SHARED STATUS AND ADVOCATING PRACTICES:
NURSES WHO WORK WITH CLIENTS WHO HAVE A CO–EXISTING
INTELLECTUAL DISABILITY AND MENTAL HEALTH PROBLEM

by

Michael John Dorofaeff

A thesis submitted to the Victoria University of Wellington

in partial fulfilment of the

requirements for the degree of

Master of Arts (Applied)

in Nursing

Victoria University of Wellington

2007

ABSTRACT

This research is informed by the interpretive phenomenology of van Manen, and explores the lived experience of nursing from the perspective of nurses who provide care for people with a co-existing intellectual disability and mental health problem. Although nursing research is commonly informed by phenomenology, there is a dearth of literature of any description written from the perspective of nurses who provide care for people with intellectual disabilities and mental health problems. As a result of the closure of many large institutions in New Zealand there are not many nurses who work with people who have intellectual disabilities and co-existing mental health problems. The study participants were four nurses purposefully selected because they provided care for people with intellectual disabilities and mental health problems. Data was collected using semi-structured interviews, and the researcher identified and wrote about the recurring themes in the transcribed interview data, which best captured the lived experience of the participants. The themes were: criticism of services, holistic caring, working with the client, issues of status, need for specialist knowledge, enduring relationships, diagnostic issues, advocating, modelling good practice; and working alongside. After further analysis the themes were encompassed within the larger interrelated themes of "Status and positioning" and "Advocating practices", and finally within a single theme of: "The status and positioning of the nurse and the client leads to advocating practices." These themes were found to be consistent with the nursing literature and with the researchers own lived experience as a nurse who works in a specialist mental health intellectual disability service.

The findings of this research have implications for a number of groups in New Zealand. Input is required from the Nursing Council of New Zealand, the nursing profession, nurse educators and the New Zealand Government to raise the status of clients with co-existing intellectual disabilities and mental health problems and the nurses who work with this client group. The roles for nurses who work with this client group are emerging and are likely to be diverse and there is a need for further research to capture the different experiences of these nurses.

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

CHAPTER 1 – INTRODUCTION TO THE THESIS

This thesis is about the experiences of nurses who work with clients who have co-existing intellectual disabilities and mental health problems. The mental health needs of clients with intellectual disabilities are a significant contemporary health issue. The population of clients who have intellectual disabilities also exhibit the full spectrum of mental illness seen in the general population (Sovner & Hurley, 1983) and according to Borthwick-Duffy (1994) the prevalence of psychiatric disorders in this group is reported to be two to three times greater. According to the Diagnostic and Statistical Manual of Disorders (4th ed.) one percent of the population have an intellectual disability (IQ of >70) (American Psychiatric Association, 1994). New Zealand's population according to the 2006 census was 4,143,279 (Statistics New Zealand, 2006). The prevalence of mental health problems in this group has been variously estimated in the literature as being between 14.3% and 67.3%, depending on definition of mental health problems adopted by researchers (Campbell & Malone, 1991). The number of individuals in New Zealand who have an intellectual disability and a co-existing mental health problem might be as great as 15,000.

The Choice of Research Topic

My interest in the nursing care of people with intellectual disabilities and co-existing mental health issues stems from my concern at the lack of discussion in the literature relating to nursing this client group and my experiences as a nurse working in the area of intellectual disability and mental health.

Historically, there have been four main kinds of nurses in New Zealand: Psychiatric, psychopaedic, registered general and obstetric, and enrolled nurses. The term psychopaedic nurse is a term unique to New Zealand, and in the United Kingdom these nurses are called leaning disability nurses. These nurses have historically provided specialist nursing care (broad health care rather than mental

health care exclusively) for clients with intellectual disabilities in New Zealand. However, changes to nursing education in New Zealand largely resulted in the demise of the specialty of psychopaedic nursing. According to the Department of Health (1988), training courses for nurses in New Zealand were transferred from the hospitals to the tertiary education system in 1973. These courses were intended to be 'comprehensive', preparing "nurses for practice in psychiatric, psychopaedic, community, medical surgical, maternal and child health areas, unlike traditional [hospital] programmes which produced nurses to work in narrower fields" (p. 1). With the closure of institutions there was additional pressure on psychopaedic nurses to become comprehensively trained to improve their future career options. In 1997, 397 registered nurses and 184 enrolled nurses reported that they worked in the field of intellectual disabilities. The numbers declined to 286 registered and 149 enrolled nurses in 2000, and 243 registered nurses and 120 enrolled nurses in 2004 (New Zealand Health Information Service, 1999, 2002, 2006). With the number of psychopaedic nurses declining it has become harder to argue that there is a specialist and visible group of nurses uniquely qualified to provide care for people with intellectual disabilities in the community.

A limited number of services in New Zealand continue to provide jobs for nurses who work primarily with people with intellectual disabilities and mental health problems. For example, I am aware of nurses who work for specialist intellectual disability services in Dunedin and Christchurch, and various non-government organisations (NGOs), including specialist behaviour support teams. Six nurses are employed by the Mental Health Intellectual Disability team in Wellington and similar specialist mental health services in Auckland and Hamilton also include nurses.

Discussion about the place of nursing in providing care for people with intellectual disabilities and mental health problems is timely because the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 provides further opportunities for

nurses. This legislation allows the criminal courts to impose compulsory care orders on defendants with an intellectual disability and a full range of care options applies, including secure care. Regional units have been established in Porirua and Auckland to provide secure care and rehabilitation for clients with intellectual disabilities who are considered to be a danger to themselves and/or other people. These units employ learning disability nurses from the United Kingdom to complement the limited number of nurses in New Zealand with this specialist knowledge. As well as jobs in secure care, nurses can be employed as Compulsory Care Coordinators, and Care Managers, new roles being created by the legislation.

Personal History

My nursing practice has predominantly been with people who have intellectual disabilities. I gained my nursing registration in 1993 and worked for three years at a psychiatric hospital, which was a combined intellectual disability and mental health facility. The two sides of the hospital were managed quite separately. Management from the intellectual disability side of the hospital were keen to emphasise the difference between mental illness and intellectual disability and their facility was given its own name to foster its separate identity.

Because of the high resident/client to staff ratio and the expectations of the institution, nurses and care assistants in the intellectual disability side looked after 20 to 30 people and did their best to support them though the essential ward routines. The institution provided the residents with little privacy and little choice in their own lives.

Many of the residents were treated with neuroleptic/psychoactive drugs. Although it was acknowledged that neuroleptic drugs were often used to treat 'behavioural problems' there were clients who were thought to have a mental illness in addition to their intellectual disability. The diagnosis and treatment of mental illness was largely the responsibility of a general practitioner who also treated the various

3

physical ailments of the population. I remember being told by a charge nurse at the time that the psychiatrists employed by the mental health side of the hospital had refused to have anything to do with the mental health needs of the clients at the residential facility. While I accepted that an intellectual disability was not the same as a mental illness, I developed a strong appreciation of how difficult it can be to diagnose a mental illness when the client has an intellectual disability. I was also beginning to understand that some health professionals were reluctant to acknowledge mental illness in this client group. Further, I noted that nurses who chose to work with this population often had to make the best of poor resources.

In my experience nursing people with intellectual disabilities in the 1990s was also perceived as being low status work by nurses and New Zealand society and most new graduate nurses would work at the hospital for a few months until they found work in other areas. Nurses, a significant labour force within the institution, were increasingly viewed as proponents of a system which had no place in the contemporary care of people with intellectual disabilities. I remember guest speakers at intellectual disability conferences during the 1990s saying that nurses are readily identified with the 'hospital model of care' and that employment of nurses in the community care of the intellectually disabled would continue to impose the medical model on people who are not sick. Institutional care for people with intellectual disabilities was gradually making way for community residential care, and few jobs for registered nurses were anticipated in the future. The clients would in future access medical or psychiatric care from generic services within their local community. Nurses who had historically provided care for people with intellectual disabilities would need to re-evaluate their future areas of employment.

I also worked briefly at a residential service established on a hospital campus for a small number of clients with intellectual disabilities, many of whom also had mental health problems. This service was an opportunity to provide care for people with intellectual disabilities in an environment that was less institutional,

4

but still able to provide intensive support. I believed it had the potential to become a model of best practice, providing specialist care for people with an intellectual disability and additional mental health problems or challenging behaviours. Unfortunately the contract for this service was taken over by an NGO and the service gradually changed its focus. I felt angry about this at the time as it seemed that the provision of appropriate services for people with intellectual disabilities (and mental health problems) was being compromised by funding decisions and the unwillingness of hospital boards to offer services for a marginalised population. At that stage of my career there seemed to be few options for nurses who wished to work primarily with clients with intellectual disabilities and I transferred to nursing in mainstream adult mental health.

In 1997 my interest in nursing clients with intellectual disabilities was rekindled and my subsequent experiences have highlighted for me political debates and pragmatic issues inherent with caring for people who have intellectual disabilities and mental health problems. I am currently employed as a nurse in a specialist mental health intellectual disability service. The primary function of this service is to facilitate access to generic mental health services for people with intellectual disabilities and I welcome the opportunity to be a part of this endeavour. Unfortunately, generic adult mental health services are reluctant to provide a service for people with intellectual disabilities. It has been my experience that generic services seem to concentrate on what they believe is their core business-the provision of mental health services for a relatively unambiguous group of consumers, who have a moderate to severe mental illness as this is defined by generally recognised diagnostic criteria. Because mental health problems often present differently in people with intellectual disabilities, diagnosis is less definitive and more debatable and they may be refused access by a mental health service. Sometimes it seems that mainstream services wish to exclude people with intellectual disabilities altogether passing the total responsibility for their care onto specialist services.

The Aims of the Project

In this study I examined the lived experience of nurses who work with clients who have a co-existing intellectual disability and mental health problem. My aims were to:

- Describe the phenomenon of nursing from the perspective of nurses who work with clients who have co-existing intellectual disability and mental health problem; and

- To contribute to the debate in national and international literature on the nurse's perspective of working with people who have a co-existing intellectual disability and mental health problem.

The Benefits and Value of the Research Project

This research will meet the requirements of a Masters of Arts thesis (Applied) in Nursing at the Victoria University of Wellington, New Zealand. The expected beneficiaries from this research will be the researcher, the nursing profession, clients who have a co-existing intellectual disability and mental health problem, the research participants and nurses who work with clients with a co-existing intellectual disability and mental health problem.

The research will also make a useful contribution to the ongoing debate over what it means to be a nurse in the contemporary world. The client who has an intellectual disability will benefit when a nurse has a better understanding of their particular role in the therapeutic relationship, and is able to plan care accordingly. The research provides some initial impetus towards exploring the role of nursing people with a dual diagnosis in New Zealand. The nursing literature in this area of practice is sparse, and nurses must rely predominantly on their clinical experience,

literature from other disciplines (such as psychology and psychiatry) or other areas of nursing (such as general mental health,) to inform their practice. While the literature from related disciplines is pertinent, it does not necessary capture fully the reality of nursing clients who have co-existing intellectual disabilities and mental health problems. There is also literature related to nursing people with intellectual disabilities which is relevant although these nurses care for clients with a range of health and social issues rather than exclusively mental health and their lived experiences may differ slightly. The exploration of the shared experiences of nurses who work with clients with co-existing intellectual disabilities and mental health problems will contribute towards the collective knowledge of a specialist area of nursing practice. While undertaking this research, I developed a clearer idea of my own role as nurse caring for this particular client group from the information obtained from other specialist nurses.

Key Definitions

In this section I define key definitions including, 'intellectual disability', 'mental health problems', 'nurse', 'psychopaedic nurse', and 'dual diagnosis' used in the thesis

Intellectual Disability

My definition of intellectual disability is consistent with the DSM IV (Diagnostic and Statistical Manual Fourth Edition) definition, although I acknowledge that in clinical practice intellectual disability is often based on judgement rather than formal cognitive testing.

The DSM IV defines mental retardation, a term that is synonymous with intellectual disability as:

> Significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test; [and] concurrent deficits or impairments present in adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work leisure, health, and safety, the onset before age 18 years.
>
> (American Psychiatric Association, 1994, p. 49)

Terms such as learning disability, mental retardation and intellectual disability are used interchangeably in my research.

Participants in this research were nurses working with clients who have a co-existing intellectual disability and mental health problem. The clients' intellectual disability would have been confirmed by formal cognitive testing or they presented with apparent deficits in their daily functioning and cognition that would lead an experienced clinician to reasonably conclude that they have an intellectual disability. Services that work with people who have intellectual disabilities typically state that a person must have an intellectual disability to meet access criteria.

Mental Health Problems

I have chosen to use the term mental health problem, rather than mental illness, because of the complexity of mental health issues relating to the population of persons who have intellectual disabilities. Diagnosis in psychiatry is reliant to a certain extent on accessing the clients internal thought processes revealed in their spoken language. However, when the client is intellectually disabled and verbally impaired, diagnosis is less definitive and more subjective, being based more on observed behaviour. While terms such as 'mental illness', 'challenging

behaviour', 'behavioural problems', or 'maladaptive behaviours' may sometimes reflect the different philosophical standpoints of various services, they are often used interchangeably in practice.

Nurse

For the purposes of the research, a nurse is defined as someone who is recognised as a registered or enrolled nurse by the Nursing Council of New Zealand, including people with qualifications obtained overseas who are able to practice as nurses in New Zealand. Participants in the study were either registered comprehensive or registered psychopaedic nurses, designations that existed before the recent change in New Zealand to a single designation of registered nurse.

Psychopaedic Nurse

The term psychopaedic is unique to New Zealand and was coined in the early 1960s by the Director of Mental Health and the English Department of Victoria University to distinguish people with a mental illness from those with an intellectual disability (Watson, Singh, & Woods, 1985). Psychopaedic nurses in New Zealand were previously called mental deficiency nurse. The psychopaedic nurse completed a specialist nursing qualification to prepare them to nurse people with intellectual disabilities. In the United Kingdom nurses who specialise in this area are referred to as learning disability nurses.

Dual Diagnosis

This term is sometimes used to refer to a co-existing diagnosis of drug addiction and mental illness but for the purposes of this research this term refers to a person who has a co-existing intellectual disability and a mental health problem.

Overview of the Thesis:

This thesis is divided into 6 chapters. This first chapter has included an overview of my own interest in the topic, the aims of the project, the expected beneficiaries and Key definitions used in the research. In this chapter I position myself in relation to the research topic by including my personal history of working with clients who have co-existing intellectual disabilities and mental health problems.

Chapter 2 provides an overview of the search strategy and the literature relevant to the research topic including: background information on the provision of services ·in New Zealand for clients with intellectual disabilities and mental health problems, psychopaedic or learning disability nursing, and literature that explores nursing from the perspective of the nurse working with a client with an intellectual disability and/or a co-existing mental health problem. The literature was located by entering key words, including mental retardation or intellectual disability, nursing, and phenomenology, into computer data bases, and by searching the catalogues of libraries in Wellington.

Chapter 3 is in two parts. Firstly it presents an overview of phenomenology and the phenomenology of van Manen which informs my research, and secondly it discusses the design of the study, ethical implications and trustworthiness and rigour. I describe how participants' interviews are converted into stories to assist the identification of commonly shared themes.

Chapter 4 presents the four participants' interview data as individual stories. Inherent in this process is an initial analysis of the participant's themes because the stories were created by removing data that is not directly relevant to my research question, and the drawing together and interpretation of theme fragments to create a more coherent narrative.

Chapter 5 presents analyses and reflects upon the common themes that occur across the participants stories and best capture the lived experience of nurses who work with clients who have co-existing intellectual disabilities and mental health problems. The chapter interprets these 'lived experiences' by showing how they emerge and illuminating what the experiences mean in relation to the literature and my own nursing experience.

Chapter 6 presents a summary and discussion of the research findings and the implications of the research for nursing practice are identified. The chapter also identifies the limitations of the study and offers suggestions for future research.

CHAPTER 2 – LITERATURE REVIEW

In this chapter I present an overview of the relevant literature on the lived experience of nurses who work with clients with co-existing intellectual disabilities and mental health problems. This will include background information on the provision of services for clients with intellectual disabilities and mental health problems, psychopaedic or learning disability nursing, and literature that explores nursing from the perspective of the nurse working with a client who has a co-existing intellectual disability and mental health problem. The approach differs from a traditional literature review given that it includes information from government reports and historical information. I adopted this approach because of the absence of research literature in the field, and because it helps to set the scene and establish the need for research in this area.

Search Strategy

I conducted an initial search of computer databases, CINAHL, MEDLINE and PSYCINFO for information on the topic of nursing and intellectual disability in New Zealand. Key words entered into the databases included mental retardation, intellectual disability, learning disability, mental handicap, intellectual handicap, mental health and nursing and phenomenology. While I was able to locate several articles via the databases manual searches of libraries was more fruitful.

Although there is considerable literature on the care of people with intellectual disability, I found that there is a dearth of literature written from the perspective of nurses who provide care for clients with co-existing intellectual disabilities and mental health problems. Learning disability nurses in the UK are similar to psychopaedic nurses in New Zealand. These nurses' care for clients who have a range of health and social issues (not only mental health) and I have included literature written by these nurses in this review. I relied mainly on government reports and official documents for background information on the historical

provision of intellectual disability services in New Zealand. Watson, Singh and Woods (1985) also provided useful information. Psychopaedic nursing in New Zealand is not covered in any detail in the literature and the history of this disappearing area of specialist practice awaits future historians.

The lack of literature on a specialist area of nursing practice was one of the reasons why this present study on the lived experience of nurses who work with clients who have co-existing intellectual disabilities and mental health problems was needed. The literature in this chapter is divided into two sections, firstly the care of people with intellectual disabilities in New Zealand, and secondly, nursing and intellectual disability.

The Care of People with Intellectual Disabilities in New Zealand

In this section an overview of psychopaedic nursing and historical residential services in New Zealand for people with intellectual disabilities is presented. This information helps to provide a context for many of the contemporary issues related to the care of clients with a dual diagnosis. The literature does not focus exclusively on nursing people with a co-existing intellectual disability and mental health problem because people with intellectual disabilities who lived in institutions did not necessary have mental health problems and clients with a dual diagnosis were not routinely separated from their peers. Nurses who work with this client group might have personal experience of the historical changes and these changes might have influenced their practice and career choices.

The literature is presented under the following sub-headings: Psychopaedic nursing, Institutional care of people with intellectual disabilities in New Zealand, Changing times – The closure of the institutions, and People with intellectual disabilities and mental health problems – Contemporary issues of care.

