was not adhering to treatment. When Dylan saw Tony that day Tony became angrier. When Dylan and his colleagues left he grabbed the telephones out of the sockets, both telephones, and went down to the garage and smashed them. Maureen was lucky Dylan, Ellen and the doctor were still outside talking while this was happening, expecting trouble. They came back in saying: "Look, we thought he would be better at home but obviously he's not." They talked to Tony about going into hospital and he agreed although he did not want to. He said: "Well, I'll go" and agreed to be driven by his friend.

#### Story 19 -- Sandra

Something was not right for a few days now. Sandra thought that her son, Tom, was just not himself. Had he been taking drugs? Who had he been mixing with? This was just not like him! Sandra was worried sick. He was so irritable. He kept walking up to her, invading her personal space, interrupting her at every possible occasion. She had tried to ignore him. She had been out with friends and with her other son, David, to get some space.

Sandra had been divorced for some years now, survivor of an abusive relationship that caused her a lot of pain. She had always worked to make her boys' life comfortable and to provide them with all the opportunities to achieve and do well. Tom had done particularly well. A bright student, he had graduated from high school with high marks and had been doing well at university. Until recently. Sandra's heart tightened as she recalled the last few days.



Although always committed to his religion, Tom had suddenly become increasingly religious, constantly reading the bible and launching into philosophical discussions about the meaning of life. He had already approached a priest, a Rabbi and a Minister to discuss these ideals, and Sandra was worried they would think there was “something wrong” with him. He was unusually intrusive in situations where he would normally have kept a polite social distance.

Now he would not leave her alone. He talked incessantly and could not control a constant outpouring of sounds and words and questions. He was irritable and could not understand why his mother did not understand what he was trying to explain. Over the last five days Tom had decided to “write a thesis” challenging Einstein’s Theory of Relativity. He wrote copious notes, scattered all over his desk. His argument ran between religion, the meaning of life and not being understood. Sandra did not know Tom had not slept for five days. She just saw his irritability, agitation. His thoughts and activities getting faster and faster. His tolerance of his mother was getting lower and he was expressing increasing frustration at being misunderstood.

The night before the schedule Tom’s behaviour worsened. His actions were becoming incomprehensible. Sandra had never seen or experienced mental illness. Yes, she had her occasional bouts of depression, but she wondered who would not with the kind of life she had? This was quite different. She thought: “It must be drugs!” She did not know whom to turn to but she knew she could not go to work the following day leaving him as he was. She feared she was going to have to sleep across the balcony door that night to prevent Tom from jumping out. Not that he had mentioned it, but he was becoming too unpredictable.

It was early on Sunday afternoon when she decided she could not go on like this. She needed help, fast. She looked in the telephone book for a crisis number, and found the local mental health team. Luckily they had a twenty-four hours service and someone was available to talk to immediately. She spoke to a mild mannered man who asked a few questions to clarify the situation and she told him of her concerns. His manner reassured her instantly. She felt understood, validated, supported. His questions were pertinent and to the point. He acknowledged her fears and her concerns. “I’m not alone,” she thought, “someone understands what is going on.” The clinician replied that he believed Tom to have a problem requiring prompt assessment and assured her that he and a doctor would be over within thirty minutes.

Tom was fast asleep, totally exhausted by the events of the last few days, when they arrived. Sandra was not sure how long he had been asleep. She spent some time talking to the health

professionals, giving them details of what was going on. She gave them Tom's notes to read. She then got Tom up to talk to them. He was quiet and pleasant. He sat for about one hour, talking and explaining what was going on. He was clearly unwell, his thoughts racing, his speech making little sense.

They decided to take Tom into hospital to ensure his safety and to provide him with adequate assessment and treatment. They asked him: "Would you go to hospital to be checked out?" Tom did not object. He had some chest pains over the last few days, probably anxiety, stress, and welcomed the opportunity to have it checked out. Sandra felt a cold sensation moving through her body. Her son had to go to a psychiatric ward! There was no one else to help her, no one she could call for support. Both her parents had died, and David, her older son, was not answering his mobile phone. The health professionals were supportive and kind, but they were concentrating on getting Tom to hospital safely.

It was all like a dream for Sandra. She got in the car with Tom. He would not go without her, and the mental health clinicians followed in their car. She was happy with that. She had no concerns about Tom's behaviour at the time, and she would not have considered calling the police. There was no need. Tom had always been a very gentle young man.

As they entered the psychiatric unit Sandra felt upset, confused, distressed. It was dreadful, just dreadful. She had some terrible things happen in her life, but this was absolutely the worst day of her life. She would never forget this day for as long as she lived. The sight of the psychiatric ward frightened her and depressed her. It was dirty and shabby and with lots of patients coming up to her, talking to her, wanting to touch her. She went home that night and thought: "What have I done to him?" She had never felt so alone in her entire life.

#### Story 20 - Violet

Violet is a 60 years old mother of three. Her daughters have long been married and live elsewhere. Alex had also moved to his own unit nearby, and Violet saw him regularly. As it happened, Alex had stopped taking his medication. He was not on a community order so there was very little that could be done. Chris, his casemanager, saw him regularly, but all he could do was to encourage Alex to take his tablets and closely monitor his mental state. When this happened, the illness took its course and Violet had no other option but to wait, while regularly discussing the situation with Chris, for Alex to get to a stage when he could be scheduled.