Psychopaedic Nursing

Before 1961 psychopaedic or mental deficiency nurses in New Zealand were registered by the Nurses and Midwives Registration Board as Psychiatric Nurses under the Nurses and Midwives Act 1945. The Nurses and Midwives Amendment Act of 1960 included a separate section of the nursing register for psychopaedic nurses. The names of 761 psychopaedic nurses have appeared on the nursing register since 1929 and of this number, 270 held a current practising certificate for the year 1979-1980 (Nursing Council of New Zealand, 1980). Statistics from Wellington Hospital Board, Mental Health Service Planning Committee (1988) indicate that there were 150 people with intellectual disabilities in Porirua Hospital). At this time the Puketiro Centre, a specialist ward at Porirua Hospital for clients with intellectual disabilities, employed 36.33 full time equivalent nursing staff. Although additional psychopaedic nurses were employed in Porirua Hospital this report does not separate out the total number of nursing staff employed who work in the intellectual disability services from their mental health colleagues.

According to Watson, Singh and Woods (1985) nurses who work in institutions for people with intellectual disabilities in New Zealand are "either trained psychopaedic nurses, psychiatric nurses or trainee comprehensive nurses, depending on the particular institution" (p.50). Watson et al. note that residents received nursing care in proportion to the degree of their physical and intellectual disability and they were encouraged to be as independent as possible with their activities of daily living. The expectations that were held of psychopaedic nurses in clinical practice can be gleaned from the hospital based training syllabus.

According to the Nursing Council of New Zealand (1980):

> generic functions of the psychopaedic nurse [include] observation, assessment and analysis to contribute towards diagnosis; [the] planning, implementation and evaluation of nursing care; case finding; health teaching and health counselling; the implementation of treatment prescribed by licensed medical practitioners; the teaching and guidance of students; creating and managing a therapeutic environment; planning, evaluating and developing the health service as a member of an interdisciplinary team; and the ordering and development of nursing knowledge. (p.5)

In my experience the work of a psychopaedic nurse incorporates a wide variety of tasks including: monitoring the health status of clients and helping with the diagnosis and effective treatment of various health conditions including traumatic injury, epilepsy, asthma, diabetes, eczema, respiratory tract infections and mental illness; supporting clients with their activities of daily living which includes verbal prompting and varying levels of hands on care, nasogastric and enteral feeding, supervising non-nursing care staff and operating in a leadership capacity; restraining and secluding clients; writing care plans, management plans, life style plans and behaviour modification programmes; facilitating multi disciplinary team input into client care; supporting clients with transition into community care; liaising with family and whanau, and advocating for clients with intellectual disability to promote independence and prevent neglect.

Changes to nursing education in New Zealand largely resulted in the demise of the speciality of psychopaedic nursing. The impetus for this change came from the review of New Zealand nursing education by Helen Carpenter (1971), consultant for the World Health Organisation. The review commonly referred to as the Carpenter Report recommended phasing out hospital based nursing training and establishing three-year courses within the education system, and various government initiatives supported this process. Bridging courses offered by

technical institutes enabled nurses with single registration (psychopaedic for example) to become comprehensive nurses (Department of Health, 1988).

Institutional Care of People with Intellectual Disabilities in New Zealand

According to Mollett (2002), people with intellectual disabilities in New Zealand were once seen as having an incurable or organic condition and were placed in institutions along with people with mental illness. In 1852 the responsibility for health services was placed on the provincial government and "a network of lunatic asylums was established" over a twenty year period. Larger asylums were later built in rural areas to cater for overcrowding and "in this way Seacliff (1878) Porirua (1887) and Tokanui (1912) were built in areas newly opened up by railway where they became self-sufficient and closed concerns" (Mollett, p. 8).

For much of the 20th century the placement of people with intellectual disabilities in institutions was seen as a positive choice. Experts would often tell parents that their child could be cared for more effectively in an institution with trained staff with access to resources. Furthermore, the move to the institution would relieve families burdened with the care of an intellectually disabled member and allow them to get on with their own lives (Central Regional Health Authority, 1995). This philosophy was encouraged by 19th century myths about intellectual disability. The unusual behaviours demonstrated by some people with intellectual disabilities and their occasionally odd appearance was seen as evidence that the person was evil or possessed (Central Regional Health Authority, 1995).

During the 1880s and 1890s the public were concerned about the immigration of intellectually disabled people to New Zealand because of the perceived risk of 'moral degeneracy'. There seems to have been a fear of both amoral behaviour, and eugenic degeneracy (Howie & Cuming, 1986). A link was made between intellectual disability and "socially unacceptable behaviours" such as prostitution, alcoholism and illegitimacy. Society felt that it needed protection from these

people to ensure that negative traits were not passed on. People with intellectual disabilities were not thought to be completely human and did not deserve the rights and privileges bestowed on 'normal' people Howie and Cumming noted. "A series of laws were passed in early New Zealand (the Lunatics Ordinance of 1846, the Lunatics Act of 1868, and the Lunatics Act of 1908) which dealt with institutionalisation of mentally ill persons and mentally retarded persons" (p. 14). In the early 1900s the role of the Inspector General of Mental Health Services in New Zealand was extended to include clients with intellectual disabilities in institutional care. With the passing of the 1911 Mental Defectives Act, there was a shift from pure custodial care, and psychiatric hospitals were required to assume the education and training of people with intellectual disabilities. In the 1920s people with intellectual disabilities were segregated into separate hospitals following policy changes which came about following pressure from Mental Health Department (Watson, Singh & Woods, 1985).

Following the Mental Defectives Amendment Bill 1928, certain institutions were established for the care and training of children with intellectual disabilities (Watson, Singh, & Woods, 1985). These institutions were later called psychopaedic, a term coined in New Zealand in the early 1960s by the Director of Mental Health and the English Department of Victoria University to distinguish people with a mental illness from those with an intellectual disability (Watson, Singh, & Woods). The first psychopaedic institution was Templeton Hospital, closely followed by Ngawhatu in Nelson. These hospitals were developed and expanded during the 1930s and 1940s to cater for the increasing number of residents. In 1945 the Health Department established the Kimberley Hospital and Training Centre in a disused Royal New Zealand Air Force Station in Levin to meet increasing demand for psychopaedic services. Mangere Hospital in South Auckland was established in the 1960s to provide 1200 psychopaedic beds for Auckland and Northland (Watson, Singh, & Woods).

A survey carried out in New Zealand in 1971 showed that nearly 40% of people with intellectual disabilities were living in psychopaedic or psychiatric hospitals and of this number 33% were moderately intellectually disabled and 15% mildly disabled (Morrison, Beasley, & Williamson, 1976). A further study in North Canterbury in 1981 revealed that hospitals continued to provide residential care for approximately 40% of people with intellectual disabilities (Prentice & Barnett, 1983). Data from the Department of Health (1981) show that there were 2261 people with intellectual disabilities living in four psychopaedic institutions and a further 1793 residing in the psychiatric institutions throughout the country. Mollett (2002) in research undertaken for the Waikato District Health Board found that in 1985, 53% of people with an intellectual disability were cared for in psychopaedic hospitals and the remainder in psychiatric hospitals or, a small percentage, in the community. Nurses were one of the primary work forces who cared for clients with intellectual disabilities in the institutions.

A different view of appropriate care for people with intellectual disabilities emerged in New Zealand in the later part of the 20th century and philosophies (principles) like deinstitutionalisation, mainstreaming, normalisation and community care influenced the development of services.

Changing Times – The Closure of the Institutions

Increased knowledge about intellectual disability brought about a re-evaluation of institutions as ideal places of care for people with intellectual disabilities. The residents often behaved adversely in response to their environment and they were given few opportunities to make choices and to learn (Central Regional Health Authority, 1995). During the 1970s a moratorium on further extensions or building of psychiatric and psychopaedic institutions signalled the start of the process deinstitutionalisation (the transition of people from institutions into community care) in New Zealand. In 1982 New Zealand decided to "gradually phase out institutions for people with an intellectual disability" (Mollett, 2001, p.

9). This decision was consistent with similar changes in other parts of the world and according to Jack (1986) a review of the literature "shows that by the mid 1960s there was an international acceptance of the superiority of community over institutional care" (p. 85).

The impetus for deinstitutionalisation of intellectual disability services was provided by the concept of normalisation. Wolfenberger and Tulman (1982, p. 23) have defined normalisation as "much as possible, the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people." The Ministry of Health produced a document in 1984 discussing the progress of deinstitutionalisation in Australia and this paper was a catalyst for discussion about "some of the basic principles on normalisation" (as cited in Mollett, 2002, p. 9).

In 1986, a major review of psychiatric hospitals for the people with intellectual disabilities reported to the Department of Health with a number of recommendations about standards of patient care and encouragement for hospital boards to develop community services (Mollett, 2002). Taylor (1986) wrote that "the philosophy behind community placement is a human rights issue" and that "the intellectually handicapped person has a right to live as normal a life style as his/her disability allows" (p. 1). A criticism of institutions by many of their opponents had been that the care they provided was essentially based on the medical model, although the client population was not necessary sick. Howie and Cuming (1986) note that "any continued reliance on hospital services for mentally retarded persons suggests a disease concept of mental retardation" (p. 15). Steadham (1993) writes: "In addition to supporting the move away from institutions, professionals in the field of developmental disabilities have also endorsed a move away from what is generally viewed to be a 'medical model' of service provision" (p. 179).

The Department of Health published the *Guidelines For Standards For Services For People With Intellectual Handicaps* in 1988, which "advocated rights,

entitlements and freedom of people with an intellectual disability" (p. 9). Various regional changes to service provision arose in response to these guidelines (Mollett, 2002). In 1988, the Intellectually Handicapped Children Society (IHC) was contracted by the New Zealand Government to provide community based support for 61 people discharged from Kingseat Psychiatric Hospital in Auckland (Mollett, 2002).

The Ministry of Health (1994) noted that deinstitutionalisation had been a national and international trend for at least 45 years, driven by improved treatment practices, changes of philosophy and the preferences of consumers and caregivers. Following on from this *Coming Back*, a document produced by the Central Regional Health Authority in 1995, includes normalisation as a basic principle in the "care of people with intellectual disabilities." Other principles emphasised in this document are "the concept of the least restrictive environment", "the need and right to live in the community", and "the principle of inclusion" (p. 8). The New Zealand Disability Strategy released in April 2001 presented a vision of a fully inclusive society.

Given the gradual change in the provision of residential services for people with intellectual disabilities in New Zealand large numbers of people with intellectual disabilities were transitioned into the community between 1978 and 1998. According to a previous Deputy Director of Mental Health, Dr Nick Judson, there were approximately 1000 intellectually disabled persons remaining in institutional care in New Zealand in 1998 (Personal Communication, May 12, 1998). Antony Paltridge (2001) writing for *The Evening Post* reported that 82 people continued to reside at Braemar Hospital in Nelson. According to Mollet (2002) 345 people were transitioned into community residential homes from Tokanui Hospital between 1989 and 1998. By 1997, Porirua Hospital no longer provided residential and inpatient services for clients with only intellectual disabilities. From that date residential services were provided by non-government organisations (NGOs) such

as IDEA Services (formerly called IHC), Pathways and MASH (Manawatu Accommodation and Sheltered Housing Trust).

In 2001 the Ministry of Health reported that the Kimberley Centre in Levin is "the last major institution of its type" (p. 14). At this time there were 379 long-stay residents at the Kimberley Centre, including 19 who lived in a ward at the Horowhenua Hospital. The Mental Health Intellectual Disability Team from Wellington assessed residents from Kimberley to determine their future mental health needs in the community from 2003 until the Centre's closure in October 2006. The closure of institutions presented new challenges for New Zealand to provide appropriate health services for people with intellectual disability and mental health problems, and for the work of the nurse.

People with Intellectual and Mental Health Problems – Contemporary Issues of Care

Many professionals working within the field of intellectual disability hoped that psychiatric problems and behavioural difficulties would diminish as individuals were integrated into the community. However, community integration increased the need for mental health and behaviour services, because behaviours that were tolerated in institutions were viewed as abnormal within the context of community living (Cutler, 2001). Nottestad and Linaker (1999) writing about the care of people with an intellectual disability in Norway note that "deinstitutionalization has not been shown to solve any problems connected with the mental health of people with intellectual disability" (p. 528). They followed 109 subjects discharged from institutions and found that subject's behaviour and mental health problems had not improved and people were receiving less service input.

There is a growing acknowledgment worldwide of the need to respond more satisfactorily to the mental health requirements of persons with intellectual disabilities (Bouras 1999; Day 1994; Jacobson 1999). People with intellectual

disabilities have an increased risk of developing a mental health problem relative to their non disabled peers. A classic study by Rutter, Graham and Yule (1970) on the Isle of White found a positive correlation between the degree of disability and prevalence of mental illness. Fifty precent of the children with severe intellectual disability had a co-existing mental illness. A recent Australian study by White, Chant, Edwards, Townsend and Waghorn (2005) found that people with an intellectual disability have a high risk of developing a serious mental illness and their illness is often overlooked because of difficulties in making a diagnosis in this population.

A research project was commissioned by the Central and Midland Regional Health Authorities in 1995 to ascertain the support requirements of people with an intellectual disability and challenging behaviours. This report recommended that the Central and Midland Health Authorities purchase regional specialist support services and supported living services to prevent and respond to 'challenging behaviour.' IDEA Services a large provider of residential and vocational services for people with intellectual disabilities also has a specialist behavioural service. In 1997 the Transitional Health Authority decided to purchase a "specialist service for people with a moderate to severe mental illness and a co-existing intellectual disability in the Central Region" (Central Health, 1997, Schedule 34, p. 1). As a result the Intellectual Disability Dual Diagnosis Service (now called the Mental Health Intellectual Disability team) was formed. There are similar specialist services in Hamilton and Auckland. All these services employ nurses as well as other health professionals. The Mental Health Intellectual Disability team has also expanded to support clients transitioned from the Kimberley Centre in Levin.

Nursing and Intellectual Disabilities

There is limited recent literature that explores nursing from the perspective of the nurse working with a client an intellectual disability and a co-existing mental health problem. While it is often recognised that clients with a Dual Diagnosis are

not well served, the role of nurses in helping to address these peoples' needs is rarely acknowledged (Cutler, 2001).

Writers such as Gabriel (1994) and Holbrook (2000) typically focus on clinical issues and draw significantly on knowledge from other disciplines, psychiatry and psychology for example, rather than nursing. There is a body of literature written from the perspective of specialist nurses who work with clients who have intellectual disabilities and a range of health and social issues. Literature from these nurses is included in my study because of the similarities with the client group.

The issues discussed in the literature appear to cluster around key topics and I have used these as headings in the following presentation of the literature. The key topics are: assessment and intervention, advocacy, and status and positioning.

Assessment and Intervention

Gabriel (1994) refers extensively to the psychiatric, rather than nursing literature, but does make a number of useful comments based on her experience as a community based mental health nurse practitioner who works with people who have a dual diagnosis. According to Gabriel diagnosing a psychiatric illness in someone who has an intellectual disability is difficult because of the person's impaired ability to communicate. People with intellectual disabilities are frequently not able to say how they are feeling or express their problems and concerns, and "an internal drive or feeling is manifested in behaviour" (Gabriel, p. 36). Gabriel uses psychiatric diagnoses approved by the North American Nursing Diagnosis Association, and lists a number of specific diagnoses that are pertinent to this client group. She notes that nursing interventions for the person with an intellectual disability are the same as those used for the general mental health population, but accommodated to intellectual disability. For example, they may require shorter time frames and more problem specific techniques, and the nurse

may have to work more closely with significant others. Holbrook (2000) notes that the nurse must use advanced assessment skills when working with patients with intellectual disabilities and to ensure "diagnostic clarity, these skills must include a thorough mental status and neurological examination specifically devised for the population with intellectual disabilities" (p. 25). Holbrook suggests several assessment tools that focus on non-verbal cues and overt behaviour of the intellectually disabled client. Raghavan (1996) suggests that nurses who support clients with intellectual disabilities could "improve the assessment process by providing clear leadership in designing and carrying out multi-professional assessments" (p. 61). By developing their own observational systems and care plans, nurses can contribute to the process of assessment.

Advocacy

Jenkins and Northway (2002), commenting from their experience of services in the UK, argue that learning disability nurses have an important role in providing advocacy for people with learning disabilities who are often a vulnerable group. Advocacy helps to counter the "marginalisation and relative powerlessness of people with disabilities" (p. 11). The authors discuss three kinds of advocacy in detail, professional (or direct advocacy), self-advocacy and independent advocacy. According to Jenkins and Northway learning disability nurses also need to examine their own attitudes and ensure that they are listening to their clients. Where it is difficult for people with disabilities to speak on their own behalf (they are severely or profoundly disabled for example) the nurse can support the role of the independent advocate. The independent advocate is independent of organisation providing a service. Kay, Rose and Turnbull (1995) note that nurses who work with people with intellectual disabilities have become very good at advocating for their clients ensuring that they are able to access to services and that their health needs are met. Bollard and Jukes (1999) believe that an integral part of the nurse role is the concept of facilitating and empowering the individual who

has an intellectual disability. This ensures that clients have a full and normal life as possible, within the constraints and boundaries of their disability.

Broadly consistent with the notion of advocacy Patterson, Higgins and Dyck (1995) make useful suggestions about how services could better met the needs of clients with intellectual disabilities and mental health problems. They argue for a collaborative approach between local mental health services and specialist intellectual disability mental health teams. These authors refer to the relevant literature regarding the prevalence of mental illness in this client group and discuss the available service provisions from their own experiences in Washington State, but they do not refer to nursing literature. Although it seems that at least two of the authors in these articles are nurses, their professional qualifications are listed with their names, their nursing background is not made explicit in the text.

Status

Mitchell (2000) argues persuasively that learning disability nurses in the UK "have been marginalised by nursing because of their work with deviant groups," and "because of their inability to fit in with nursings central work" (p. 80). Learning disability nurses are predominantly working class, male and not involved in the care of the sick. Learning disability nursing is seen as out of place within nursing which emphasises the sickness model of care (Mitchell, 2000). Learning disability nurses have for many years worked in institutional settings. Mitchell (2003) notes that a series of scandals such as in the 1960s and 70s demonstrated that things were not well within many institutions, and nursing as a dominant profession within the institutions, bore much of the criticism. The bad publicity was an embarrassment to the whole nursing profession. Learning disability nursing was perceived as inappropriately placed in nursing and bound to a discredited institutional system.

Like Mitchell other writers have suggested that the status of the nurse is influenced adversely by the low status of their clients. For example, Waizkin (1991) says that when a group of clients has low status, such as those who have an intellectual disability, this results in professionals who care for them "having limited credentials." Over the long term, nurse interventions are likely to be supportive rather than "highly technical" which further reduces their status. Brooke (1999) says "to be blunt, the reason learning disability nurses are so marginalised is the general contempt in which society holds our clients" (p. 28). Moore (1986) writes "somehow I sense an attitude that I am less of a nurse because I work in a department of mental health facility for the" [learning disabled] (p.4).

Nurses who work with clients with intellectual disabilities often need to justify the work that they do to their profession and to wider society but according to Parrish and Sines (1997) learning disability nurses have found it difficult to explain their role to the public and to other health professions. Many people continue to have traditional images of the 'hospital nurse' and nurses who worked in long stay learning disability hospitals were encouraged to train in general nursing so ensure their recognition by the nursing profession. Unfortunately clients with intellectual disabilities may be non-verbal and therefore not able to speak about the value they have received from nursing input. In a similar vein Jukes and Bollard (2002) note that learning disability nurses "have always had to deal with professionals and public whose attitudes and value base is such that they exclude anyone who appears outside the mainstream" (p 297). Alaszewski, Gates, Ayer, Manthorpe and Motherby (2000) note that learning disability nurses often have to fight for recognition, constantly explaining and justifying their role and purpose to government and nursing groups, who chose to exercise exclusivity, to ensure their survival. According to Mathieson (2001) "learning disability nurses have always had a raw deal" (p. 32) and they are despised by their nursing colleagues and social care professionals are wary of nurses because of the potentially overlapping work roles. "The fact is nurses have an ongoing battle to prove they have something to offer in the care of people with learning disability" (p 32). Jones (1998) and

Turnbull (1999) note that the potential marginalisation of nurses and social workers who work in leaning disabilities and their struggle for professional credibility continues to be an issue after many years.

The survival of the learning disabilities as a specialist area of nursing practice has been threatened in the UK. With the move from institutions to community care there has been a debate about the continued need for specialist nurse to work with the client group. In the United Kingdom the Report of the Committee on Nursing (Briggs Report) suggested that nurses working in the field of mental handicap (intellectual disability) should not, in the long run be part of the nursing profession (Department of Health and Social Security, 1972). Following on from the Briggs Report the Jay Committee (Jay, 1979), established to inquire into the issue of mental health nursing and care recommended that mental handicap (learning disability) nursing be phased out in favour of a social care profession. After considering the Jay Committee's recommendations the Government in 1980 urged the general nursing council and the central council for the education and training of social work to introduce joint training for those working in mental handicap services (as cited in Mitchell, 2003).

Penningston (2000) reports comments from Wolverson, a lecturer/practitioner in Learning Disability, that disability nursing has historically been based in institutions which offered medical models of care and nurses "had little choice but to engage in task orientated care" (p. 48) They had little opportunity to practise holistic and individualised care. Nurses were viewed as asylum attendants who controlled and contained those labelled as deviant. Indeed, learning disabilities nurses may also have been held in the same low esteem as the people they cared for.

Positioning

Although nursing clients who have intellectual disabilities is sometimes seen to be a low status area of nursing various authors focus the contemporary role of these nurses and the particular skills they bring to nursing practice.

Mobbs, Hadley, Withering, and Bailey (2002) note that the gradual move from the institution to community care, for people with intellectual disabilities in England created the role of the community nurse, learning disabilities. This discipline has continued to evolve in response to the needs of the client population and various political demands and changing philosophies of care. Today, the specialist community nurse, learning disabilities, might work with clients with various needs in addition to their intellectual disability including, epilepsy and mental health needs and challenging behaviour.

Gabriel (1994) believes that a nurse's ability to view a client holistically is helpful because individuals with a dual diagnosis have the full spectrum "of physical disabilities and abilities" (p. 37). Nurses' holistic approaches and their skills in clinical advocacy mean they have a vital role coordinating services for clients who present challenges to community services. Cutler (2001) and Crouch (2003) have emphasised the skills that nurse bring to the care of people with intellectual disabilities. According to Cutler much needs to be done to improve services for clients with a dual diagnosis, and argues that nurses, with their ability to assess and plan care holistically, and their skills in client advocacy, team leadership and care coordination, have much to contribute to this health field. Crouch believes that nurses who work as Learning Disability Nurses feel they have something special to communicate to the profession as a whole.

According to Naylor and Clifton (1994) there is some evidence that mainstream mental health services do not feel that they have the skills to meet the needs of this client group. Day (1994) argues that understanding of mental health needs in this

client group requires special skills that learning disability nurses have been able to acquire. Mathews (1996) notes that there has been a strong focus on the social needs of clients with intellectual disabilities in the UK in recent years, and the health needs of these clients are being left to non-specialist services which are not able to meet these needs. Mathews argues that "many people with" intellectual disabilities "have special needs, and have the same right as anyone else to expect specialist services to meet these needs" (pp. 37-38). Koch, Marks and Took (2001) interviewed clients with intellectual disabilities and their parents to evaluate the effectiveness of a specialist nursing service programme in Adelaide South Australia for people with intellectual disabilities living in the community. The specialist programme was established under the umbrella of generic community health service after a negative report on the standard of care provided by generic health care agencies. Participants felt that the specialist service was able to take into "account complex needs of the clients with intellectual disability as well as education and the information requirements of care staff" (p. 362).

Gilbert, Todd and Jackson (1998) question the appropriateness of contemporary approaches in psychiatric nursing for working with people who have severe to profound intellectual disabilities, given that this group presents particular challenges to diagnosis and treatment. They believe that the clinician requires unique skills to work therapeutically with individuals who have severe and profound intellectual disabilities. The clinicians need to "develop a uniquely client-centred view without necessarily having access to either thought or language" (p. 1153). Jones (2003) notes that learning disability nurses often work with complex clients (and their families) over long periods of time and are likely to have developed established working relationships and can facilitate communication. The difficulties generic health services have in providing quality services for people with learning disabilities can be minimised through the intervention of learning disability nursing.

Chapter Summary

During the later part of the 20th century in New Zealand institutions made way for community based residential care for people who have intellectual disabilities. Over a similar period of time there has been decline in the number of psychopaedic nurses as nursing education has moved to a tertiary based comprehensive training. It has become harder to argue that there is a group of nurses who have specialist knowledge of intellectual disability. Community integration has increased the need for mental health and behaviour services and New Zealand must find new ways of addressing the mental health needs of clients with intellectual disabilities.

Recently specialist services have started to develop in New Zealand and this has presented new opportunities for nurses who are interested in caring for people who have intellectual disabilities and mental health problems. While there is a dearth of literature written from the perspective of nurses who specialise in this area, various authors have presented and discussed issues that may inform the practice of the nurse who works with this client group.

It is possible to obtain a glimpse the nurse who works with clients who have co-existing intellectual disabilities in the nursing literature. This nurse must have special skills for working with clients who have intellectual disabilities. They need to modify their assessment and interventions to allow for the clients intellectual disability. The nurse must focus is more on non-verbal cues and observed behaviour, they must work more with significant others, and work with shorter time frames. They need to be aware that the client's response to medication can be idiosyncratic. The nurse often works with complex clients who multiple needs and challenge services. Their approach to client care must be holistic and because they are able to work with these clients and their families over extended periods of time they are often able to development relationships and communicate with individuals more effectively than general or non-specialist nurses. They are advocates for a vulnerable and marginalised population and this

includes empowering individuals and promoting changes to systems and collaboration to better meet the needs of their clients. The work that they do is often held in low esteem and they must continue to justify there existence. Some of the issues identified in the literature were used to inform the research, including the status of the nurse and client, the nurse as advocate, and the attempts made by nurses who work with clients with intellectual disabilities to validate or position themselves.

In the next chapter I present the guiding methodology of this study, phenomenology, in particular the phenomenology of van Manen which informs my research, and I present my research method.

CHAPTER 3 – RESEARCH METHODOLOGY AND METHOD

This chapter is in two parts. Firstly I present my research methodology, phenomenology. In the second part of the chapter I discuss the research process, ethical considerations and trustworthiness and rigour.

There are different forms of phenomenology and this research project, the lived experience of nurses who work with clients who have a co-existing intellectual disability and mental health problem, was informed by the phenomenological approach of van Manen, a researcher and professor in education. According to Roberts and Taylor (1998) van Manen is a contemporary phenomenologist who is often referred to in nursing circles. He "applies a mixture of phenomenological concepts, such as bracketing and the value of understanding lived experience" (p. 108). van Manen studied pedagogy (the principles, practice and profession of teaching) in the Netherlands and was introduced to phenomenology and hermeneutics. He is influenced by the European (Dutch and German) traditions of this human science discipline.

I was particularly attracted to van Manen's approach to phenomenology because I felt that he was able to write about a complex topic with relative clarity, without providing an overly prescriptive or 'cookbook approach' to research, and is well suited to inherent limitations of a two paper thesis. While some qualitative approaches to research are descriptive van Manen's approach seemed to me to be more interpretive, allowing me to explore my research topic in greater depth. van Manen's phenomenology also avoids strongly preconceived research techniques or procedures and seemed to offer the best option for exploring the participant's lived experiences relatively unfettered by prior suppositions. My research question, 'what is the lived experience of nurses who work with clients with co-existing intellectual disabilities and mental health problems' cannot be reduced or readily

subjected to numerical analysis. I am in agreement with van Manen when he writes that:

> The preferred method for natural science since Galileo, has been detached observation, controlled experimentation, and mathematical or quantitative measurement.... In contrast, the preferred method for human science involves description, interpretation, and self-reflection or critical analysis.
>
> (van Manen, 1990, p. 4)

Phenomenology is qualitative and qualitative research methods are well suited to human science questions because "qualitative research is interested in questions that involve human consciousness and subjectivity, and values humans and their experiences in the research process" (Roberts & Taylor, 1997, p. 15).

Phenomenology: An overview

> A phenomenon is a thing or entity. Defined simply, 'phenomenology' is the study of a thing. In human sciences, phenomenology concerns itself with the study of things within human existence, because it acknowledges and values the meanings that people ascribe to their own existence. (Roberts & Taylor, 1997, p. 107)

Phenomenology is a human science approach which has its origins in philosophy (van Manen, 1990). Two philosophers who have made significant contributions to the history of phenomenology are Edmund Husserl and Martin Heidegger. According to Plager (1994) van Manen's phenomenology is a mixture of "Husserlian and Heideggerian philosophical underpinnings" (p. 78).

Husserl was critical of modern science and philosophy because he believed that it was making statements about the world that were not verifiable:

> Only through systemic unity can the sciences achieve genuine rationality, which as they have developed so far is missing. What is needed is a radical reconstruction which will satisfy the ideal of philosophy as being the only universal unity of knowledge by means of a unitary and absolutely rational foundation. (Husserl, 1929, p. 43)

According to Husserl the philosopher needs to suspend all his/her existing beliefs and reconstruct knowledge based on pure sense impression or aspects of reality that the philosopher has direct experience of. The philosopher's goal is to withdraw within themselves and destroy and subsequently rebuild all previous knowledge, "using his own absolutely self-evident justifications" (Husserl, 1929, p. 44). Husserl called this total detachment from apriori points of view regarding the objective world the 'phenomenological epoch.'

> We must regard nothing as veridical except the pure immediacy and givenness in the field of the ego cogito' (self awareness) 'which the ego has opened up for us. In other words, we must not make assertions about that which we do not ourselves see. (1929, p. 50)

The setting aside or suspension of an existing thesis or belief as we strive towards the 'phenomenological epoch' is termed bracketing (Husserl, 1931, p. 98).

Heidegger was a student of Husserl. His main focus was on the concept of 'Being.' "The meaning of Being" according to Heidegger "is the fundamental question of philosophy" (1962, p. 95). He uses the term "Dasein" to refer to the entity that has existence and as a characteristic of its existence, the ability to enquire into its own nature of being. He believed that other philosophers have traditionally failed to describe Being because their attempts have been overly theoretical. He argued that a person's Being is only revealed as they engage in a practical way with the world.

Heidegger used the phenomenological method to reveal the essential structure of human existence. For him Phenomenology is about opening up and revealing that which we would usually take for granted in everyday life (Heidegger, 1925). It is about bringing something to our attention that is not usually apparent (Heidegger, 1967).

Heidegger does not appear to argue for the kind of apartness from the world that Husserl felt necessary for true philosophy. van Manen's view on bracketing differs from Husserl's, and is probably closer to Heidegger's. van Manen (1984) argues that the researcher should make known their pre-understandings (or presuppositions) and assumptions, noting that "if we simply try to forget or ignore what we already know, we may find the presuppositions creep back into our reflections" (p. 46).

Although the ideas of phenomenologists who followed Husserl and Heidegger may have differed in certain respects, the influence of these 20th century philosophers can be found in contemporary writing on phenomenology. Baker, Wuest and Stern (1992) say that the phenomenological researcher attempts to leave aside their preconceptions, to "describe the phenomena" or uncover the "essence of the phenomena" in the way that individuals experience it. Researchers using phenomenology are interested in how people comprehend their world. Individuals and groups experience and interpret what happens around them differently in various contexts (Polit & Hungler, 1993). A person's actions and the language they use reveal more than is immediately apparent. According to Polit and Hungler, the phenomenologist's job as researcher is to reveal the many "conscious and unconscious ways in which humans express themselves and how they 'live' their experiences" (p. 41). Phenomenology affords nursing a new way (differing from a traditional logical positive perspective) to interpret the nature of consciousness and of an individual's involvement in the world (Beck, 1994).

The phenomenological researcher borrows other people's experiences and reflections on their experiences to better understand an aspect of human experience (van Manen, 1984). Phenomenological research "aims at establishing a renewed contact with original experience" (van Manen, p. 31). Phenomenology:

> Differs from almost every other science in that it attempts to gain insightful description of the way we experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it. So phenomenology does not offer us the possibility of effective theory with which we can now explain and/or control the world, but rather it offers the possibility of plausible insights that brings us in more direct contact with the world. (van Manen, 1990, p. 9)

van Manen elaborated further on his views regarding phenomenology and he wrote that:

> phenomenological research, unlike any other kind of research, makes a distinction between appearance and essence, between the things of our experience and that which grounds the things of our experience. In other words, phenomenological research consists of reflectively bringing into nearness that which tends to be obscure, that which tends to evade the intelligibility of our natural attitude of everyday life. (van Manen, 1990, p. 32)

The phenomenological approach is a means of describing the experience as it is perceived or understood by those who have lived it. It can make visible the essence of that experience, and thus enrich the understanding of the taken for granted dimensions of everyday live (van Manen, 1990).

Phenomenology and Nursing Research

Many nurse researchers use phenomenology and a sample of this research is provided below. These examples have been chosen because of there relationship to the research topic. The researchers all used small research samples, and

identified the lived experience of participants. Reading this research was also important to appreciate the analysis process used by the researchers.

O'Brien (2000) constructed "an interpretation of the experience of the nurse-client relationship in the context of community psychiatric nursing" (p. 184). Her study was informed by hermeneutic phenomenology. O'Brien engaged in a series of conversations with five participants and her study revealed key overlapping themes that are important aspects of the nurse-client relationship. The key themes are: 'Being there'; 'Being concerned'; 'Establishing trust'; and 'Facilitating transition'. O'Brien (2000) notes that "uncovering the structure of the relationship highlighted the complexity of nursing care for clients with serious mental illness, which has implications for education, supervision, and the development of appropriate nursing services" (p. 191).

Walsh's (1999) study of the nurse's experience of the nurse/patient encounter was informed by the phenomenology of Heidegger and Gadamer. The purpose of the study was to "uncover meaning and generate understanding of being a psychiatric nurse" (p. 2). Walsh's data analysis revealed 'three existential elements': 'Being-with' as understanding, 'Being-with' as possibility, and 'Being-with' as careful concern. These three elements were unified by the underlying theme of 'shared humanity.'

Walters (1994) carried out a hermeneutic analysis of the nurse's role in comforting clients in critical care. In her study which involved nurses, "comforting is described with reference to the following foci: providing support to the patient, relief from pain, relief from anxiety, communicating, using touch, facing death, comforting family and friends and supporting other nursing staff" (p. 1).

Berg, Hallberg and Norberg (1998) interviewed 13 nurses who provide care for clients with dementia. She describes the complex interdependent relationship that develops between the nurses and their very dependent patients as a delicate

interpretive process. The nurses needed to rely on their considerable skills to interpret the often non-verbal communication of the clients and by working closely with their patients in achieving often very intimate tasks, they developed a good understanding of what was important to them.

Research Process

van Manen (2003) does not provide specific guidelines for research, and he says:

> Phenomenological methodology, in particular, is challenging since it can be argued that its method of inquiry constantly has to be invented anew and cannot be reduced to a general set of strategies or research techniques. Methodologically speaking, every notion has to be examined in terms of its assumptions, even the idea of method itself. (p. 3)

Although van Manen (1984) cautions against adopting a rigid research method, he offers four interacting procedural activities which can serve as guidelines for conducting phenomenological research. These are: turning to a phenomenon which seriously interests us and commits us to the world; investigating experience as we live it rather than conceptualise it; reflecting on the essential themes which characterise the phenomenon; and describing the phenomenon through the art of writing and rewriting. Each of these activities was addressed in this research.

Turning to a phenomenon which seriously interests us and commits us to the world – the question and selection of participants

"Every project of phenomenological inquiry is driven by a commitment of turning to an abiding concern" (van Manen, 1990, p. 31). My choice of research topic was guided by my own personal interest. I currently provide nursing care for people who have intellectual disabilities and mental health problems. In the introduction

to the thesis I wrote about my experience of nursing clients who have intellectual disabilities and mentioned some of the issues which seemed personally relevant to the phenomenon of nursing this client group. I believe that there is a dearth of nursing research written from the perspective of nurses who work in this area. I anticipate that there will be new employment opportunities working with this client group in the future and that it is important that nurses with a personal interest contribute towards the identity of this specialist area of practice. I assumed that my participants also have a strong interest in the phenomenon given that it has a direct relationship to their clinical practice.

Given that little has been written on nursing from the perspective of nurses who provide care for people with intellectual disabilities and mental illness, I believe that it is important to start by trying to capture the actual clinical experiences of these nurses. I believe that nurses currently working with clients who have intellectual disabilities and mental health problems are 'experts' in providing care for a particular client group. By investigating the lived experience of my participants, I am providing an opportunity for their voices to be heard.

The selection of research participants was therefore purposeful given that potential participants would need to have certain attributes. Nurses were invited to participate if they were currently a registered nurse working predominantly with clients who have intellectual disabilities and mental health problems; and not a member of my work team. Participants were also expected to be knowledgeable and insightful of the phenomenon being researched. Participants were only sought within the greater Wellington area because a time constraint made long distance travel impractical. An invitation to participate was displayed within worksites where suitable potential participants were employed (Appendix 1). Potential volunteers were given an information sheet (Appendix 2) to read and contacted after one week to see if they had further questions about the study and to see if they were interested in participating. Participants were asked to sign a consent

form (Appendix 3) and a convenient time and venue were agreed upon for the interviews.

Four nurses who worked with clients who have intellectual disabilities and mental health problems responded to the research invitation. They agreed to take part in the study after reading the information sheet and signed the consent form before the interviews began.