When unwell, Alex displayed erratic behaviours and his personal hygiene deteriorated. He would stop washing himself and did not change his clothes. He would become a danger to himself by going out at all hours, walking in front of traffic, stopping cars in full motion demanding to know what the driver was up to. He would also get involved in fights. He would go to the local Pub and be aggressive with people for no apparent reason. He had been in trouble with the police on several occasions.

On the day of Alex's last schedule, Violet talked to Chris about her growing concerns. Chris rang the EHT and they arranged to meet at Alex's home. It was about midday. A doctor and an EHT clinician arrived and talked briefly with Alex. Alex said he did not want to go to hospital, but was told that if he did not go in, if he would not agree to go in, that they'd have to call the police. Alex agreed to go. Nevertheless, the doctor decided to write a schedule, to be safe. Violet was not sure as to why he was scheduled. She believes it was because the doctor could do so within the Act, he was able to schedule Alex within the terms of the *Mental Health Act*. However, she knew that once Alex reached the point of requiring hospitalisation medication was no longer useful by itself. Alex needed containment. Alex complained about having to be admitted, but was resigned to the situation and did not want the police involved. He went peacefully with the mental health clinicians.

#### Story 21 - Penny

Penny is a 32 years old woman who lives with another female in supported accommodation. She had been scheduled a number of times in NSW and in Queensland. She was not feeling well and had contacted the local mental health team on the advice of a doctor she saw, asking for counselling. When she rung the centre they told her they did not provide counselling and she was to look for help elsewhere, within the private system.

A few days later three clinicians from the local mental health centre, including a medical doctor, arrived at her door. Penny did not know why they visited or who asked them to. No one had rung up to let her know they were coming and they introduced themselves stating that they were worried about her health. She had rung mental health services on several occasions trying to see someone and they never sent anyone out. After a short talk, the clinicians said they would come back later but Penny decided not to wait.

Penny remembered hitchhiking to the country, to see some friends, but going in the wrong direction. She could not remember much of the circumstances preceding the arrival of the police. She remembered wedding plans. She had been seeing Tim for a long time; they had

met during an admission and had decided to get married. She trod on a nail a few days before and this seemed to have put her sleep out; there was a bit of pain! She blamed her mental illness on lack of sleep; it happened every time. This time she had bad paranoid delusions. The house was bugged. She was constantly being followed by a government agency. Tim got tired of her behaviour, did not feel he could cope anymore, so they broke off. She was working as a shop assistant -- the pressures of work, the marriage, it all got too much.

She remembered being desperate and out of control before being picked up by the police. She had tried to get herself admitted to a psychiatric unit but told she was out of area. She was not seen by any clinician, despite being "very off the air," so she decided she wanted to go north again. The police found her very early in the morning, the sun was just rising, hitchhiking on a very busy road. When she saw the police officers Penny tried to run away but they were fast.

#### Story 22 - Susan

Susan was in her mid-fifties. She migrated from England many years ago, with her husband, to settle in Australia. They bought a house. He had a good job. They had a daughter and a turbulent relationship. He was very abusive towards Susan, both verbally and physically. He was fiercely possessive and a heavy drinker, and Susan's behaviour when unwell would easily trigger and escalate his violence. He did not accept that she was mentally ill. He called her "a slut, a good for nothing." Some days she could not go out. The bruises were too obvious.

Susan had multiple admissions to the local psychiatric unit. Her husband would call the police because "she was crazy" and the police would come and take her away. She remembered her first admission to hospital, many years ago. Her daughter Sylvia was only seven then. Susan had been behaving inappropriately, quite out of character, walking around naked in the street. Susan remembered Sylvia screaming, while held by a social worker, when the police dragged her away. She thought that Sylvia would never understand why her mother had left her in that disturbing way. Sylvia, like her father, was not able to face the reality of Susan's mental illness.

Eventually, Susan and her husband separated. It happened during one of her admissions. He had another woman and there was no further contact between them. Susan was not able to return to her family home, and was placed in public housing, a two-bedroom unit, with her daughter. Admissions to the psychiatric unit continued over the years, often requested by Susan who feared for her own safety. Sylvia eventually moved out to live with a girlfriend.

Susan described their relationship as close, but Sylvia had not been able to come to terms with Susan's mental illness, and they could not live together.

Susan was diagnosed as having a bipolar disorder when she was in her late twenties. She used to go on shopping sprees, stay up nights cleaning the house, and at times be sexually disinhibited. Occasionally she would become verbally aggressive. Her last schedule was on Christmas Day. Sylvia visited and thought that Susan was not well. She told her: "Mum, you're off the tree again," and went home. Susan was upset by this reaction, as she did not feel ill. She had wanted to spend time with Sylvia on that important family day. She decided to go and visit her only close friend, Iris, who lived some thirty minutes away.

Iris became concerned as soon as she saw Susan. She appeared quite elated, laughing inappropriately and talking non-stop. She appeared to have been drinking. When asked how she felt, Susan said: "It is Christmas Day and a time to celebrate and be with friends." Inside, she longed to be with her daughter and be back home with her family, feeling loved and cared for. Iris expressed concern about Susan's mental state and suggested she get some help. Susan felt something tighten up inside. She did not want to get angry on Christmas Day. She wanted to be with people, be cared for. Be happy! She left Iris' house and returned home feeling lonely.

Susan lived in a large housing estate near the sea. Dark long corridors, many stairs, red bricks. Windows looking the same except for the way they were dressed. Some had black blinds pulled all the way down. Always down. A statement of either privacy or suspiciousness. Others had blankets and sheets keeping the light away for people who could not afford, or be bothered with, curtains. Others were bare, allowing full view of the empty grey insides, the same as all the others, vacant units for more disadvantaged people. She wondered who would move in! She looked up at the rows of units and windows. "Would any of her friends be home? What friends? Everybody took advantage of everybody else in those estates." Junkies, freaks, the unemployed. Pensioners like her, through age, disability, or misfortune. She thought of the guys she had made friends with. The one she had sex with to see if she could still get pregnant. The other she had sex with so she could share his heroin. Yet another she had sex with who came to her house and robbed her of all her money. She thought: "Had she been unwell on those occasions or had she been longing for love and affection? Did she feel a sense of belonging in that strange environment, that brick and cement block that contained her new life?"

It was still Christmas Day and the sun had set on the beach, the evening drawing to a close, it was nearly ten o'clock. Suddenly there was a knock on the door. "People! Someone had remembered her and they were visiting!" She opened the door feeling full of the Christmas spirit. Two men were standing outside. She hurried them in, laughing and inviting them to have a few drinks. She had never seen them before. They started talking, asking questions. They did not say who they were, but she knew.

Susan had an urge to go and walk by the beach. The two men followed her. One was holding a mobile phone. He started talking into it. Reality was losing its focus for Susan. Her thinking was becoming cloudy. Her legs functioned on automatic. She was only aware of the sea breeze entering her nose and filling her lungs, a warm comforting feeling. It was very dark. Her body continued to move towards the beach, towards the sea. She saw the bright lights, crashing into the darkness and giving her a sudden jolt. The police. She knew immediately what they were there for. Susan's body knew what to do. It walked towards them, sounds of sea inside her head, warm air in her lungs. She walked towards the car and got in.

#### Story 23 - Rosa

Rosa lived in a large suburban house with her husband, Tony, and their teenage son, Mario. The family ran a successful business and the son attended an exclusive boarding school in the country. Rosa had always been house-proud. This was difficult with a teenage son who would just drop things around and not clear up after himself. One evening Mario returned from boarding school for the holidays. Within moments the house was a mess, bags and shoes dropped everywhere, Mario lounging in front of the TV demanding dinner. Rosa got angry and told him to get up and start putting things away.

Mario was a big boy. He was not afraid of his mother and had often witnessed his father losing his temper with her. Tony used to slap Rosa across the face and shout abuse at her during the initial stages of her mental illness. Her behaviour then was erratic, her thoughts were all over the place, and she was highly irritable. She failed to turn up for work at their business, became overly friendly with customers, and caused staff to resign. A series of incidents led to a diagnosis of bipolar disorder, followed by multiple admissions to the local psychiatric unit, always scheduled.

On this occasion, Mario started hitting Rosa with a walking stick. They were in the bathroom and Rosa was worried the shower screen would brake. She took the stick off Mario but slipped on the floor and, suddenly, he was on top of her, hitting her in a rage. Tony intervened

and separated them. He concluded that Rosa was “becoming high” because she was angry and screaming at their son. Tony decided to contact Norelle, Rosa’s new casemanager.

When Norelle arrived accompanied by Dr. Zilman, a psychiatric registrar, Rosa was red in the face after the struggle trying to release her son’s hands from around her neck. They assumed her redness was anger and elevated mood and they gave her a tablet to help calm her down. Rosa was worried, as she knew the process of being hospitalised. She knew that nothing she would say or do would be of any use to avoid hospitalisation. They always believed Tony anyway.

As her mood remained angry and agitated, she avoided eye contact and refused to answer questions. This continued resistance was seen as evidence that she must have spat out the medication, proof of how unwell she was and that she would be unwilling to accept voluntary treatment. “I was willing to go but they didn’t ask me!” she said. The doctor wrote the Schedule II and called the police to take her. She was angry but said nothing, thinking: “They only say that you are sick, that you don’t know what you are talking about!”

Over the years, Tony had recognised the effects of the illness on Rosa’s behaviour and his abusive behaviour towards her stopped. However, Rosa could seldom express any intense emotions without him concluding that she was yet again affected by mental illness. She expressed this constant pressure in saying: “When you are mentally sick, the first time you are cranky about anything straight away they think you’re manic. I can’t even get angry. I shut up or go away from the room or I go to hospital.”

She thought she was lucky this time. The police officers who arrived were friendly and gentle. She told them she did not want to go in the paddy wagon, she wanted to go in the car, but they said that was not possible. What could they have been worried about? She did not want to go alone! Tony volunteered to go in the back of the wagon with her, but as she followed him in he turned around and got back out. The doors closed on her. She heard the lock sliding across the doors. It was dark, cold, and very uncomfortable. She felt alone, “like a dog.”