Investigating experience as we live it rather than conceptualise it – the interview

According to Sorrell and Redmond (1995):

> The interviewer wants the respondent to describe the experience,
> rather than interpret it. In this way, the researcher can gain a holistic
> understanding of the experience that forms an important part of the
> respondent's day-to-day existence. (p. 1120)   ,

The participants were nurses who worked with clients who have intellectual disabilities and mental health problems. I asked them to reflect on their own nursing practice. I offered the participants the opportunity to speak about experiences drawn from their clinical practice, rather than to share their thoughts on a subject of which they have little or no direct knowledge. It is their 'lived experience' which I attempted to capture.

In phenomenology the researcher is the major instrument for collecting data. Beck (1994) writes that "it is through the developing of relationships that occur in the in-depth interviewing process that essential descriptions of a lived human experience are obtained" (p. 500). Each participant was interviewed individually and the interviews were approximately one and half-hours duration. The first interview was suspended because of technical problems with the tape recorder and resumed at a later date. In retrospect this incident may have been helpful because it allowed me to reflect on the interview and listen to the data that I had collected.

When I resumed the interview I was able to explore in more depth topics that I had initially passed on too quickly.

I was interested in the activity/action/ process of nursing revealed by these nurses, and given that I had some idea of the kind of information I was seeking from my participants, the interviews were semi-structured and essentially conversational. Participants were encouraged to reflect upon and share their own experiences while four prepared questions enabled me to remain on track (I remained orientated to the research phenomenon) and reduced the amount of interview text (research data) that was not relevant to (or did not illuminate) the phenomenon of concern. van Manen (1984) writes:

> Unless the researcher remains strong in his or her orientation to the fundamental question or notion, there will be many temptations to get side tracked or to wander aimlessly and indulge in wishy-washy speculations, to settle for preconceived opinions and conceptions, to become enchanted with narcissistic reflections or self-indulgent preoccupations, or to fall back on taxonomic concepts or abstracting theories. (p. 33)

All participants agreed for their interviews to be audio taped recorded. I transcribed the interviews verbatim.

I commenced the interviews by stating "I am researching the phenomenon of nursing from the perspective of nurses who work with clients who have intellectual disabilities. I have four questions, which will provide me with a basic structure, although my interviews will be essentially conversational, with the participants being encouraged to share what is important to their practice." I choose these questions because they are open ended and encourage a comprehensive response, and because of there relevance to my research topic. They also focus on the clients own lived experience rather than generalities. The interview questions were:

> ➤ Tell me how you came to be working with people who have a co-existing intellectual disability and mental health problem?

> What is nursing people with a co-existing intellectual disability and mental health problem like for you?

> Describe the key challenges that you experience working with people who have intellectual disabilities and mental health problems?

> Give me an example from your own practice that captures what nursing is for you?

In the introduction to the thesis I wrote about my own experience as a nurse working with people who have intellectual disabilities. I was aware during my conversations with participants that many of their experiences resonated with my own. I resisted the temptation to share my own views with participants, or to conceptualise their experience until I collected the data from the participants. Rather than 'bracketing' however, I accepted that my personal experiences helped me to recognise issues and potential themes and probe more deeply. van Manen (1984) argues that that the researcher should make known their pre-understandings and assumptions, noting that "if we simply try to forget or ignore what we already know, we may find the presuppositions creep back into our reflections" (p. 46).

The participants appeared to enjoy the opportunity to share their stories and I was able to explore the topic in depth.

Reflecting on the essential themes which characterise the phenomenon – the process of beginning data analysis

Data analysis commenced at the time of the first interview when I journalled my reflections on the interview content. Following each interview I converted participant's interview data into stories and identified issues which emerged from individual stories and common themes across all stories which seem to characterise or best capture the phenomenon that I was researching. I hoped that these themes would resonate with other nurses who read my research. This process involved firstly reading and editing the transcripts and removing any

content that was not relevant to the research question. The content that was removed included redundant words, repeated words, incomplete sentences, and non words (ums, aahs etc). I also removed content which I felt was too general, opinions on the state of mental health services for example, and not directly related to the participant's own lived experience. Participants revisited issues more than once during the interviews and I grouped these fragments together when I felt that this would create a more chronological and focused narrative. I used an approach to thematic analysis van Manen (1990) calls the selective reading approach. Using this approach the researcher "listen[s] to or read[s] a text several times and ask, what statements or phrases seem particularly essential or revealing about the phenomena or experience being described. These statements we circle, underline or highlight" (p. 93). It became apparent that certain topics recurred in all the participants' stories. A table was constructed, (not included in the final thesis) to summarise issues and helped with identification of common themes for later analysis.

Describing the phenomenon through the art of writing and rewriting – completing the analysis

van Manen (2003) refers to the practice of writing in descriptive and interpretive studies as the research methodology that remains 'relatively hidden' and 'in the background' and he notes that "it is precisely in the process of writing that the data of research are interpreted and that the fundamental nature of the research question is perceived" (p. 1).

By a process of and writing, reading and reflecting the themes common to the participants were refined, analysed and interpreted, and the lived experience of the four participants, gradually emerged. The process of 'writing and rewriting' was a lengthy process and involved numerous drafts as I explored and interpreted the participants' lived experience of nursing people with co-existing intellectual disabilities and mental health problems. During the writing process it was

necessary to focus strongly on the written material, excluding outside interruptions so that the key ideas or themes could be illuminated. It was my intention to allow the participants' stories to emerge relatively unfettered by my own prior assumptions. van Manen (2002) notes that the phenomenological writer engages with the text to the extent that he/she becomes submerged within it. They leave the world of everyday to enter the reality of the textorium. During the process of writing the words draw us in. As words draw us and carry us away, they seem to open up a space: a temporal dwelling space where we may have reality experiences, "realizations we never imagined possible" (p. 6).

Trustworthiness and Rigour

The research method is qualitative and the findings are not generalisable and can only be transferred with due regard to the context of the study. At all stages of my research I was mindful of my research question: 'what is the lived experience of nurses who work with clients who have a co-existing intellectual disability and mental health problem.' By continually referring back to this question I was able to ensure that my literature search, data collection, interpretation and discussion remained focused. I chose the semi-structured interview as my research method because it enabled me to collect information on a complex phenomenon and is therefore congruent with phenomenology, my research methodology.

While the quantitative researcher might talk about a study's validity and reliability; "qualitative research is no less rigorous than quantitative research, but uses different words to demonstrate the ways of making explicit the overall accuracy and trustworthiness of a project" (Roberts & Taylor, 1997, p. 172). Sandelowski (1986) writes that rigour in qualitative research can be ensured if the criteria of credibility, fittingness, auditability, and confirmability are addressed. The confirmability of my research relates to the degree in which I have successfully met the other three criteria. A study has high credibility if participants and researchers recognise their own lived experiences captured by the researcher.

Roberts and Taylor (1997) suggest that "the methods for ensuring validity in qualitative research involves asking the participants to confirm that the interpretations represent faithfully and clearly what the experience was/is like for them" (p. 15). Transcripts and the interpretations of the transcripts were submitted to the participants to verify that the information they gave was interpreted accurately. Fittingness refers to the relevance that readers find in the research. This will be achieved if nurses who work with clients who have co-existing intellectual disabilities read my research and find that it has personal significance and relates to their own nursing experiences. I have attempted to achieve audibility by clearly outlining the methods and processes of my research so that it is intelligible to other researchers.

According to Guba and Lincoln (1989) the trustworthiness of a study can be established if due attention is given to the criteria of credibility, transferability and dependability and by ensuring a good grasp of the research method (phenomenology) I strengthened my research with respect to these three criteria. The findings of my research was appropriately derived from the research data, the participant's stories, and sufficient information provided on the context of my research so that the reader can make inferences on the usefulness of the study. I discussed all aspects of the research with my research supervisor to ensure its credibility.

The Ethical Implications of the Research

I consulted with my research supervisor at all stages of the research and consulted with a cultural adviser where appropriate regarding issues of particular relevance for Maori. My personal prejudices and values were acknowledged during the interview process so that the stories of participants were not obscured. My own views invariably influenced the interpretation of the participant's stories in Chapter 6 and this is acknowledged.

It was difficult to guarantee confidentiality for the participants because there are relatively few nurses in New Zealand who work with clients who have intellectual disabilities and mental health problems. However, pseudonyms are used to protect their identity and any names of clients or other people revealed during the study were deleted from the submitted final research project. Specific information from the transcripts was not used when participants requested that it be deleted.

This study would not benefit from any intentional deception of the participants and the information sheet was open about the intention of the research. Participants were given a thorough description of purpose and design of the study so that their consent was well informed. Participants were informed that they may withdraw from the study at any time. Participants were told how research findings will be disseminated in scholarly journals and at conferences. Future consent will need to be renegotiated before research finding can be used in ways not agreed to by prior arrangement.

By focusing on the primary research question I was able to limit the risk of harm and while this research did not intend to explore issues which the participants find personally distressing, given the exploratory nature of the semi-structured interview process, it was possible that I might have uncovered issues which were upsetting for participants. I asked the participants to let me know if they wished to discontinue the interviews at any stage, none made such a request. I also invited participants to contact me should they experience adverse effects from involvement in the study and at the time of submission I had not been contacted by any of the participants.

Ethical approval for this research project was obtained from the Manawhatu/Wanganui and Wellington Ethics Committees (Appendix 4). These committees have jurisdiction over the geographical area that the participants reside within. In response to feedback from the committee I made the following key changes to my initial submission:

- I documented what my response would be if participants revealed evidence of malpractice during the study and included this information on the information sheet for participants. I would be obliged to report this according to the protocols and polices of their workplace.

- I included on the information sheet an invitation to participants to contact the researcher should they experience adverse effects from the study.

- I agreed to distribute a notice to potential participants inviting then to volunteer. I would no longer be approaching potential participants directly, limiting the risk of researcher coercion and bias.

- I noted on the consent form and information sheet for participants that participants would be able to edit interview transcripts to ensure that their views are represented accurately.

- I acknowledged my research would have some impact on health resources given that I might be contacting and in some cases interviewing participants during work time.

There were a number of smaller changes made at the committees' request. I made it clear that my submission had been sighted and approved by the head of the Graduate School of Nursing and Midwifery at Victoria University of Wellington, I noted that raw data would be kept for a minimum of 10 years and also said that while I would endeavour to protect the identity of participants, confidentiality could not be guaranteed.

Although the committees also advised me to further protect the identity of participants by not including direct quotes from participants in my study, they accepted my reply that direct quotes are necessary in phenomenological research.

I informed the committee that I would be using pseudonyms and excluding personal identifiers to protect participant's identity.

The committee approved my amended proposal although they did suggest several small technical changes that I readily complied with. Copies of final ethics application and the committee's approval letter were lodged with the Graduate School of Nursing and Midwifery and with ethics committee at the Victoria University of Wellington.

Summary and Introduction to the Participants

In summary, this research explores the lived experience of nurses who work with clients who have co-existing intellectual disabilities and mental health problems and it is informed by the interpretative phenomenology of van Manen. Four nurses agreed to participate in the research. The transcribed data from the four interviews were condensed into stories, which are presented in the following chapter, so that the key themes in the participant's accounts could be identified more easily. Essential themes that encompassed the issues shared by the four participants were identified and written about in relation to the research phenomenon. These themes are presented in Chapter 6, but before moving onto this chapter the four nurses are introduced individually.

David

David is a psychopaedic nurse and he has worked at a psychopaedic hospital for approximately 16 years. He came from a background that had nothing to do with nursing and when he started at the hospital he did not know what to expect. He enjoyed working with the clients and regrets that he did not start working at the psychopaedic hospital earlier in his life. Psychopaedic nurse training was hospital based, and during his training David worked with a range of people with intellectual disabilities, including those who displayed challenging behaviour or in

some cases a co-existing intellectual disability and mental health problem. David also left the hospital for a short time to obtain experience in forensic mental health. David recently accepted a job with a service which will be providing community care for people with intellectual disabilities who have left hospital.

Shelby

Shelby graduated as a comprehensive nurse. Her first nursing job was in a mental health ward for women with intellectual disabilities and complex/challenging behaviours. Although she had no particular desire to work in this field at the time, she successfully applied for a job vacancy and remained in this job for five years. The women she nursed had diverse needs and covered a broad age span, and in addition to their intellectual disabilities some required support for a mental illness. Others required full physical nursing care. After having time off to have a child, Shelby resumed her nursing career in an acute mental health inpatient unit. She had many opportunities to work with clients with intellectual disabilities and co-existing mental health problems within the inpatient unit and because of her previous experience with this client group she would often be asked to nurse these clients. With the closure of the acute inpatient unit, Shelby moved to a new inpatient forensic unit for clients with intellectual disabilities and challenging behaviours.

Ashley

Ashley is a comprehensive nurse. She recalls that she had her first experience of people with intellectual disabilities when she was 6 or 7 year old. A friend of her parents who worked in a hospital for people with intellectual disabilities would bring the clients to visit. When she was doing her nursing training Ashley worked part-time as a care giver for a community based intellectual disability residential provider. After graduating Ashley worked in a mental health acute unit and a long

stay mental health rehabilitation unit. Although at this stage of her nursing career Ashley was more interested in mental health than working with people who have an intellectual disability, she recalls that there were people with intellectual disabilities within this environment. She currently works in a specialist forensic inpatient unit for clients who have intellectual disabilities and mental illness and/or extremely challenging behaviours. She was initially invited to work in the unit for six months but enjoyed the experience so much she decided to stay longer.

Diane

Diane is a comprehensive nurse. After graduating she worked four years in a forensic psychiatric unit. There were a variety of clients within this environment. Most had a mental illness in addition to their offending; others had a dual diagnosis. Diane wanted to provide better care for clients with intellectual disabilities and mental health problems and when a colleague left the forensic service to establish a more appropriate service for these clients Diane accompanied her. Diane now works for a community specialist service that works with individuals who have high and complex needs.

CHAPTER 4 – THE PARTICIPANT'S STORIES

In this chapter the data from the participants will be presented. The participant's interview transcripts were converted into stories about what it means to nurse clients who have intellectual disabilities and mental health problems. This process of creating a story involved reading and rereading the interview transcripts, the deletion of irrelevant and unnecessary information (my questions from the text, and other information which did not illuminate the research topic) and the creation of stories which incorporated the main thoughts of participants. Where I felt that the participant's own words best capture their thoughts I have included them in italics. I have chosen to tell the participants stories in the first person to capture the poignancy and immediacy of their accounts. The stories were returned to participants to check for accuracy.

The order that I have presented the participant's stories is of no significance in terms of the design of the study and the discussion of the emerging themes.

David's Story: Making a Connection and Nursing the Whole Person

I started working with people with intellectual disability without a clear sense of vocation, I simply 'needed a job.' My knowledge of people with intellectual disabilities was based on my limited exposure to them and on stereotypes:

I grew up in this community yet I knew so little about the place, the
perception was, and I guess still is, that people with an intellectual
disability are the bouncy friendly Downs Syndrome kids that you see
on IHC ads and that was certainly the perception I had.

The problem with stereotyping any group of people is that it does not acknowledge the differences which characterise people as individuals and some people in the community who have limited experience of people with intellectual disabilities continue to retain these stereotypes.

My initial exposure to this client group made a powerful impression on me and:

> *When I got there I got quite a shock to find people lying on beds and*
> *twisted sort of bodies, contorted bodies with tubes in their noses and*
> *huge heads and all sorts of weird and wonderful things.*

The graphic reality was so different from the stereotype, and although this description may reflect only a memorable segment of the residents at the hospital, I always remember the client's dependency on other people. I enjoyed working with clients with intellectual disability and regret that I did not start working at the hospital earlier in my life.

> *I like working with the people. I like helping this particular group of*
> *people because I see them as a needy group and people deserving of*
> *being cared for and that gives me a lot of personal satisfaction to be*
> *able to do that, and to be able to do it well.*

I was concerned by the care the clients received within the hospital. The hospital did not employ a specialist psychiatrist and a general practitioner was largely responsible for the mental and physical health of clients. Mental illness was not covered extensively in psychopaedic nurse training either, and nurses were probably not well equipped to identify mental illness in the client population.

> *People were more seen as intellectually disabled than mentally ill, or*
> *intellectually disabled with challenging behaviours and were*
> *generally controlled by medication and they were zonked out and*
> *didn't know what the hell was going on.*

The hospital focused too strongly on the medical model. Nursing is more of a caring profession than a medical profession and nursing models have reflected this difference by adopting a holistic approach to care. However, although I didn't agree with the kind of care provided for clients at the hospital I stayed for as long as I did because I thought that I could make a difference.

> *I felt I had a role there. If only just to do what little I could for people*
> *I guess in my own way, and I thought that if everybody who disagreed*
> *with the way places like ran and got out who the hells going to be*

there to look out for the rights of the residents? So that was my
justification I guess, although I certainly don't agree with the [medical
model] *way of looking after people, it is very limited.*

I left the Intellectual disability hospital for two years to obtain mental health experience within a forensic service. There were clients with intellectual disabilities within the forensic service and I don't believe that they were well placed within this environment. They were at risk of being victimised by other clients, and the forensic staff didn't have much understanding of the needs of people with intellectual disability. Some of these staff would admit to me that they had:

Never worked with what they called dongs. They were seen as a
pain in the butt quite frankly. They were certainly very vulnerable
and certainly by the staff they were seen as people who came into the
system who were very difficult to get out of the system. You are
supposed to have a two year turn around but people with intellectual
disability would get in there and stick there and be very hard to
place. There were no real services out there at that time for those
with an intellectual disability who had any kind of mental illness.

To some extent I was able to demonstrate how to nurse clients with intellectual disabilities to other nurses within the Forensic Service although I was the 'new boy' and needed to learn more about mental health and the forensic mental health services in particular before I could seriously criticise existing practices. My experience of working with clients who have intellectual disabilities provided me with useful nursing skills. This made me a better forensic mental health nurse and I was highly regarded by management:

I was better equipped than a lot of people generally in that sort of
nursing because of my abilities to read the non-verbal sorts of things
that were going on with people. A lot of the time people aren't
willing to open up to you. Whether it is just myself or something I

have leant working with people with disabilities, my whole approach
to people, and the way I relate to people I think helped me be quite
good at my job in forensics.

Looking back I believe that Forensic Services could better meet the needs of people with an intellectual disability but staff working in these areas would need to learn more about the needs of the client group and the forensic service would need to change to some extent to accommodate clients with intellectual disabilities. I was able to take some of my newly acquired knowledge of mental health back to the intellectual disability hospital.

With the closure of institutions I am concerned generally about the care provided for people who have intellectual disabilities and mental health problems. Clients will be moving into community homes to be looked after by people who have little knowledge of intellectual disability and mental health and don't know the clients history:

When people go out into the community out into houses looked after
by people, being paid... as care givers, and who have little or no
knowledge, how are we going to expect the level of care that is going
to be required for some of these, the more specifically dual diagnosis
people... specifically I guess, the people who do have a real co-
existing mental health issue, to be looked after by people who aren't
skilled, you could have problems I guess.