#### Story 24 - Alfred

Alfred sat in his lounge-room, staring at the television. He had not been feeling well lately. In fact, he was not a very happy young man since being diagnosed with bipolar disorder. He was only 24 years old. He had been having difficulties maintaining a job and his parents decided to set him up independently. He shared his unit with a friend who was away that day.

Alfred had been seeing Dr. Smart for a few months now, to ensure he remained well. He had a couple of voluntary hospitalisations, and he knew it was important to take his medication regularly. Early that morning he decided to ring Dr Smart. He really did not feel on top of the world, he was restless, irritable, having difficulty going out. He was not in the mood for socialising.

It was 8 in the morning. Two men from the EHT arrived at his door to talk to him. Alfred did not want to see them. He was expecting Dr Smart. He had told him he would come and visit him. What were these guys doing there, anyway? He did not want to talk to strangers. Alfred was frustrated so he hit the TV cabinet door. He needed to vent his frustration! The clinicians left, saying they would come back later, when he was feeling better.

Now Alfred felt even more annoyed. Why had Dr Smart sent John and Bruce? Why had he not come himself? Suddenly a crashing noise through the back yard made him jump. He looked around, his balcony door was open, and four police officers came running through his back gate, straight up to him. Behind were Alfred's mother and sister. Alfred could not believe what he saw. Why was this happening? Had they thought he was dangerous because he hit the cabinet door? He was angry. He saw no reason for them to be there with the police. He did not think the police should be involved at all!

Alfred had no choice but to follow them. It was a waste of time trying to resist four police officers. Big ones! It was a no win situation. He felt angry and humiliated. He felt like a criminal. He did not want to be locked up. He should have been told. After all, he had asked for help.

He was angry with his mother because he thought she had something to do with it. His mother and sister stood by and watched while the police took him away. That really pissed him off! He should have gone in the car with his mother, not in the paddy wagon. They should have warned him "if you don't come with us we will schedule you." They left him in no man's land, not knowing what was going on.

#### Story 25 - Paul

Paul sat at his computer. He enjoyed surfing the net, looking for like-minded people with whom to connect. He was an avid reader, had an inquisitive mind, and strong opinions about most things. The marketing career he held for many years, and his marriage, had both collapsed years ago, when he first became unwell. On that occasion, his family took him into



hospital by giving him drugs to make him sleep. They crushed the tablets into his food. At the hospital he was “held down and pumped up with more drugs,” waking up three days later.

He had since moved to another State, living in a small rented unit he shared with a flatmate. In this unit, there were books everywhere, on every wall. An enormous fish tank, with tropical fish of many colours and sizes, added a calm hue to the room. Too much time on his hands. Being unemployed is hard for someone who was previously able to hold a successful career. Finding a new job is even harder, especially with a mental illness.

That day, his father, Roger, and his sister, Naomi, came to visit. That was a common occurrence as they were always concerned about him, ever since his first admission. He found that annoying at times. They did not understand his “great mind, his ability to perform minor surgical procedures despite not being medically trained.” He had practised a lot as a child, on animals. Now he wanted to practice on others. “No big deal! Many non-medical people practised their healing techniques on others.”

Roger told Paul his mother would be along soon with some lunch. They were very quiet. Paul could not understand why. They were usually chatty, and often got involved in lively discussions on their different beliefs about medicine, religion, whatever. Then, there was a knock at the door. Paul answered it expecting to see Doris, his mother. Dr. Berry stood in the doorway and with him were two policemen and a member of the crisis team. Paul looked at them blankly, thinking: “What is going on? What are they doing here?”

Dr. Berry looked at Paul, and then quickly gazed inside the small two-bedroom unit. He saw Roger and Naomi sitting at the kitchen table, looking sullen. They got up as soon as they saw who was at the door and moved into the lounge-room. Dr. Berry looked at Paul and after some small talk said: “Under Section 21 of the Mental Health Act you are coming with us.” Paul could not believe what was going on. He began to argue. Dr. Berry had no grounds to take him into hospital. He had done nothing wrong, just tried to help a friend.

Dr. Berry waved a piece of paper in his hand. He said: “I have this paper here which gives us the right to take you into hospital.” Paul asked: “Can I see it?” Dr. Berry bluntly said: “No, you cannot see it!” That was difficult for Paul. Were they afraid he would tear it up? He had heard of people doing that. Could they not keep a spare one, just in case, and explain it properly to him? He would have liked to see the document.” He was curious, and had always enjoyed knowing about legal matters.

He felt anger. "Who the hell did Dr. Berry think he was?" Paul would have had the right to kill him there and then if they had been in some other country! No, he had no intentions of murdering Dr. Berry. He just wanted to give back some of the intimidation he was receiving. See how he liked it! He walked into the kitchen and pulled a carving knife from the drawer. He noticed the slight movement in the police officers' posture. He saw his father and sister looking at each other. Did they think he would do anything stupid? He was just testing how much control he had left. None! The officers asked him to put the knife down. He obliged. What choice did he have? Paul decided there was no point in arguing any longer.

He went quietly. He was upset about it, but what could he do? He thought this was probably to do with what had been going on in his life: the assault charges, the loss of job. Someone must have been out to get him. He knew too much, he was too bright, dangerous for some. Maybe they were taking him to prison, maybe he would never get out again. He walked out of the unit followed by the police officers and the mental health clinicians. He looked back for a second at the fish tank. He was worried about his fish. Would his parents look after them? He would miss them. He would miss his home.