The Mental Health (Compulsory Assessment and Treatment) Act 1992 excluded people from the act who did not also have a mental illness. I believe that it was a good thing to make a distinction between a mental illness and intellectual disability, but in practice people who have an intellectual disability can be disadvantaged by the change. They are less likely to receive a psychiatric diagnosis even when they are mentally ill and might be unjustifiably excluded from the act. People with intellectual disabilities might also be excluded from mental health services because of funding:

When a psychiatrist is sitting there looking at a person and, for instance, the acute units are busting at the seams and he can't see a way of discharging anyone to take on this other person, he is going to be looking at everything he can to exclude that person...The question of intellectual disability comes along and they are more likely to be at the total bottom of the line.

Access to care is often determined by diagnostic labels. Labels are:

Useful for some things, funding I guess. It's useful for people to receive services. It seems to be almost one of those necessary evils in our society. I don't agree with people having labels at all but unfortunately in this capitalist society in which we live, you have to have a label to get funding.

Nursing for me is about advocating for the client, and forming a therapeutic relationship by making a deep connection, gradually developing trust and recognising what you are working with, and improving the lives of vulnerable people. I am able to develop an intense 'therapeutic relationship' with my clients. The core features of this relationship are 'making a connection', 'doing right' by a 'vulnerable group', and helping them to develop 'trust' in you as a nurse:

You know that the people themselves have lived such a life of being controlled and to actually make a connection with a person and know that they look on you as somebody who... they trust and that you are not going to do them any harm and trust that you're there to help them and that moment that you make that connection with the person is what nursing is all about.

My specialist knowledge of intellectual disability and skill in caring for these clients helps me understand the individual needs of clients have a dual diagnosis. I have worked intensively with the clients at the hospital over many years and know them very well. This personal knowledge makes you better able to understand

when things are going wrong for them. My nurse/client relationships have been enriched by time.

A lot of residents know me and remember things we did years ago and that's really quiet humbling for me that somebody who is quiet severely disabled can... look at me and know my name and know something that happened like ten years ago and that to me says something about the impact I might have had on that persons life.

I remember one client that has had a profound effect on me. This client had a gastronomy tube inserted into his stomach and was no longer able to enjoy the taste of food or the sensation of having water in his mouth:

I was working with this guy about six months ago and advocating for him. It became a whole issue of his right to live and die. The whole ethical issue of quality verses quantity of life, because this guy was clearly saying he didn't want this tube in his stomach by pulling it out at every opportunity and ending up in hospital with peritonitis and all sorts of things. And his elderly parents, the emotion of all that, it was just ripping them apart to see their son in that state and not being able to do anything about it. So that whole role of liaising between parents and medical professionals and looking at myself and the ethics of what I am doing, that self analysis. Am I doing the right thing? That to me is nursing, doing the best thing for your patient.

There are sometimes people who have a different idea of what is best for a client and advocating for the client and mediating between different groups is also an important aspect of nursing. I accept that in mental health and in intellectual disability nursing you might have clients who do not welcome the nurse's attention and the nurse's therapeutic role might sometimes be accompanied by a custodial role. When you are nursing people with intellectual disabilities and mental health problems it is sometimes required to put restrictions on their behaviour and autonomy, but this is not inconsistent with advocacy. Nurses who work in other areas of health care might see this as a custodial rather than nursing approach but

client care at the hospital is influenced to a certain extent by legislation and legal requirements:

> *It's not always you saying what's best for them. People were generally under a welfare guardian order and the courts had decided where that person needed to be, so you didn't actually make that decision you were just acting in the legal framework and certainly I could justify myself and my actions in providing or stopping those people going or... because I knew myself it was in their best interests to be there and to do that.*

However, I would 'advocate strongly' for the client if I felt that the restrictions on them were unjustified.

During the early years of my career I recall that nurse training was increasingly being taken over by tertiary institutions and the hospital paid for some people to bridge to comprehensive nursing registration. Even during my nurse training there were rumours of deinstitutionalisation and hospital closure 'in the wind.' Although many of the more able clients had already left the hospital:

> *The talk of closure became more earnest and we were actually told by the head nurse at the time, who came into our class and made an announcement that the hospital would be closing in 7 years time, and the qualification that we ere half way towards completing would be worth nothing. I remember that quite clearly. That's when the talk of the actual nursing school at the hospital closing started as well.*

I have proudly retained my psychopaedic registration and strived to remain a valuable employee by adding to my knowledge and skills base:

> *I guess it has been a matter of keeping up to date with things and I guess specialising. I sort of specialised in legislative things in the forensic area and the mental health act and things like that.*

My understanding of nursing was limited to psychopaedic nursing and I was not really aware of other areas of specialist practise. I clearly remember that registered

nurses were better paid and given greater respect than non-registered staff. Although nurses I have met in mental health and general nursing have 'valued' my expertise within my specialty, I have sometimes felt inferior to comprehensive nurses and been acutely aware that there are limitations on the scope of my practise. I left the hospital for a time to work in a forensic service to learn more about mental health and took me six months to convince management that I had the requisite skills to work in the forensic area:

> *I think something happened down in a psychiatric hospital with psychopaedic nurses working in a psychiatric area and something went down and suddenly the nursing council started talking about section 57 of the Nurses Act and nurses working outside their scope of practice.*

I believe that there needs to be people with specialist knowledge of intellectual disability working with this client group. It was a mistake to do away with psychopaedic training. You need to have a good understanding of the aetiology of the person's disability to plan good care for them. Comprehensive nursing training only includes a very basic introduction to intellectual disability and although:

> *The human service certificates and degrees have picked up on intellectual disability… it's more about the values and working with challenging behaviours and caring for people, not really that deep understanding of aetiology.*

I rather like the English nursing training in learning disability which includes a social work component, an aspect that was missing from nurse training in New Zealand, but:

> *Because nursing hasn't involved that intellectual disability component really in New Zealand, I guess there won't be specific intellectual disability nursing. People with intellectual disability aren't sick, so in terms of that specialised medical nursing, they will come into contact with nurses the same way as we all do.*

I have recently accepted a job with a community agency that will be providing residential care for clients discharged from a psychopaedic hospital. I have been employed as a team leader/nurse and I am excited because I believe that in this new role I will be able to provide better care for clients with intellectual disabilities.

> *What I am doing at the moment is closer to what I think nursing is than I have ever been in the position of doing. It's a more whole look at the person... it's more involved in the whole process of the care provision for people. As well as the daily care planning stuff, I'm also doing the liaison with family and liaison with funding providers and the business side of it as well. I'm ...working with the staff and organising staff education, so I am doing the whole thing. It's coordinating the whole care of the person, and that's what I see as a nursing role anyway..., in that I have that holistic look at that person and looking at the aspects of care that impact on that person.*

Clients within the community service will access mainstream adult mental health services when this is necessary. However, generic health services cannot be expected to meet all of their needs and there will be roles for nurses in providing care for people with intellectual disabilities in the future. There will be a role for nursing in the primary health care of people with intellectual disabilities, the management of epilepsy for example, and possibly also in mental health. Perhaps nurses will also be able to provide an interface with the doctors because of the issues around communication. People with intellectual disabilities often have difficulty communicating and it is useful if someone is able to act as an intermediary between the client and the person they are trying to talk to. In the future I see an opportunity for nurse practitioner who specialises in intellectual disability, to triage clients before they get to the need for medical interventions.

Shelby's Story: Role Modelling, Leading by Example and Teaching

I started working in a ward for woman with intellectual disabilities and mental health problems as a new graduate, although I had no particular desire to nurse this client group. I started my new job as an optimistic new graduate who thought that I would be able to significantly improve client care, but soon found myself unprepared for, and horrified by the ward environment and the care the clients received. I am still affected by my memories of the ward:

> *It was a very institutionalised place. I saw women literally being beaten by workers. I saw things like teapots being thrown across rooms at clients by workers and people chased down the corridors with brooms and mops. I saw people being showered in the courtyard by a firehouse.*

Although I don't condone the ill treatment of the clients and feel guilty that I did not do more to stop these practices, the women were often violent and physically almost disgusting in their personal hygiene, and the staff were not well trained to manage the extremely challenging behaviours they were almost constantly exposed to.

When I started at the ward I was a junior nurse and not involved in the decision making process. When I became a senior nurse I still found that the culture of the environment was so powerful I did not feel able to instigate significant changes. Although some of the senior nursing staff were supportive I didn't feel that I had enough support or the confidence and authority to improve things.

I was also concerned by the poor working conditions of the staff. The ward was seen as inferior to other wards because of the extreme and unappealing behaviours of the residents. Nurses in the ward were not well regarded by other nurses in mental health.

We were ostracised within our own group. You know we were bottom

of the heap anyway, working with woman with intellectual disabilities.

We had no respect among our peers or colleagues.

The ward was very isolated from the rest of the hospital. Nurses and support staff often did not get to hear about educational opportunities or conferences that could have improved their knowledge base, and it was often difficult to find staff who wanted to work there.

We were like the poor cousin that got nothing, and we had to fight to

get a doctor around or a house surgeon if somebody was ill, that sort

of stuff.

Although the ward was deemed to be a rehabilitation facility the staff who worked there felt that the ward was used as a 'dumping ground' for clients that were not wanted anywhere else. There were few opportunities for clients to engage in community activities. It is very difficult to successfully rehabilitate a person who is 'kept in a locked ward all day.' I was frustrated that clients were not moving on and I felt sorry for the clients because although it was a terrible place to work I couldn't imagine having to actually live there.

You were told almost from day one that 'these guys aren't going

anywhere in a hurry, so don't panic about things.' You don't have to

be terribly motivated or work hard... I guess they did progress in their

own ways but, to me rehab was sort of doing community based stuff

and getting people out into the world and that sort of thing, and

actually coping with the realities of life. It was very hard to do

rehabilitation with people who were locked in a ward all day.

Not all of my memories of the ward were negative however. Some of the staff genuinely cared for the women and did what they could to improve their lives. I also noticed that the clients made some progress, be it incremental. In general though, I left the ward with a strong belief that clients with intellectual disabilities and mental health problems deserved better care.

After having time off to have a child, I resumed my nursing career in an acute mental health inpatient unit. I had many opportunities to nurse clients with intellectual disabilities and co-existing mental health problems within the inpatient unit and one of my first impressions was of how much better the environment was to my previous work place.

Because of my previous experience with this client group I would often be asked to nurse these clients because the other nurses didn't appear to have a clue. The clients with a dual diagnosis often required more physical nursing in addition to their mental health needs and they might be more intrusive towards the other clients. Clients who have intellectual disabilities don't understand things that other clients would grasp straight away and you need to them more slowly and use language they can understand. I also welcomed the opportunity to work with a woman I had looked after in the intellectual disability ward and was delighted with the progress they had made since moving into community care.

I felt more assertive than I did in my previous ward and willing to object if things didn't seem right for the clients. I was far more confident at this stage in my career and I remember advocating strongly for one particular woman at a multidisciplinary team meeting:

> *Other staff felt that they were just behavioural and shouldn't be in the*
> *unit. I realized that there is a pressure for beds, but this woman was*
> *too unwell to be discharged. Staff couldn't accept that a person could*
> *have an* [intellectual disability] *and be mentally unwell.*

I was able to make more of a difference to the lives of clients with intellectual disabilities and mental health problems within the acute setting and the other nurses did learn how to care for the clients to some extent by observing my example.

With the closure of the acute inpatient unit, I moved to a new inpatient unit for clients with intellectual disabilities and challenging behaviours. Some of these clients also have mental illness and all are detained under the Mental Health Act (1992) and required to undergo compulsory treatment. Although I had a choice of several wards I chose the intellectual disability ward because it seemed like an exciting prospect. It was a new unit and I liked the idea of being there from the start and having a say in the policies. I believed that I could help to create the kind of environment that benefits clients with intellectual disabilities and mental health problems. I was determined that the quality of care would be far superior to the care the clients had received in the intellectual disability ward.

I found that it was necessary to find a balance between the client's independence and the community's right to be kept safe. Many of the clients would reside in the ward for a long time, and the staff wanted it to be a comfortable home for them. However, because of the clients challenging behaviour, which included assaults, they had to back track. The staff found themselves in a dilemma. Clients initially require a secure environment and constant supervision and sometimes choices get taken out of their hands completely. While some people might find it hard to accommodate a custodial role within a therapeutic nurse/client relationship, on reflection it was necessary.

> *They are there for a reason, and there are very good reasons if you look at their forensic histories. Some of our guys could have killed, in fact one has. You have to weigh up their rights and things, as opposed to the public rights.*

Although I sometimes feel despondent about the slow progress clients make, I accept that this is part of nursing these clients who have intellectual disabilities and mental health problems. The long term goal of the ward is to move all of the clients into community care and I believe that all of them could be supported within a community setting. However, the success of future community placement is dependent on the staff being sufficiently skilled to work with the clients. I am

concerned that clients will not always receive a high standard of care when they move back into the community care because of the lack of skilled staff in community homes to work with the clients.

Nurses have much to offer in the care of people with intellectual disabilities:

> *I think there is definitely a place for nursing. , nurses generally have that level of understanding of physiology.... things like epilepsy...you need to understand something before you can work out the whys and whens and hows. You need to be able to work symptoms out, and triggers, those sorts of things.*

Nurses are also essential in the intellectual disability secure unit where I work because:

> *Nurses have a higher level of understanding, especially of the legal needs within a secure service. We can legally seclude somebody within that service, and nurses are trained in it, and understand what you should and shouldn't do...There is a place for support workers...but they should complement the nurses...The nursing role is... within our ward education as much as anything, for the lesser trained people...role modelling... you have got to lead by example*

Central to my own nursing philosophy are the concepts of role modelling, leading by example, advocacy, caring and teaching and treating clients as individuals with their own standards, values and beliefs:

> *Advocacy is a huge part of what we do... for our clients. They don't articulate for themselves very well sometimes and we have to get to know them and build that relationship with them well enough to get to know what it is they will be asking from us*

The care of clients with intellectual disabilities by nurses should extend into the community. The community care for client with intellectual disabilities would be

improved if more nurses were employed in this area. It is because nursing skills have been in short supply in the past that clients have ended up in the unit. Why not give people with intellectual disabilities the best possible standard of care we can, as opposed to the minimum standard?

> *I think nurses have a huge role really, and I believe nurses should be the only people who look after intellectually disabled people, as opposed to support workers. Just their whole different way of thinking makes the difference in their treatment, or for their treatment.*

New Zealand requires nurses with specialist knowledge of intellectual disability. I disagree with the 'normalisation' argument that any nurse is equipped to care for clients with intellectual disabilities in hospital or within a community setting. This is a specialised area of nursing and should be given the respect it deserves. The psychopaedic nurse requires different skills to look after people with intellectual disabilities. The nurse who looks after people with a dual diagnosis must distinguish between a client's intellectual disability and their mental health problem and disentangle the complex overlap of these two diagnoses. While diagnostic clarity is usually possible, in many cases it is likely to take a longer period of assessment and distinguishing between a mental illness and a behaviour problem in the client group is one of my biggest challenges.

In New Zealand the old specialist qualification of psychopedic nursing (nurses who worked exclusively with people who had intellectual disabilities) was discontinued in favour of the generic qualification of comprehensive nursing. I favour training that ensures a basic level of nursing comprehension. Nurses should be able to branch out into a specialty area at postgraduate level. Based on my observations of learning disability nurses from the United Kingdom, I believe that learning disability nursing is a major specialty and these nurses have quite a different way of thinking about things from the mental health nurses on the ward.

I experience negative feedback from my nursing colleagues because I am a nurse who works with clients who have intellectual disabilities. Nursing people with intellectual disabilities is still perceived as low status nursing and I feel that this view discourages people who might consider working in this area.

> *We are the bottom of the heap as far as mental health nursing goes...*
> *we are the really poor cousin of the mental health aren't we? So*
> *finding nurses who want to work in learning disabilities is a huge task.*

I also received criticism from sections of the intellectual disability sector. I work in an inpatient service, providing care that is seen by some people as contrary to the principles of 'normalisation' or community based care:

> *I noticed that mostly when I was on the standards committee for*
> *developing an intellectual disability standard. Within the sector itself*
> *there is such ... different philosophies, and I was ... scorned on you*
> *know, for even having a concept that people should be locked up, who*
> *had intellectual disabilities. They just did not want to see that some*
> *people are dangerous, or could be dangerous.*

To raise the status of nursing people with intellectual disabilities I believe that nurses who work in this area have to articulate the reality of what they do, so that people can:

> *appreciate how difficult it can be, and how stressful a job it can be.*
> *Because the public perception is they are* [people with intellect
> disabilities], *so therefore they are easy... a sort of lazy nurses thing,*
> *because you don't have to work much... The public perception of*
> [people with intellectual disabilities] *is the Downs Syndrome, nice,*
> *friendly, loving type of person, and the reality of it is quiet different.*

The attitude of my colleagues who work in other areas of mental health will improve once clients are successfully discharged from the ward. You have to prove yourself, especially within nursing because we are very hard on each other as a group. I still feel somewhat isolated or 'cut off' from the rest of the hospital,

but I feel that this is not necessarily a bad thing. The new ward offers a unique service and needs to shape and protect its own identity. They are planning care for people whose needs differ from clients in other parts of the hospital.

While the clients in the ward have more opportunities than the clients in the ward where I started to practice as a new graduate, I am still critical of care provision for this client group. The environment of the intellectual disability ward is not conducive to working therapeutically with the clients. For example, there are insufficient trained staff on the unit, and if this doesn't improve in the future, the unit will become another institution. I will probably return to nursing in the mental health mainstream in the near future. I enjoy working with clients with intellectual disabilities but I am frustrated by the inadequate resources for people with intellectual disabilities within my current work area and within New Zealand generally.

Ashley's Story: Providing Structure and Accepting Gradual Change

My first experience of people with intellectual disabilities was when I was 6 or 7 year old. A friend of my parents who worked in a hospital for people with intellectual disabilities would bring the clients to visit. This early experience of people with intellectual disabilities may have been the start of an interest that would re-emerge some years later. I thought it was pretty wonderful...these people with unusual behaviours and things like that.

While doing my nursing training I worked part-time as a care giver for a community based intellectual disability residential provider. At this time I did not know very much about mental illness and knew even less about intellectual disability. I had never been exposed to people with intellectual disabilities who also had challenging behaviours, because these people were less visible in their communities, tending to live in institutions. Intellectual disability was not really

covered during my nursing training and if it was included at all it was probably covered within the mental health syllabus.

> *As far as intellectual disability, I thought Downs Syndrome, happy*
> *smiling... and as it turned out, that was not the case.*

At this time people with intellectual disabilities were starting to move into community care and I wondered why there was a sudden move to discharge everyone with an intellectual disability from hospital. It seemed that clients were separated from their friends, from staff they knew and from familiar routines and moved into communities that were ill prepared for them.

> *What I was seeing was lots of people who weren't ready, or able, or*
> *wanting to move on, being evicted from what has been their home for*
> *a long time and dumped where they got no support and they had no*
> *skills to survive in what's termed the 'real world.'*

Sometimes clients were ill treated by members of the public. I remember that a young man with an obvious intellectual disability was beaten up by group of teenagers on public transport. The offenders were apprehended and they actually thought what they had done was funny, that it was an amusing thing to do. When the clients lived in hospital they were in a 'sheltered' environment and with people with intellectual disabilities and/or mental illness who were more likely to accept them because they had something in common. Here they are in the public eye being scrutinized and watched and often being victimized because they are so different. The people who left the hospital should have had more say in their move and there should have been more community supports in place and more campaigns to educate the general public in advance of the moves.

Although I was interested in continuing to work with clients with intellectual disabilities there were few opportunities for registered nurses at the time and after graduating I worked in a mental health acute unit and a long stay mental health rehabilitation facility. At this stage of my nursing career I was more interested in

mental health than working with people who have an intellectual disability, but I recall that there were people with intellectual disabilities within the ward. I don't believe that clients with intellectual disability were well placed within this environment because:

I don't think mental health rehabilitation rehab offered the expertise and the understanding of intellectual disability necessary to care for this client group. I mean some of the behaviours that you were seeing were obviously related to their intellectual disability and not mental health...the focus was on the mental health and the [intellectual disability] was a secondary. You can't change it, why do anything about it?

The clients would engage in:

Self destructive, self harming, head banging, rocking, and getting very angry, for what we thought they was not getting their way, and in hind sight now they didn't understand. It was out of frustration. We thought that this person was obviously not well because they are still acting out, so let's increase their medication.

There was a tendency to relate their behaviour, perhaps erroneously, to a DSM IV mental health diagnosis and medicate accordingly. Although naming a cluster of symptoms might help with planning treatment, the label is not very important:

As long as you are dealing with what you see and measuring their response, it doesn't matter what you call it. I still feel mostly you treat what you see.

The emphasis in the rehabilitation ward was on treating the persons' mental illness, rather than focusing on their intellectual disability, and discharging them to a community provider. If a client had additional problems related to an intellectual disability this was seen as the responsibility of a community intellectual disability services. Unfortunately there was limited community residential options for these

clients and existing intellectual disability services weren't all that happy about taking people with a co-existing mental illness because that wasn't their forte. This made it difficult for people to move on.

When I was working in the mental health rehabilitation ward, I thought that clients with a dual diagnosis were a lot more complex than straight mental health clients:

There was not only the mental health side of things to contend with, there was also the [intellectual disability] *and trying to get an understanding of what was going on for them. Trying to work out whether it was their illness and what service they really fitted into.*

I also remember positive examples of the care of client with intellectual disabilities within the rehabilitation service. Staff who had previously worked with clients with intellectual disabilities treated them differently. They were gentler with them and more tolerant and spoke with them using language they could understand.

Currently I work in a specialist inpatient unit for clients who have intellectual disabilities and mental illness and/or extremely challenging behaviours (predominantly violence directed towards other clients, staff and towards the environment). The purpose of this unit is to protect the clients and the community from the violent behaviour and to rehabilitate the client as much as possible. This is an intellectual disability rather than a mental health ward and within this environment the client's intellectual disability, rather than a mental illness, is the primary focus of care. Although some of the clients have a mental illness, others do not. I was initially invited to work in the unit for six months, but enjoyed the experience so much I decided to stay longer.

Before moving to the unit I didn't believe that there was much you could do about a person's intellectual disability. Client's progress tends to be slow and I was initially frustrated by this, and saw this as a lack of response to my interventions,

but as I look back over the past year and reflect on the pessimism of my colleagues from the rehabilitation service it feels good.

> *I've seen some of our guys come an incredible long way. It's taken time, but looking back, given their abilities and how people had written them off beforehand, it's astounding.*

When you work so closely with clients you develop a bond with them and it can be hard to see them leave the ward.

> *We often sit and talk about how little these people have got. Some of them have this horrendous history of abuse. A lot of them have been discarded by family because they are just too difficult to deal with. They have no job, no self-esteem, nothing, and just to be able to be there a couple of hours a day and to make a difference, that is what nursing is about for me to see this guy walking around looking good and feeling good because people are commenting...and him saying 'you helped me do this.'*

You would hate for them to fall down and be right back to where they started. Successful management plans might seem unduly harsh or rigid to care givers in the community who don't really understand where the person has come from. If these plans are not followed the old challenging behaviours will re-emerge. Most of our people have a very strict management plan which gets adjusted, tweaked, depending on how they respond to it. I am thinking of one particular client who has made great progress. He is now showering himself independently and is no longer assaulting people. This client could do well in any environment provided caregivers continue with the strict management plan:

> *It's what he knows. It's what he feels safe with because he knows the boundaries and has learnt new coping skills and stress management. Remove the plan, even where he is now and he will go right back to the previous behaviours.*

Nurses have been employed to work with client with intellectual disabilities within the impatient unit partly for historical reasons. Many of the clients in the ward are on medication which, in a hospital, needs to be administered by a nurse. However, I also believe that nurses have useful skills for working with this population. Nurses (unlike care givers or allied health professionals) are able to respond to client's physical health needs and people with intellectual disabilities are more likely to suffer from physical health issues than other mental health clients. People with intellectual disabilities can also suffer from depression and other mental illnesses. Also nurses might have an understanding of the different causes of intellectual disability, and associated behavioural traits and physical ailments, which might help with planning client care.

> *I think that it is more to do with the fact that they are trained and they might have an understanding of the different causes of intellectual disability, what works what doesn't work* [and] *nursing models that can be implemented in their care.*

Although there are other health professionals and caregivers who work within the intellectual disability secure unit, nurses have a unique relationship with the clients. Registered nurses have more of a bond and they become more involved in the persons life. Other health professions have more specific roles. For example, while a psychologist might teach the person how to manage their anger nurses are more concerned with everyday things. The nurse might also support the work of other disciplines in their own practice and pull everything together at the multidisciplinary meeting to focus on the client's individual care.

Unfortunately working with clients who have intellectual disabilities is perceived as a low status area of practice by other nurses.

> *Amongst nurses in general, mental health is seen pretty low on the food chain. You are not real nurses. But even amongst mental health workers, working in* [intellectual disability] *is even lower. You're at the absolute bottom.*

This perceived low status may have an historical basis:

I think traditionally it's where the burnt out staff were dumped. This is the end of the road for you, you're working in [intellectual disability]. *I still hear that a lot around the campus. What have you done wrong, you've ended up working there! But it's definitely not like that. But I think that's the traditional view.*

Maybe once upon a time in the dark ages it may have been the case that intellectual disability nursing was inferior, when the knowledge wasn't out there, and maybe these people where just a waste of time, simply because the expertise wasn't there. Society will gradually realise that people with intellectual disabilities have specific needs. They need specialized help and care and more nurses are required to oversee the untrained non- degree sort of people, the health care assistants. Most future nursing jobs in intellectual disabilities will be in inpatient services.

Although I feel that I am knowledgeable about mental health I have still has much to learn about intellectual disability. Many of my colleagues are proficient in intellectual disability or mental illness but few in both and this can make it difficult to address a clients complex needs. Unfortunately there is little information on intellectual disability and mental health from a New Zealand context and some of the information I have found over the internet is unreliable or it is American and the cultural and socio-economic factors are quite different. There is much I can learn from colleagues who have more experience in this area, especially some of the nurses from England who are trained as learning disability nurses. These nurses:

Bring a wealth of information, including very specific strategies on how to deal with these challenging behaviours. I wouldn't say there's anyone from New Zealand that is hugely knowledgeable or experienced in [intellectual disability], *but definitely there is a lot to be learned from the overseas nurses.*

I will probably continue nursing clients with intellectual disabilities and mental health problems for a while. Compared to mental health nursing, nursing people with a dual diagnosis:

Is a whole different world, more challenging and I like challenges. Not one day is the same as any other. Sometimes it's frustrating because of the slowness of progress, but when you finally get there it's awesome. I think that's what motivates you to keep going.

I think that that intellectual service will continue to develop. I work in a national unit, a service that could be a trend setter and role model for the rest of the country. There is a real shortage of resources in the area of intellectual disability and even more so in the area of dual diagnosis.

I no longer feel uncomfortable by the attitudes of my nursing peers and I am now able to confront my colleagues with my hard won success stories.

It doesn't worry me because I can actually come back to them and say, you're wrong because look at such and such. It has been eight months since he has assaulted, it's been eight months since he was secluded, and they see the two of us walking along the campus together, and they actually come out and talk to him, and you can tell they are absolutely amazed by the progress made.... I hope that is dispelling the myth that [intellectual disability] is the end of the road for patients and staff, because it is definitely not. It is probably more challenging than general mental health.

Diane's Story: Falling Though the Gaps and Providing a Voice

After I graduated with comprehensive nursing registration I worked in a forensic psychiatric unit for four years. There were a variety of clients within this environment. Most had a mental illness in addition to their offending; others had a dual diagnosis (intellectual disability and a mental illness). A small number of

clients with an intellectual disability might not have had a mental illness but because of historical reasons relating to service provision or because clinicians have found them to be a diagnostically ambiguous these people had found themselves within a mental health service. Some of the clients with intellectual disabilities had been in a mental health facility for many years and the forensic service was still trying to provide a deferential diagnosis.

There was a fundamental change in the staffing of the forensic unit which had a detrimental effect on client care, and especially on the care of clients with intellectual disabilities. Psychiatric assistants who lacked formal qualifications were gradually replaced with registered nurses. This was supposed to reflect a move towards greater 'professionalism' in health care, but the registered nurses were not as 'street wise' as the psychiatric assistants, and were not always able to relate to the clients at their own 'level of understanding' and use language they could understand. To relate to people with intellectual disabilities you need to be able to get on their 'wavelength.' The nurses needing to be able to 'come down to where that person is coming from' but client care was also being increasingly shaped by legislation and the requirements of the mental health act and became less flexible and less client centred as a result.

The forensic environment didn't suit the needs of clients with an intellectual disability. You cannot support clients with an intellectual disability as you would someone with a mental illness because the needs of these two clients groups are different.

> *The people with an intellectual disability, seemed to be the odd ones out, and seemed to be picked on. They were quite scared too if somebody who had a mental illness became unwell. They weren't perhaps some of them very street wise and didn't really have the skills to be able to cope with that.*

There was not enough emphasis on teaching the kind of life skills clients with an intellectual disability need to live in the community. Although many of the nurses in the forensic service had a good understanding of mental illness their knowledge of intellectual disability was very limited. Some staff did not want to work with clients who had intellectual disabilities. They didn't have an open mind and understand where that person was coming from and have a good understanding of intellectual disability.

I wanted to provide better care for clients with intellectual disabilities and when a colleague left the forensic service to establish a more appropriate service for clients that really slipped through the gaps with regards to mental health verses intellectual disability, I accompanied her on her journey. I now work for a community specialist service that works with individuals who have high and complex needs. While clients arrive in the service via differing routes (health, justice or voluntarily) the goal for all clients is rehabilitative and holistic, with staff helping them to achieve their goals.

> *There wasn't a lot of community organisations that were offering anything like the idea of intellectual disability and mental health services and verses being say in the prison system and to be able to provide some sort of robust service for that group of people. That's really what intrigued me, and wanting to work within that.*

This job calls for diverse skills, and I 'wear many hats', but I still see myself as 'very much a nurse' because of my previous experience and training. Nursing is my 'background' and provides me with a useful 'toolbox.' I already have many skills from working in mainstream mental health and I am adding to these skills in my new work area:

> *being in that area, already having some tools in the tool box if you like, but now developing those more and more, so having a set of wooden tools and then having stainless steal tools that kind of thing in that particular area really.*

76

Caregivers in the service come from a range of backgrounds and I value this diversity, but I also note that caregivers need to learn how to relate to the client group:

A lot of our clients are supported by support workers who don't necessarily have any qualifications.... They need some sound guidance, and if that was from a nurse or working along side our staff, then I think there is most certainly a role to play. [The clients] *are individuals but they have needs,* [particular to their intellectual disability] *and unless the people who are working with them understand that, then we won't make headway.* [There] *is a lot of nurturing.., the staff and peers and such, into understanding how to work with individuals and stuff.. but they may not have nursing backgrounds in themselves, so it's a lot of education for non- nurses, and basically empowering them to do... what is required to support that individual.*

The individual's personal qualities also determine the standard of care they provide for the client who has an intellectual disability:

You may have a qualification as a nurse and be useless. You could also have a qualification as a nurse and be absolutely amazing. I think as a nurse you are sort of given a set of tools for your tool box but as part of our practice as nurses we are learning and always achieving. But it is really that background of things like compassion and bringing that up and knowledge, communication, all those attributes. You don't have to be a nurse to have that, but perhaps just a little bit more qualifications in those kinds of things.

The competent nurse should bring to the care of clients with intellectual disabilities professionalism; a good general knowledge of medical issues (and medication) and different genetic conditions pertinent to intellectual disability; good communication skills, a commitment to adding to their knowledge base as the need

arises and a commitment to advocating for their clients. Nurses can also provide guidance to support workers who work with clients with intellectual disabilities.

There is sometimes too much emphasis on the medical model in this area of practice. Medication does make a valuable contribution to client care but we must not rely on a pill to provide a 'quick fix' or short- term answer for clients who may be annoying or upsetting. It is more helpful in the long term to develop interventions that acknowledge the clients' level of understanding, and their problem solving skills, in addition to medication.

Assigning diagnostic labels (such as those used in mental health for example) when the person has an intellectual disability can also be helpful. Sometimes it is possible to clearly identify symptoms related to a person's diagnosed mental illness or their intellectual disability but often there is quite a bit that can overlap. There are multiple factors that can cause intellectual disability (for example, the consumption of drugs or alcohol during pregnancy, birth trauma and head injury) and the resulting symptoms can be difficult to distinguish from a mental illness. Some things, anxiety for example, clearly cross the boundary. People with intellectual disabilities are often anxious because of their limited coping skills and exposure to traumatic life events but anxiety can also underpin a distinct mental illness. Psychiatrists are very dependent on the quality of the information they receive from caregivers to make an accurate diagnosis. Information provided by someone who has a sound knowledge and understanding of behaviour would assist the diagnostic process, and while a trial of medications might still be necessary with this client group to hit something on the head, hopefully successful treatment can be found more quickly.

Nursing someone with a co-existing intellectual disability and a mental health problem is not really any different from nursing anyone else. The person is an individual and I am supporting that individual holistically. Working with clients who have a dual diagnosis is really about teaching them problem solving:

It is about the client... I am here, to be one of the vehicles to actually move them to the optimum... whatever that is for them. .... and of course in an area that is a bit more of a specialist area if you like, intellectual disability/mental health, it takes a certain type of person and individual to be able to do that.

When the client has an intellectual disability and an adjunct mental illness the nurse will need to be able to meet their needs in both areas, and find the appropriate support networks. Unfortunately there doesn't always seem to be good services out there to be able to do that.

It is important that the staff in the service, nursing and non-nursing staff, know how to talk with and relate to clients who have an intellectual disability and mediate between the client and other services, police, medical staff etc, they may come into contact with. Often other services don't have the knowledge the time or patience to find out what the client is saying and the client's voice may be lost. I am passionate about my role as a nurse who advocates for my clients. Advocacy is part of what it means to be a nurse. Advocacy includes *empowerment, talking to clients in language they can understand* and translating the client's perspective for others:

I believe [advocacy] *is part of being a nurse really, and is one of the many hats that we wear as nurses....* [It requires a lot of energy] *to advocate for* [a client with an intellectual disability], *to show other people that they are a person in that community and to get them to appreciate that...and* [show them] *how simple it is to work with this client.*

Advocacy is about:

Looking at that person as an individual instead of putting them in a box .. ...they are very much an individual and ...maybe in involving that person in their life, instead of maybe doing it all for them.

And:

it is a real balancing act in not doing for clients, getting the client to involved or individual involved with me. ..empower the individual to, to get around decision making, ... and it takes a lot of energy, and also continually talking in a way that maybe the client can understand what they are saying too,

I acknowledge that the nurse's role of advocating for a client might potentially clash with the requirement that they are loyal to an employer. It is important for clients to have advocates who are independent from the organisation providing care, but I remain committed to my role as a client advocate who might need to 'step in' if an official advocate is not doing their job:

I have been in situations when I have been there with an advocate and the advocate perhaps isn't doing that job... as I would like [and] I will step in and say [to the client] well do you understand what that lawyer has just said to you? And I think that [advocacy] is quite an assertive role as well... because this client base is very vulnerable and so you have got to be switched onto some of the silliness that goes on too.

Although I work with clients who have intellectual disabilities and mental health problems this area was not covered much in my nursing training. I see myself as a pioneer rather than an 'expert' in this field. I am expanding my nursing knowledge, finding information on the internet and attending conferences in intellectual disability or related areas. However, the information I am finding is more likely to be based on overseas rather than a New Zealand context. I sometimes feel isolated being a nurse working in a small specialist field but I am currently doing graduate studies and value the contact I have with nurses who work in other areas.

Mental health nursing and nursing clients with intellectual disabilities are regarded as low status areas of nursing by society and by nurses in general. Students might

be reluctant to consider these career options because unlike their colleagues in other areas of nursing, mental health nurses might not be the immediate recipients of thanks or gratitude from clients or family and might be subjected to violence:

> *...somebody comes in with a broken leg, they leave and the family may give the nurses a cake or something, and thank them very much for their support, whereas in mental health you don't get that, it's perhaps a little bit more longer term. You might get punched in the nose, or whatever, and not have a lot of thanks for what you do... why go into mental health were that can happen.....Perhaps intellectual disability* [nursing] *isn't as juicy as something like orthopaedics or surgical nursing or something like that, but really it takes somebody kind of special to nurse in any given area. I think once you are immersed in that area you get to appreciate that.*

I wonder if the traditional split between mental health (the mind) and other areas of nursing (the body) has helped to foster the low opinion of mental health and intellectual disability nursing (which has often been seen as synonymous with mental health). It is easier to stigmatise care recipients in mental health and the people who care for them because they are seen as separate from other care recipients and from the health system that everyone else uses.

The clients we work with, in mental health and intellectual disability, are perhaps perceived as being bottom of the rung so it is not surprising if the nurses who care for them are seen as having lower status than other nurses. Mental health and intellectual disability are also portrayed negatively in the media which tends to reinforce poor public perceptions of the clients and care staff. Fortunately attitudes could be improving because of deinstitutionalisation. Building up the knowledge base of intellectual disability nursing will help to lift its status. Nurses who work in this area should be developing their practice by doing research and talking with nursing students. Nurse training schools such as Polytechnics would welcome a proactive approach by nurses who are keen to share their expertise.