#### Story 26 – Steve

Steve thought there was something wrong. He had a similar experience the year before. He remembered feeling out of sorts, somehow not grasping what was happening to him. He saw a doctor then and was given some medication. He did not know what it was, but it had settled his thoughts, he felt less anxious. He was glad it had worked for him. He had an important job. People relied on him and he earned good money that enabled him to live an independent life.

Steve stopped taking his medication once he felt well. He had a lot to do and a full life to live. He wanted a relationship, to settle down. He did not want slowing down, feeling sluggish. Soon he started behaving oddly. Was unreliable at work, felt he could not get out of bed, that something was going to happen. It all started one night when he was out with friends and talking to a girl. She was pretty and he wanted to walk her home. Steve bought her a drink. They danced a little. Then she said she was going to the Ladies and did not return. He saw her walking out of the door, laughing with her friends. She briefly glanced his way but did not wave goodbye. He felt something move through his body, his head felt hot.

A few weeks later Steve walked out of his job. He gave them no explanation and no notice. He was behaving a little strange with his mother, Ms Davis and did not go down to see her as

he used to do. He felt more irritable than usual. He did not know what he was saying anymore. People were looking strangely at him and he just wanted to scream at them.

Then one day his GP rang him. He told him his mother was very concerned about his behaviour. "What is going on Steve?" he asked. Steve replied: "Nothing! Nothing is going on but people will not leave me alone!" His head was hurting. His thinking was muddled. He knew his mother was worried but it was none of her business anyway! The GP rang a couple of times to see how Steve was doing. Steve knew his mother had spoken to him. He knew that maybe he should have gone back when he stopped the medication, when his head started to feel heavy again.

Then one day his mother told him he had to see the doctor and "dragged him along." Steve remembered acting quite bizarrely in the doctors' office. He felt very suspicious, not sure that the doctor was who he said he was. He told Steve he needed to make an appointment to see the crisis team, but there was no way he was going to do that. The GP was concerned.

A few days later a couple of people came down to Steve's house to talk to him. Then another doctor came. Steve did not know him and did not want to let him in, did not want to shake his hand or anything. The doctor left and came back shortly after holding some papers. Steve knew they were to get him scheduled. John came down as well to tell him he was going to hospital.

Steve told them he did not want to go to hospital and John said he had to. Steve replied that he was not going to go and that was when the police came and that was it. He was apprehensive. The event suddenly became the real thing, not just people talking to him. He was going to hospital. Steve began arguing, resisting, but he realised that he had no option. So he packed some personal belongings in his bag and went with John. He got into John's car and a policeman got in with him and they drove away.

#### Story 27 - Teresa

Teresa had been in Australia for a while. She had been scheduled a number of times back home in Europe and was keen to prove she was well now. Her life, however, was not going too well, and she was taking illicit drugs again. She had been taking speed for two weeks, which she had not done before, and was smoking a bit of pot. She was in a bad way and she knew she needed to see Olwyn, her primary clinician, soon.

Teresa contacted Olwyn saying that she needed help. She was not sure what she needed. Olwyn looked at her and saw she was unwell. She could not do much unless Teresa stopped taking drugs. Teresa went back home, with a follow-up appointment to see Olwyn in a couple of days.

Teresa's brother, Brad, lived in another Australian state but had always kept close contact. He knew of Teresa's history and worried she would become unwell again. One night, after speaking to her over the telephone, Brad felt concerned. Teresa was living in her car. She had been for a while and did not have the courage to tell Olwyn. She would park the car in public car parks in the middle of the night to sleep, and occasionally would walk to the unit she shared with a friend to use the telephone.

One night Brad was so concerned that he tried to arrange for a flight down to see Teresa. However, no flights were available. He decided to drive, getting into town the following afternoon. He had contacted Olwyn, and had arranged to meet at the centre that day, at the time of Teresa's follow-up appointment. When Teresa arrived, she saw Brad's car outside the mental health centre. She walked up to meet them. Olwyn and Brad were sitting outside discussing the options: Outpatients, Detoxification, etc., and that was when Dr. Finley appeared.

Teresa wondered who the young doctor was, what she wanted. Dr. Finley talked to Teresa for a little while and then moved away. Teresa was annoyed over why they wanted her in hospital! She did not want to go, and told them so. "I don't want to go to hospital! I'll do outpatients! I'll do whatever!" Her brother stood with her, discussing the different options at the front of the building. Teresa thought Olwyn must have known something about what was happening! Olwyn knew something had to be done. Teresa went up the stairs towards Olwyn who said: "We really need to talk." Teresa was beginning to feel distressed, a feeling of foreboding, and said to Olwyn: "What are we going to do?"

Teresa was shaking: "Look, why don't we sit out in the garden like we normally do?" Olwyn agreed and they walked out into the front yard. Teresa's brother was waiting. Neither realised however, that Teresa was being scheduled as they spoke. They were sitting out on the pavement and Brad was reiterating all the options to Teresa and saying: "Come on Teresa, you're sick and you know it." Olwyn had gone back in, looking for Dr. Finley. Teresa did not know the police were being called.

Teresa walked away. She was getting upset because they kept trying to get her to go to hospital. Hospital! Hospital! Could they not let go? She had promised herself, no, she had sworn to herself she would never go to hospital again! How could this be happening? Many bad things happened, wrong decisions were made back home, and she was drugged up to the eyeballs and was going around like a zombie, shaking very badly! When she reflected on this, she felt depressed. She was trying to fight her own case with these people but felt she was against the hardest psychiatrists and doctors. She believed her brain was not functioning properly: There are times when one can not help but being emotional, and times when you know exactly what's happening all around you.

Suddenly, in full view of passers-by, the police officers arrived. Olwyn had a Schedule II form in her hand and said: "Jesus, it's out of my control." Teresa wondered, why bother discussing options? Why had they gone to all that trouble? Why give her false hopes? She was ready to go back to the table to discuss those options further! Instead, she was thrown in the back of a paddy wagon. It was so public, so humiliating! She felt claustrophobic, as though choking to death.

Teresa was on her own, thinking: "I'm in full view of everyone, every Tom, Dick and Harry who's passing by in cars and trucks and doesn't know who I am and why this is happening." She could hear Brad screaming to one of the officers: "I'm in control, here! You take your hands off my sister you're man-handling her." However, the policewoman turned around and said: "Take your hand off my arm or you'll be charged." Teresa thought it was very distressing for Brad. If it were an ordinary police car, they would not have felt so bad.

#### Story 28 - Tom

It was difficult for Tom that day. He felt normal, like an every day young man. He did not really feel any different from any other day. In his mind he believed something strongly and wanted to tell everyone about it. He finally understood the flaws in Einstein's Theory of Relativity and spent many hours writing it up and discussing it with anyone willing to listen. He was always like that. He would tell anyone he encountered. He wanted to convince a number of people of what he believed, but nobody believed his theory! He went home that day, tired and frustrated, and went to bed.

Tom's mother, his brother, David, and a friend of the family were in the unit when he was scheduled. Two clinicians arrived. Tom did not know them, but he was too sick to recognise anyone. It was night, pouring with rain. He did not know what was going on. He had

difficulty finding out what was going on from day to day. Tom felt like a dummy. He did not know what was going on and no one was telling him. He felt he was just told what to do. He believed that the mental health clinicians came in, sat him down, talking to him for about 10 minutes. "They decided what they thought I had and they said I was going to hospital. Didn't even find out about staying in until I got there!" Tom did not take anything with him because his family and the clinicians did not want him to think that he was going away for a while. He felt he was not given a choice, and probably should have run away when he could. Should have disappeared when he could.

He felt nothing towards the clinicians. Did not have any thoughts about it really! He did not even know who they were. There were two people, they came into his house and they told him they wanted to talk to him. He talked to them! He was actually not given an opportunity to! To be quite honest, he could not tell anyway.

Tom did not like going into hospital. It was not very pleasant. Just the way they went about it. How they took him in, and no one talking or listening to him. It was just driving him nuts! They would not even talk to him. They would not even tell him what was going on. They were taking his shoelaces and his drawstring and filling him with drugs. They put him in a padded cell, and they just put him to sleep and that was it. They did not give him any explanations. Sure, he probably would not be able to rationalise it anyway. Jesus! He just felt so lost.

#### Story 29 – Mike

Mike was under the care of the crisis team that weekend. He had been unwell for a while and they were trying to treat him at home. They gave him some pills to take. Tanya from the EPOCH team saw Mike regularly. Mike knew he was not doing very well too. They decided to change his medication and this caused Mike to become unwell again. He became distracted and did not remember to take the medication. He did not remember where he put it! He looked everywhere and could not find them.

Tanya saw him becoming unwell and gave him some drugs to take that were supposed to knock him out. However, he was already too high by then; he was not quite ready to take anything. Instead, he stayed at a friend's house overnight, avoiding contact with the clinicians. Then the next day he went home.

Mike started seeing things and hearing things. His parents were away and left the station wagon behind. Mike decided he wanted to take it for a drive. He wanted to take some stuff to

a storage place and he wanted his sister, Jessica, to drive him there. He knew he was not supposed to drive while on medication. However, she was asleep and he did not want to wake her so he grabbed the keys. In the mean time his sister woke up and was not very happy with what Mike was doing. They had a fight and she called the police because Mike would not give her the keys back. Worried, Mike returned the keys but she would not cancel the police. He got upset and they started “mucking around.”

Jessica did not understand! She did not know whom to call so she resorted to the police. Mike was very disappointed by this choice. He had contacted the crisis team and they said: “Stay at home. Do what you’re doing and take some Valium at night. Try and get some sleep.” It was a Sunday, harder to get the team to go out. Jessica did not know that Mike had spoken to the team. In fact, Mike doubted that his sister actually knew of the existence of the crisis team, despite his ongoing involvement with them.

When the police officers arrived, they had a short conversation about the events preceding their arrival. His sister informed the police of Mike’s history of psychosis and the police officers felt it would be safer to take him away. He was asked to go in the back of the paddy wagon and he did not oppose them.

Mike thought that he would not have been scheduled if the EHT had turned up. Maybe they could have given him more of the tablets they’d given him before. Who knows! Mike knew what was happening. He knew he had scared his sister and that he was not very well.