81

Summary

In this chapter the participants' interview data was presented as individual stories. There are similarities and differences in participants lived experiences and these will be presented and discussed in the next chapter. In chapter six I will be discussing and illuminating the overall themes shared by the four participants that best capture the 'lived experience of nurses who work with clients who have a co-existing intellectual disabilities and mental health problem.'

CHAPTER 5 – INTERPRETATION OF THE COMMON THEMES

In the previous chapter the participant's stories were presented and analysed and the following themes were identified. These themes for the participants were as follows, for David: criticism of care, holistic caring, issues of status, the need for specialist knowledge, advocating, diagnostic challenges, and enduring therapeutic relationships; for Shelby: criticism of care, diagnostic challenges, enduring therapeutic relationships, the need for specialist care, issues of status, advocacy and modelling good practice; for Ashley: criticism of care, the need for specialist knowledge, diagnostic challenges, issues of status, and enduring relationships; for Diane: criticism of care, need for specialist knowledge, working alongside, issues of status, and advocacy. By linking these themes using a table (not included in thesis) commonalities emerge. Four participants are critical of the services for clients who have intellectual disabilities, and three participants discuss client advocacy. The issue of diagnosis, the status of the nurse and the need for specialist care for clients who have co-existing intellectual disabilities and mental health problems was also apparent across participant's stories. Further analysis of these themes revealed two overlapping "lived experiences", "status and positioning" and "advocating practices."

In this chapter I present and interpret these "lived experiences" by showing how they emerge and illuminating what the experiences mean in relation to the literature.

Analysing the Common Themes:

Commentary on the status of nurses and clients is apparent in the participant's stories. The four participants refer directly to the status of nurses while the status of clients with a co-existing intellectual disability and mental health problem is largely implied by the participant's criticism of services. The four participants also attempt to validate the nurse who works with clients who have a co-existing

intellectual disability and mental health problem. While this attempt to position these nurses as having particular skills or qualities might indicate a certain amount of self interest, participants argue that nurses have a role to play in providing quality care for these clients. Participants are not only advocating for clients but for their own nursing role. The participants attempt to position or validate the role of the nurse and the needs of the client leads to advocating practices. The two themes of "Status and Positioning" and "Advocating Practices" are interrelated themes that can be encompassed by an overarching theme of "The Status and Positioning of the Nurse and Client Leads to Advocating Practices." The lived experience of the nurse who works with clients with co-existing intellectual disabilities and mental health problems encapsulates a strong recognition of their shared status and their endeavours to raise the position of both groups.

Status of Clients:

The four participants are critical of services for clients with co-existing intellectual disability and mental health problems. David believes that there is too much emphasis at the psychopaedic hospital upon managing a client's problem behaviours. The incidence of mental illness is reported to be two to three times greater in the population who have an intellectual disability than their non-disabled population (Borthwick-Duffy, 1994) but the psychopaedic hospital did not employ a psychiatrist and the nurses had little training in mental health. David recalls that rather than treating clients appropriately with medication, they were *generally controlled by medication. They were zonked out and didn't know what the hell was going on.* He also believes that the hospital focused too much on the medical model of care rather than holistic, nursing the whole person, approach which for David is more what nursing is about.

Shelby was horrified by the care clients with intellectual disabilities received in an intellectual disability ward when she first began nursing. She recalls abuse similar to the terrible treatment that has been reported at other institutions in New Zealand,

such as Lake Alice (New Zealand Herald, 2006, September) and Ngawhatu Hospital (New Zealand Herald, 2004, June). According to Shelby the staff who worked there felt that the ward was used as a 'dumping ground' for clients that were not wanted anywhere else and there was no expectation that clients would move-on. Shelby is also critical of the specialist forensic ward for clients with intellectual disabilities where she currently works saying that the *environment itself is not conducive at all to any therapeutic stuff.* Shelby is concerned by the lack of resources in this area of client care in New Zealand, and she says that she may leave this area of nursing practice altogether in the future and return to mental health nursing.

Concern about service provision and access to mental health care for clients who have an intellectual disability is also found in the literature and is consistent with my own nursing experience. Cutler (2001) notes that much needs to be done to improve mental health services for clients who have intellectual disabilities. In the introduction to this study I shared my own experiences of nursing this client group, and referred to, for example, the high client to staff ratios, the lack of client privacy, lack of acknowledgement of family and the negative labelling of clients. I also wrote about the barriers to mental health services for clients with intellectual disabilities. I suggested that one of the reasons clients with intellectual disabilities may be denied access to mental health care is because their mental health diagnosis is ambiguous and more open to debate.

Proponents of normalisation argue that clients with intellectual disabilities should access mental health care from mainstream mental health services because this reduces stigmatisation and ultimately results in a higher standard of care. Mathews (1996) writes that the "philosophy of community care demands that mainstream services be used to met the needs of people with learning disabilities as far as possible" (p. 37). However, Mathews goes on to say that the "ability of the services to do so is limited" (p. 37). While the participants are critical of the care clients received in specialist services they are also critical of the care provided

in the community (or available in a community setting), and generic mental health rehabilitation and forensic services.

Ashley recalled that when she worked in a long stay mental health rehabilitation facility there were people with intellectual disabilities within this environment. *I don't think mental health rehabilitation offered the expertise and the understanding of intellectual disability necessary to care for this client group.* David and Diane have both worked with clients with intellectual disabilities within a mental health forensic service and didn't believe that these clients were well placed within this service. According to David the prejudice of staff against clients with intellectual disabilities was apparent. Some staff admitted that they had *never worked with what they called dongs* and these clients were *seen as a pain in the butt quite frankly.* Mental health services (including forensic services) need to move clients through the system to free up beds for admissions. David found that it was difficult to move on clients with intellectual disabilities because there was a lack of community services willing to accept them and because clients with intellectual disabilities typically progress more slowly than their non-intellectually disabled peers. Recalling her experience in a forensic ward Diane argues that you cannot support clients with an intellectual disability as you would someone with a mental illness because the needs of these two clients groups are different. She says that *the people with an intellectual disability, seemed to be the odd ones out, and seemed to be picked on.* Interventions need to focus on using language that clients understand and teaching social skills and coping strategies. Diane recalls that more registered nurses were employed in the service in an attempt to *"to raise professional standards"* but these nurses appeared to have more difficulty relating to clients with intellectual disabilities than the support workers they replaced. It is interesting that a nurse education system, which is presumably intended to prepare nurses to relate to a broad range of clients, has left them unprepared. Perhaps a nurse's professional responsibility allows them less time to work with clients and build a therapeutic relationship than their non-professional colleagues.

Three of the participants are concerned about the standard of care clients will receive once they leave a hospital environment. David and Shelby worry that clients will move into community homes to be looked after by care givers with limited knowledge and skills. David is also worried that clients will find it difficult to access appropriate mental health treatment when they need it. According to David *the question of intellectual disability comes along and they are more likely to be at the bottom of the line.* During her nursing training Ashley wondered why people with intellectual disabilities were being transitioned from hospital into community care. In effect, they were being *evicted from what has been their home for a long time and dumped where they got no support and they had no skills to survive in what's termed the "real world."* Reflecting on current clients Ashley wonders if well meaning but clinically naïve care staff in the community might discontinue strict management plans, which provide clients with clear boundaries and allow them to feel safe, causing the client to decompensate.

The potential for exclusion of clients with intellectual disabilities from generic mental health services was identified in a report commissioned by the Central and Midland Regional Health Authorities (1995):

> Many health services will not serve people on the grounds of their
>
> intellectual disability. Although this can be explained as being caused
>
> by such things as diagnostic overshadowing and a lack of training on
>
> the part of professionals, the result is a situation that can be described
>
> as overt discrimination and denial of services. (p. 15)

My experience and the experience of the participants suggest that exclusion remains an issue.

Status of Nurses:

David was challenged to reflect on the value of his psychopaedic training early in his career. At the time of his nursing training talk of hospital closure had become more prominent and students were told by the head nurse that *the qualification that*

we were half way towards completing would be worth nothing. Later he was made acutely aware that there were limitations on the scope of his practise. It took David six months to convince management that he had the skills needed to work in the forensic area. Although David had the option of bridging to comprehensive nursing, he was proud of his psychopaedic qualification and decided to ensure his ongoing employability by doing additionally relevant training.

Ashley says that *mental health nurses are seen as pretty low on the food chain* by nurses generally. *You are not real nurses. But even amongst mental health workers, working in* [intellectual disability] *is even lower. You're at the absolute bottom.* She suggests that this perceived low status may have an historical basis, because the wards with clients with intellectual disabilities were *traditionally ...where the burnt out staff were dumped. I still hear that a lot around the campus. What have you done wrong, you've ended up working there.*

Shelby recalls her experience in the intellectual disability ward and says that nurses there were seen as inferior to nurses in other wards because of the extreme and unappealing behaviours of the residents. Nurses in the ward were not well regarded by other nurses in mental health. *We were ostracised within our own group. You know we were bottom of the heap anyway, working with woman with intellectual disabilities. We had no respect among our peers or colleagues.* Shelby was upset by the practices she saw, and did not participate actively in the abuse, but she felt powerless to do anything to change things. The culture of the environment was too powerful and her objections could be expected to fall on deaf ears and probably dismissed as her clinical naivety. Diane, like Shelby makes a connection between the low status of clients and nurses who care for them saying that *the clients we work with, in mental health and intellectual disability,* are *perhaps perceived as being bottom of the rung* so it is not surprising if the nurses who care for them are also seen as having lower status than other nurses. Mitchell (2000) also notes that the low status of people with intellectual disabilities in society primary contributes to the low status of nurses who care for them. Waizkin

(1991) says "a client group with low status, such as those with [learning disability] leads to professionals who support them having limited credentials, particularly as interventions in the long term are likely to be supportive rather than highly technical." Brooke (1999) says "to be blunt, the reason learning disability nurses are so marginalised is the general contempt in which society holds our clients" (p. 28). The marginalisation and low status of nurses who work with clients with intellectual include is also acknowledged by Moore (1986), Parrish and Sines (1997), Jones (1998), Bollard and Jukes (1999), Turnbull (1999), Penningham (2000), and Mathieson (2001).

Referring to the contemporary status of nurses, Shelby believes that intellectual disability nursing is still perceived as low status work by other nurses and feels that this view discourages people who might consider working in this area. *We are the bottom of the heap as far as mental health nursing goes... we are the really poor cousin of the mental health aren't we?* Shelby has found that the value of these nurses is also questioned by others within the disability sector and she says that: *I noticed that mostly when I was on the standards committee for developing an intellectual disability standard and I was ... scorned on ..., for even having a concept that people should be locked up, who had intellectual disabilities, they just did not want to see that people were dangerous, or could be dangerous.* In the introduction to my thesis I recalled from my own experience in an intellectual disability hospital that nursing people with intellectual disabilities was perceived as being low status work. I also noted that nurses within the institution were not welcomed into the community care of people with intellectual disabilities and were viewed as proponents of a discredited and inappropriate care system, and purveyors of the medical model. According to Cutler (2001) while it is often recognised that clients with a Dual Diagnosis are not well served, the role of nurses in helping to address these peoples' needs is rarely acknowledged.

Advocating Practices- Positioning Nurses

All the participants argue (or attempt to position) that there is a role for nurses who have expertise in intellectual disability. Comprehensive nursing training, according to David, only includes a very basic introduction to intellectual disability. David believes that his specialist knowledge of intellectual disability and his skill in caring for these clients helps him to understand their individual needs. He also feels that his experience of working with clients who have intellectual disabilities provides him with useful nursing skills which made him a better forensic mental health nurse and he was highly regarded by management. *I was better equipped than a lot of people generally in that sort of nursing because of my abilities to read the non-verbal sorts of things that were going on with people.* David is saying that the skills he has acquired as a psychopaedic nurse have a broader application beyond nursing clients with an intellectual disability, a view that might be shared by other psychopaedic nurses. According to Crouch (2003) nurses who work as learning disability nurses feel they have something special to communicate to the nursing profession as a whole. Munro (2000) quotes Colin Beacock, a learning disability policy adviser, who says "the skills of learning disability nursing have a greater transferability than previously thought, in particular in areas in areas such as dementia care and enduring mental illness" (p. 14).

Shelby also argues that nurses have much to offer in the care of clients who have intellectual disabilities because *nurses generally have that level of understanding of physiology.... things like epilepsy... level of understanding of these things.... you need to understand something before you can work out the whys and when's and hows.* She believes that nurses who work with clients with intellectual disabilities need to articulate the reality of what they do, so that people can *appreciate how difficult it can be, and how stressful a job it can be.* According to Shelby nurses in the forensic intellectual disability ward have an important role educating others and role modelling appropriate client interventions. Shelby

believes the care of clients with intellectual disabilities by nurses should extend into the community and she believes that fewer clients with intellectual disabilities would be *re-institutionalised* if community care staff were more skilled. She disagrees with the 'normalisation' argument that any nurse is equipped to care for clients with intellectual disabilities in hospital or within a community setting. *It actually takes quite a different skill to* look after people who just have an intellectual disability and clients who have a Dual Diagnosis. The specialist Dual Diagnosis nurse is required to have the expertise to distinguish between a client's needs arising from their intellectual disability and those arising from their mental health problem and to be able to disentangle the complex overlap of these two diagnoses. According to Naylor and Clifton (1994) there is some evidence that mainstream mental health services do not feel that they have the skills to meet the needs of this client group. Mathews (1996) argues that "many people with intellectual disabilities have special needs, and have the same right as anyone else to expect specialist services to meet these needs" (p. 37- 38).

While Diane acknowledges that the requisite skills for looking after people with intellectual disabilities, such as *compassion, knowledge, communication,* are not the sole preserve of nurses, because of your education and training as a nurse you could be expected to have these skills in greater abundance. Diane adopts a metaphor to describe her growing expertise as she moves from a generic to expert practitioner working with dual diagnosis. She has *some tools in the tool box* [and is] *now developing those more and more, so having a set of wooden tools and then* [transferring to] *stainless steel tools.* A nurse has particular skills and abilities which enables them to practice competently and care for people who have a co-existing intellectual disability and mental health problem. A nurse may also have the potential to develop specialist expertise in this field with education and experience. However, according to Diane working in the area of *intellectual disability, mental health it takes a certain type of person.* They require some knowledge of genetics and medical issues related to their client group but also they nurse must be able to relate to the clients at their own 'level of understanding' and

use language they understand. Shelby also identifies some of the specialist skills the nurse might require to work with clients who have a dual diagnosis. These clients often required more physical nursing in addition to their mental health needs, and they are sometimes more intrusive towards other clients which may require careful management. According to Shelby clients who have intellectual disabilities don't understand things that other clients would grasp straight away and you need to them more slowly and use language they can understand. Day (1994) argues that understanding of mental health needs in this client group requires special skills that learning disability nurses have been able to acquire. Holbrook (2000) writes about the particular skills the advanced psychiatric nurse practitioner must utilise when working with patients with intellectual disabilities who are experiencing psychological and behavioural problems.

Ashley feels that to some degree nurses have been employed to work with client with intellectual disabilities within the inpatient unit for historical reasons but she also believes that nurses have useful skills for working with this population. According to Ashley nurses (unlike care givers or allied health professionals) are able to respond to client's physical health needs and people with intellectual disabilities are more likely to experience physical ill health than other mental health clients. Also nurses *might have an understanding of the different causes of intellectual disability,* and associated behavioural traits and physical ailments, which might help with planning client care. Although there are other (allied) health professionals and caregivers who work within the intellectual disability secure unit, *registered nurses have more of a bond* [and] *they become more involved in the person's life.* Ashley believes that most nursing jobs in intellectual disabilities will be in inpatient services in the future and that it will become more apparent that people with intellectual disabilities *need specialised help and care and* [that nurses are required] *to oversee ... the health care assistants.*

Nurses who work with clients who have co-existing intellectual disabilities and mental health problems need to find way of communicating their concerns about

client care in ways that bring about change and communicate the value of the work that they do. I believe that one of the sad things that occurred with the closure of the psychopaedic institutions in New Zealand was the lack of a clearly defined role for nurses. Anecdotally I have heard many stories of nurses being told that there would not be a place for them in the lives of clients they had known for years. They were told that they were part of the problem, not the solution. The enduring relationship that many nurses who work with clients who have dual diagnosis should be acknowledged and valued because it has the potential to enrich the lives of clients.

Advocating Practices – The Practice of Nursing Clients with a Co-Existing Intellectual Disability and Mental Health Problem

Although participants were rarely in a position to make substantial changes to organisations or systems, they were able to demonstrate better care through example. The participants concern for the welfare of clients with intellectual disabilities and mental health problems appears to have an impact on their career choices and their nursing practice. It seems to act as a catalyst, with participants attempting to provide better nursing care. All of the participants were motivated to provide better care for clients within a service and three of the participants choose to work in a different service because it appeared to offer hope of better care for clients with intellectual disabilities.

Although it seems that participants are constantly having to justify the work that they do and are critical of the standard of services for their clients it is apparent that they do find their work rewarding and value their clients. The joy they take in their work is evident from the descriptions they give of clients. For example, David remembers that his initial exposure to clients with intellectual disabilities was different from the *bouncy friendly Downs Syndrome kids that you see on IHC ads,* but actually more profound as a result. David says that *I like helping this particular group of people because I see them as a needy group and people*

deserving of being cared for and that gives me a lot of personal satisfaction to be able to do that, and to be able to do it well. Diane left the mental health forensic service to help a colleague to establish a more appropriate service for clients who *slipped through the gaps with regards to mental health versus intellectual disability.* Ashley's description of clients she works with is as poignant as David's. She says *some of them have this horrendous history of abuse. A lot of them have been discarded by family because they are just too difficult to deal with. They have no job, no self-esteem, nothing.*

Nursing for David is about providing holistic care. *It's coordinating the whole care of the person,* advocating for clients, forming a therapeutic relationship by making a deep connection, gradually developing trust and recognising what you are working with, and improving the lives of vulnerable people. According to Jones (1999) "nurse's talk about holistic care [and] learning disability nursing is probably the best example" (p. 61). These "nurses support their clients health needs, social aspirations, welfare and educational requirements" (p. 61). Speaking about clients he has worked with David says that *they trust that you are not going to do them any harm and trust that your there to help them and that moment that you make that connection with the person is what nursing is all about.*

The therapeutic relationship for David is enriched by time. *I have worked intensively with the clients at the hospital over many years and know them very well.* David believes that this personal knowledge enables the nurse better able to understand when things are going wrong for the client. Although he didn't agree with the model of care the hospital provided for clients he decided to remain at the psychopaedic hospital for as long as he did because he thought that he could make a difference. *I felt I had a role there. If only just to do what little I could for people I guess in my own way... if everybody who disagreed with the way places like that ran, and got out, who the hells going to be there to look out for the rights of the residents?*

94

The lengthy and enduring nature of the nurse/client relationship is also apparent Shelby's and Ashley's stories. Shelby sometimes feels despondent about the slow progress clients make but she accepts that this is part of nursing these clients who have intellectual disabilities and mental health problems. Ashley was initially frustrated by this, and saw this as a lack of response to her interventions, but as she looks back over the past year and reflects on the pessimism of her colleagues from the rehabilitation service she says, *I've seen some of our* [clients] *come an incredible long way. It's taken time, but looking back, given their abilities and how people had written them off before hand, it's astounding.* The enduring nature of this relationship is also reflected by Shelby and Ashley's concern for the standard of care clients will receive was they return to the community. Jones (2003) notes that learning disability nurses often work with complex clients (and their families) over long periods of time and are likely to have developed established working relationships and can facilitate communication. The difficulties generic health services have in providing quality services for people with learning disabilities can be minimised through the intervention of learning disability nursing.