#### Story 30 – Alex

Alex had been with mental health services for many years. More than he could remember. He told the story in short quasi-monosyllabic sentences. He remembered the doctors coming out and his mother and they took him to the acute ward. They came to his house. He was not sure how they came to know he was unwell. His mother probably told them. He did not know either of them. It used to be different people turning up anyway! It was four in the afternoon and he was asked to get in the mental health service car. There was very little conversation. Alex knew what to do anyway! He knew why they were there. He packed his bag and went. He was scared though. He did not like it in the hospital, but he knew there was no choice.

**Appendix D**

**Community Schedule Interview Questions**

**(Please note that this questionnaire is to be used as a guide for the interviewer, NOT as a self-administered tool)**

Date of survey \_\_\_\_ / \_\_\_\_ / \_\_\_\_

**1. Demographics**

1. Date of last schedule \_\_\_\_ / \_\_\_\_ / \_\_\_\_

2. Date of birth \_\_\_\_ / \_\_\_\_ / \_\_\_\_

3. Male / Female

4. Diagnosis (if any/known) \_\_\_\_\_

5. Country of birth \_\_\_\_\_

6. Other language \_\_\_\_\_

7. Source of income

1. Disability Support

2. Unemployment

3. Age Pension

4. Wages      F/T      P/T

5. Other \_\_\_\_\_

8. Living situation (circle all applicable)

1. Alone

2. Partner

3. Children

4. Share with friends

5. Share with others

6. With parents

7. Other \_\_\_\_\_

9. Can you remember how many times you have been scheduled into hospital? \_\_\_\_\_

10. Do you believe you had a mental illness at the time of the schedule?    Y / N / Not sure

**2. Personal experience of the event**

Think back to the last time you were scheduled.

1. Could you describe the event? (Prompts: Who contacted the mental health staff; Who else was involved at that time; At what time of day/night did the schedule occur)

2. Were you given an alternative to admission? (Prompts: compliance with medication, voluntary admission)

3. How were you transported to hospital?

4. How resistant were you to being hospitalised?

1. Not at all

2. Mildly

3. Moderately

4. Extremely

I \_\_\_\_\_ I \_\_\_\_\_ I \_\_\_\_\_ I \_\_\_\_\_

Please explain:

\_\_\_\_\_



**3. Feelings at the time of the event:**

How did you feel at the time of the event?

- a) When approached by the mental health staff in the community
- b) Towards the person who initiated the schedule
- c) If police were involved, about their involvement and use of paddy wagon

**4. Knowing others present at the time**

1. Did you know any of the people involved in taking you to hospital?

- a) Who did you know?
- b) How did this make you feel?
- c) Did it affect your relationship with your
  - 1. Casemanager
  - 2. with police?
  - 3. family member?
  - 4. GP/Doctor

In what way?

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**5. Explanations about events**

Was what was happening explained to you at any time before or after being taken to hospital?

- a. Were you aware of the Mental Health Act legislation before being taken to hospital?
- b. Were you aware of your rights as a mental health client?
- c. Were you aware of the possibility that you may be taken into hospital when you first became involved with the mental health Service?
- d. Were you told what might happen? (ie. police involvement, the legal power of Mental Health staff, the assessment process, etc.?)
- e. Do you think it would be beneficial to know in advance that this can happen?
- f. At what time do you think you should be told? (circle)
  - 1. Never
  - 2. When first coming into contact with the service
  - 3. When you are becoming unwell
  - 4. At the time of being taken to hospital
  - 5. Later when in hospital
  - 6. After discharge
  - 7. At regular intervals thereafter

**6. Trust in the mental health system**

1. Has your experience of being taken to hospital increased or decreased your trust in the mental health service? Increased/Decreased/No change

2. Please tell me if you agree or disagree with the following statements:

a. When in crisis I am prepared to contact community mental health staff

1.strongly agree	2.agree	388.not sure	3.disagree	4.strongly disagree
I	I	I	I	I

b. Involvement with community mental health staff may increase the chance of being scheduled

1.strongly agree      2.agree      88.not sure      3.disagree      4.strongly disagree  
I \_\_\_\_\_ I \_\_\_\_\_ I \_\_\_\_\_ I \_\_\_\_\_ I \_\_\_\_\_

c. Involuntary hospitalisation is sometimes necessary when acutely ill

1.strongly agree      2.agree      88.not sure      3.disagree      4.strongly disagree  
I \_\_\_\_\_ I \_\_\_\_\_ I \_\_\_\_\_ I \_\_\_\_\_ I \_\_\_\_\_

### **7. Improvement**

1. How could this process be improved?

a. By giving you the opportunity to discuss the schedule afterwards?

b. By involving your family more in your treatment?

c. By giving you information about what can happen before it does?

### **8. Done well or helpful and the worst part of the event**

1. What was done particularly well or was helpful?

2. What was the worst part of the event?

3. Did you believe at the time that the decision to schedule you was helpful?

4. Do you believe now that the decision to schedule you was helpful?

### **9. Effects on general wellbeing**

- |  |        |
|--|--------|
| a. Feeling safer knowing there is help available     | Y/N/NS |
| b. Loss of trust in people generally                 | Y/N/NS |
| c. Brought the family together                       | Y/N/NS |
| d. Feelings of anger when thinking about the event   | Y/N/NS |
| e. General feelings of powerlessness/loss of control | Y/N/NS |
| f. The community is more tolerant                    | Y/N/NS |
| g. Suicidal thoughts                                 | Y/N/NS |
| h. Nightmares relating to loss of freedom, etc.      | Y/N/NS |
| i. Others will call for help when needed             | Y/N/NS |
| j. Sudden crying spells                              | Y/N/NS |
| k. Feelings of shame                                 | Y/N/NS |
| l. Poor self-esteem                                  | Y/N/NS |
| m. Currently afraid of being taken back to hospital  | Y/N/NS |
| n. Feeling guilty of a 'crime'                       | Y/N/NS |
| o. Other (please explain)                            |        |

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This is the end of the questionnaire. Thank you for your time and information. Is there anything else you would like to add? Or are there any questions you would like to ask? Please feel free to ring me at Bondi Junction (93871644) if you want to discuss anything else at a later date. Thank you again and goodbye.

Developed and adapted from: 1. Lucksted, A. & Coursey, R.D. (1995) Consumer Perceptions of Pressure and Force in Psychiatric Treatments, *Psychiatric Services*, Vol.46, n.2. pp. 146-152; 2. Parrish, J. (1993) Involuntary Use of Interventions: Pros and Cons, *Innovations & Research*, Vol.2, n.1, pp.15-22; 3. Joseph-Kinzelman, A., Taynor, J. et al (1994) Client's Perceptions of Involuntary Hospitalization, *Journal of Psychosocial Nursing*, Vol.32, n.6, pp. 28-32.

## Appendix E

### South Eastern Sydney Area Health Service Community Health Services And Programmes Consent Form

#### **Community Schedule: Can the Effects Be Minimised?**

You are invited to participate in a study of the effects of being taken into a psychiatric hospital. We hope to learn about your experience and what you feel that our service could be providing that would make the experience more meaningful. You were selected as a possible participant in this study because you have been scheduled (transported against your will for further assessment) to hospital and I feel that you may have valuable information to contribute.

If you decide to participate, I will:

- \* Visit you in your own home or a place chosen by you, and interview you on your experience and how it has affected you, either positively or negatively. The interview shouldn't take more than one and a half hours. You will only be interviewed once.
- \* The only inconvenience to you will be the time taken by the interview. You will not need to write anything or fill in any forms as I will be completing the questionnaire as we talk. If you so permit, the interview will be taped.
- \* You may at times feel uncomfortable because of talking about a personal and delicate subject. If this is the case you are free to terminate the interview at any time, or we can have a break and start again later.
- \* It is very improbable that any problems will occur due to this interview, but because this is a very sensitive topic you may feel overwhelmed by anger or very upset as you are telling your story. If this happens, and you want to, the interview will be stopped. Many people get some relief from telling their story, but you may find later that you are still upset and need to talk to someone. If this happens, please ring Bondi Junction on 9387-1644 and ask for an appointment with Dr. Jackie Curtis, a psychiatrist, who will see you to talk about your feelings.
- \* We hope this study will benefit all clients of the service, their families and friends, and the mental health staff by providing information that will be used to develop better ways of working together.

#### **We cannot and do not hold that you will receive any benefits from the study**

Any information about you that is obtained in connection with this study will remain confidential and will be disclosed only with your written permission. However, the results of the study may be published or disclosed to other people in a way that will not identify you. The interviews and tape will be stored in a folder, kept in a filing cabinet in a locked office and will be disposed of by shredding after five years. The data collected and the analysis will be stored on disk and on a Personal Computer kept in a locked office, and will be disposed of by deleting the files after five years.

Whether you take part in this study or not, it will not make any difference to the medical treatment you receive from the Eastern Suburbs Mental Health Service or your casemanager.

If you decide to take part in this study, you can still withdraw at any time and this will not make any difference to your medical treatment either.

If you have any questions Dr. Doughty - 93871644 will be happy to answer them. You will be given a copy of this form to keep.

## CONSENT FORM

### CERTIFICATION BY INVESTIGATOR AND CONSUMER:

I hereby certify that I have fully explained the study, in terms readily understood by the consumer.

Signature of Investigator: \_\_\_\_\_ Date: \_\_\_/\_\_\_/\_\_\_

### CONSENT BY CONSUMER:

I hereby certify that I have read and understood all the information provided and have been given the opportunity to ask any questions. I agree to participate in the research proposal described to me.

Signature of Consumer: \_\_\_\_\_ Date: \_\_\_/\_\_\_/\_\_\_

Signature of Witness: \_\_\_\_\_ Date: \_\_\_/\_\_\_/\_\_\_

Nature of Witness: \_\_\_\_\_

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### REVOCAION OF CONSENT BY CONSUMER:

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment, or my relationship with Bondi Junction Community Health Centre, or my casemanager, or my relative's treatment, or my relationship with my relative's casemanager.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**The section for revocation of consent by the patient should be forwarded to:**

Ms. Renay Atkinson (Program Manager)  
Bondi Junction Community Mental Health Centre  
26 Llandaff Street  
BONDI JUNCTION 2022