Nurses who work with clients who have a dual diagnosis are often required to work with diagnostic ambiguity. Diagnostic labels are an important part of contemporary mental health services because they influence a person's access to treatment. However, when a client is non-verbal and cognitively impaired their presentation of mental illness can be atypical (Menolascino, Gilson, & Levitas, 1986; Reiss, 1982). They might not receive a diagnosis, they might receive a less precise diagnosis or they might receive the wrong diagnosis. A study in Australia by White, Chant, Edwards, Townsend and Waghorn (2005) found that people with an intellectual disability have a high risk of developing a serious mental illness and their illness is often overlooked because of difficulties in making a diagnosis in this population. David accepts that diagnostic labels are *one of those necessary evils* and although he is opposed to labelling people he acknowledges that you have to *have a label to get funding.* Shelby says that distinguishing between a

behaviour problem and a mental illness when a client has an intellectual disability can be a lengthy and difficult challenge. According to Ashley assigning a diagnostic label to a client may help with treatment planning but ultimately you focus on the individual and their symptoms and *treat what you see*. Reflecting back on her time working in a rehab ward, she believes that the clients with intellectual disabilities engaged in challenging behaviours out of frustration because of their inability to communicate. Unfortunately their behaviours were related to mental illness, the focus of treatment on the ward, and their medication adjusted accordingly. Diane also acknowledges the usefulness of diagnoses in planning care but notes that *there can be considerable overlaps between the client's intellectual disability and their mental health* and says that *psychiatrists are very dependent on the quality of the information they receive from caregivers to make an accurate diagnosis.*

The importance David attaches to advocating for a vulnerable individual is captured by a beautiful example he gives of a client who had a *profound effect* on him. This client had a gastronomy tube inserted into his stomach which meant that he was no longer able to enjoy the taste of food or the sensation of having water in his mouth: David had to liaise with parents and medical professionals and also reflected upon his own attitudes and values while presenting the client's voice. *Am I doing the right thing? That to me is nursing, doing the best thing for your patient.*

Shelby and Diane like David, also mention advocacy. According to Shelby *advocacy is a huge part of what we do... for our clients. They don't articulate for themselves very well sometimes and we have to get to know them and build that relationship with them well enough to get to know what it is they will be asking from us.* Shelby advocated strongly for a woman with a dual diagnosis at a multidisciplinary team meeting while working in an acute mental health unit. *Other staff felt that they were just behavioural and shouldn't be in the unit. I realised that there is a pressure for beds, but this woman was too unwell to be*

discharged. While describing what nursing is for her, Shelby's appears to relate the following concepts to advocacy: role modelling, leading by example and caring and teaching. For Shelby advocating for clients is integrated into the practice of nursing. Non-professional care staff should gain an understanding of how to provide appropriate care for clients with intellectual disabilities by observing and following the example of the nurse. With her nursing practise she attempts to treat clients as individuals with their own standards, values and beliefs and hopes that others will do the same.

Diane says that advocacy for her includes empowerment, talking to clients in language they can understand and translating the client's perspective for others. *I believe* [advocacy] *it is part of being a nurse really, and is one of the many hats that we wear as nurses....* [It requires a lot of energy] *to advocate for* [a client with an intellectual disability], *to show other people that they are a person in that community and to get them to appreciate that...and* [show them] *how simple it is to work with this client.* As an advocate Diane sees herself as *one of the vehicles to actually move them to the optimum and work with them to whatever that is for them.* Kay, Rose and Turnbull (1995), identify advocacy as an important role for nurses who work with clients who have intellectual disabilities. Bollard and Jukes (1999) believe that an integral part of the nurse role is the concept of facilitating and empowering the individual who has an intellectual disability.

According to Jenkins and Northway (2002), while there might be an expectation that nurses will provide direct/professional advocacy, it may not always be appropriate for them to do so. In certain cases, nurses may find that their loyalty to their employment organisation conflicts with the interests of their clients. However, nurses can also support client self-advocacy and independent advocacy by helping people with intellectual disabilities to develop the skills to self-advocate and by working with others to erode barriers to these forms of advocacy. Diane acknowledges the importance of advocates who are independent from the organisation providing care, but notes that remains committed to her role as a

client advocate who might need to 'step in' if an official advocate is not doing their job.

Advocacy is also discussed more broadly in the nursing literature. For example, De Santis and Ekegren (2003) and Schapiro (2005) say that it is important that paediatric nurses advocate for mental health services for children, a vulnerable group in society. Jarmen (2002) writes that "mental health nurses working in the community must be able to advocate for their clients with a wide range of agencies" (p. 22). Jarmen works for a mental health assertive outreach team in New Zealand and she describes how she successfully accessed much needed support for a client while overriding peer pressure. According to Smith (2004) there are a number of conditions that contribute to the nurses' role as advocate, these are: the clients vulnerability due to illness, complex health care systems and complex health information, and possibility of loss of human rights. Parsons (2002) refers to several tragedies in New Zealand, blaming in part inadequate resources in mental health. He argues that nurses have an emerging role of "advocating for change in regional and national systems and structures that are not delivering the standard of care and the safe environment patients need in order to be cared for and nurses need to work effectively and safely" (p. 25).

David noted that sometimes when you nurse clients with intellectual disabilities and mental health problems, advocacy can mean putting restrictions on their behaviour and autonomy. *I could justify myself and my actions in providing or stopping those people going or... because I knew myself it was in their best interests to be there and to do that.* Shelby and Ashley are also aware of the realities of advocating for clients with a co-existing intellectual disability and mental health problem. Shelby has found that it is necessary to find a balance between the client's independence and the community's right to be kept safe. People are in a forensic unit *for a reason, and there are very good reasons if you look at their forensic histories.* Ashley says that successfully management plans might seem unduly harsh or rigid to care givers in the community who don't really

understand where the person has come from but if these plans are not followed the old challenging behaviours will re-emerge. It is important that nurses examine their own motivation as advocates. The reluctance of the nurse to let go and trust others to care for the client might be an indication of an enduring therapeutic relationship, and a positive regard for their own specialist knowledge, but it could also be seen as paternalism. The nurse is often an important person in the client's life, but rarely are they the only significant person, and they must learn to communicate and work with others to benefit the client. The dilemma for the participants is that they are working with clients who will always require a certain amount of support from others. Allowing them too much autonomy, to soon might be setting them up to fail.

Summary

Participants' are concerned about the availability of mental health service for their clients and argue that nurses with specialist knowledge of intellectual disability are necessary to provide a high standard of care. They do not believe that the mental health needs of people with intellectual disabilities can be addressed by existing mainstream services. Pervading ideologies often take on a momentum that is difficult to stop and the individual needs of clients can be lost in the enthusiasm. Sometimes nurses also need to stand up and proclaim that the "emperor has no clothes." This chapter has presented and interpreted the themes of the participants' that emerged from their individual stores. Participants discuss the status of nurses and clients argue that both groups are worthy of more respect. The lived experience of the participants who work with clients who have a co-existing intellectual disability and mental health problem can be captured with the theme of "The Status and Positioning of the Nurse and Client Leads to Advocating Practises."

CHAPTER 6 – CONCLUSION

In this chapter I summarise the thesis and discuss the implications of the research finding for nursing practice, the shortcomings of the study and offer suggestions for future research.

Summary of the Thesis

There are few nurses in New Zealand who work with clients who have intellectual disabilities and mental health problems. These nurses are on a journey of discovery. What is it that makes them unique specialist nurses? My participants have shared some of their experiences on their personal journey which highlights how all nurses respond to challenges and how their practise is shaped by it. This study used a qualitative approach; it was informed by phenomenological writings of van Manen, to reveal the lived experience of nurses who work with clients who have a co-existing intellectual disability and mental health problem. I interviewed four nurses and identified the common themes that occurred across their stories.

The participants were critical of the level of past and existing services for clients with a co-existing intellectual disability and mental health problem and shared their concerns about the care their clients might receive in a community environment. While not opposed to the attempts by the mainstream services to address the mental health needs this population, they argue that specialist services including nurses who have specialist knowledge of intellectual disability and mental health are required to ensure a high standard of care. Participants' frustration at both the low status of their clients and of the nurses who care for them is apparent, but so too is the passion and the enthusiasm with which they argue that both groups deserve more respect. Participants all attempted to provide good nursing care in services that were less than optimal and or moved to other services that offered the promise of better care. Their relationships with clients tended to be prolonged and they shared how their interest in the clients' welfare

continues beyond the period of the direct nurse/client encounter. Through their example of nursing clients, participants endeavored to educate nursing and non-professional colleagues likely to come into contact with individuals with intellectual disabilities and mental illness. The lived experience of these nurses could be captured best with a single theme of "The Status and Positioning of the Nurse and Client Leads to Advocating Practises."

There is a dearth of literature written from the perspective of the nurse who works with clients who have a dual diagnosis. The available literature however, does mention some of the issues that were prominent in the participant's stories such as, the low status of clients with an intellectual disability and the nurses who care for them, the nurse as advocate, and the importance of nurses who have specialist knowledge of intellectual disability. The nursing literature is from overseas and my study provides a New Zealand context to the nurses' experience. I also noticed that the participants concern about the quality of community care for clients with co-existing intellectual disabilities and mental health problems was stronger than the literature suggests, and this may be because deinstitutionalisation and the development of specialist mental health and forensic intellectual disability services is relatively recent in New Zealand's history.

Implications for Nursing Practice

The research highlights the low status of clients with co-existing intellectual disabilities and mental health problems and the nurses who care for them.

There has been a growth of opportunities for nurses to work with people who have intellectual disabilities and mental health problems because of the increase in specialist mental health and forensic services. With the demise of the psychopaedic nurse as a unique registration it remains to be seen whether New Zealand has enough nurses with the requisite qualifications and the enthusiasm to work in this area. The findings of my research has implications for the Nursing

Council of New Zealand, organisations that employ nurses, the nursing profession, nurses who work with clients with intellectual disabilities, nurse educators and government. The aforementioned groups need to explore ways of raising the status of nurses who work with clients who have co-existing intellectual disabilities and mental health problems and their clients.

The scope of practice for psychopaedic nurses in New Zealand has been clearly prescribed by the Nursing Council and there has been a strong incentive for psychopaedic nurses to complete additional training to broaden their career opportunities. I noted in the introduction to the thesis that nurses are being imported from the UK to fill job vacancies in New Zealand. The Council must ensure that attempts to prescribe nurses scope of practise doesn't unfairly disadvantage nurses with the traditional psychopaedic (or learning disability) registration. Under current requirements these nurses are only able to work with clients with intellectual disabilities. This creates potential dilemmas for nurses who want and are needed to work in mental health intellectual disability teams, a position that they might be well qualified for. On a note of optimism, I was encouraged recently when a colleague approached the Nursing Council for permission to extend her scope of practice through extra training, and she was asked whether she would continue to nurse clients with intellectual disabilities (Personal Communication, December, 2006). The Council is aware of the need to retain experienced nurses in this area and I encourage them to continue to inform nurses about the career opportunities should they wish to continue nursing people with intellectual disabilities and mental health problems.

Organisations that employ nurses who work with clients with co-existing intellectual disabilities and mental health problems must consult with nurses when developing or reviewing policies and procedures which impact on nursing practice. They must also ensure that clinical supervision is available to nurses. Training opportunities, conferences and workshops should be offered to these nurses so that they can continue to develop their nursing practice. Agencies must also ensure

that nurse performance appraisals are conducted by senior nursing staff that are knowledgeable about, and apply nursing council competencies appropriately to the nurse specialty.

Nurses are a significant labour force within mental health services generally, and they need to ask themselves whether they support the exclusion of people with intellectual disabilities from mainstream services. The research participants also reported that they have felt devalued by other nurses and this presents a challenge to a profession that should celebrate its diversity and value all its members as it shapes its identity for the future.

Nurses who work with clients with co-existing intellectual disabilities and mental health problems can help to raise the status of the profession and their clients. The closure of the institutions may have signalled the end of the traditional role of the psychopaedic nurse, but the move towards community based care has also led to the development of new opportunities for nursing. Nurses must be prepared to adapt to changing circumstances and transfer their skills to new challenges. Some of the nurses who worked in the old institutions will choose to practise in other areas of nursing, mental health care for example, and these nurses will have the opportunity to nurse clients with intellectual disabilities in new care settings, and pass on their expertise to colleagues. Recently there has been a growth of new opportunities for nurses interested in working in specialist intellectual disability and forensic settings. There are also less traditional roles for nurses. They are able to apply for jobs that have been created by the Intellectual Compulsory (Care and Rehabilitation) Act 2003, including the role of care co-ordinator and care manager. I am also aware of nurses with extensive psychopaedic experience who have moved into senior roles in behaviour support teams within one of the larger non government residential providers.

Nurses need to communicate the work that they do. Minto (2001) writes that learning disability nurses in the UK can help to legitimise and develop a distinct

identity for their specialist area by describing and disseminating their "practice within a research and development framework" (p. 25). I believe that nurses must contribute to nursing publications, conferences, research and professional nursing forums. There are also opportunities for nurses to make submissions when new legislation or an official report is preposed. Nurses who work for government organisations are able to pass on their concerns to the Ministry of Health, albeit often indirectly via line management. In availing themselves of these opportunities nurses are ensuring that they have a voice and they cannot easily be ignored. Regular meetings with colleagues who work in the same or different areas of practice is important because opportunities to met, talk and share stories with other nurses helps to establish a shared identity and build a sense of solidarity. Specialist mental health (and forensic) intellectual disability services in New Zealand met on a yearly basis and this provides opportunities for specialist nurses and other clinicians to compare experiences and learn of each other.

Nurses should talk about the work that they do with nursing students at undergraduate level and new graduate level. New nurses often enter mental health services in New Zealand through new graduate programmes. These programmes provide the new graduate with opportunities to sample areas of practice and select an area of particular interest. They also provide nurses who work in mental health intellectual disability teams with an opportunity to share their knowledge and job satisfaction and nurture potential specialist nurses.

Nurses need to avail themselves of clinical supervision and employers should fund this. Low status could be expected to reduce the moral of a professional group and perhaps reduce their ability to practise effectively. Supervision is an important forum for nurses to discuss issues of practice and find ways of practicing more effectively. Effective practise will also benefit clients.

Nurses must be willing to establish working relationships with others involved in the care of clients with intellectual disabilities and mental health problems,

including other health professionals, client advocates, self-advocates and family. They also need to acknowledge the contribution of Maori and Pacific Island perspectives on health and disability. Many of these individuals have risen in prominence with the closure of institutions and could be useful allies with providing client care. Working with these different groups is consistent with contemporary guidelines of best practice in New Zealand promoted by the Mental Health Commission (1997) in the *Blueprint for Mental Health Services in New Zealand*.

Nurses who have concerns about client care have a number of options. If they witness client abuse there will be reporting mechanisms within an organisation to ensure that investigations are carried out and appropriate action is taken. The Nursing Council of New Zealand is able to censure and in serious cases, remove nurses from the nursing register if they are found to have abused clients. Nurses should be able to advocate in cases were they feel that the client should be receiving more or different care. If a nurse feels that a client with an intellectual disability is excluded from mental health services unfairly they are able to complain to the disability commissioner or inform the client and their family or caregivers of their right to make a formal complaint.

I urge the New Zealand government to meet with key stakeholders, including nurses, to develop a clearer vision of specialist of mental health services for people with intellectual disabilities. Service development in New Zealand following deinstitutionalisation was initially influenced by philosophies of normalisation and mainstreaming. Small specialist services were developed, in Wellington for example, to address the mental health needs of clients with intellectual disabilities in partnership with generic mental health services. Unfortunately mainstream services do not appear to have the will, the resources or the expertise to work with clients who have intellectual disabilities. Mainstream services require clear direction from government and the Ministry of Health regarding their responsibilities towards clients with intellectual disabilities. Alternatively it may

be necessary to further develop specialist services so that they can function more autonomously.

It is unlikely that psychopaedic nurse training will be reinstated in the future. However, undergraduate nurse training does not appear to equip students with sufficient knowledge or enthusiasm of intellectual disability to practice in this area. Fortunately in some areas of the country students have placements in an inpatient intellectual disability forensic area and with specialist mental health intellectual disability teams. If nurse educators do not feel able to do justice to the topics of intellectual disability and intellectual disability and mental health, they should invite guest speakers, specialist nurses for example, to cover these topics.

Limitations of the Research

The research methodology, phenomenology, is a useful means of exploring a topic that cannot be readily reduced to numerical data. However, it is a qualitative methodology and the findings cannot be readily generalised. I hope that the lived experiences of my participants will resonate with other nurses who work with clients who have co-existing intellectual disabilities and mental health problems, but I cannot assume that my study tells me anything about the experience of nurses who were not part of my study.

The lived experiences of the participants might resonate more with nurses who have the opportunity to develop traditional therapeutic relationships with their clients. I believe that there will be emerging roles for nurses who work with clients with intellectual disabilities in the future but these roles may be diverse and it might be difficult to describe the 'common thread' that identifies all of them as nurses. I currently work for a consultation liaison team offering one-off mental health assessments for clients who have intellectual disabilities. Many of my clients are non-verbal communicators and information is often obtained from secondary or tertiary sources and unlike my participants I do not have extended

contact with clients. Some of the participant's experiences resonate more strongly with me because I have been able to work with more intensely with clients in previous jobs.

The limitations of a two paper thesis prevented me from exploring my participant's lived experiences in depth. I am mindful that participants' interviews covered long periods of their nursing careers and future researchers might like to consider interviewing participants more than once to enable further interpretation of themes. For example, one participant referred in general terms to exclusion of clients with intellectual disabilities from mainstream mental health services, a topic that is worthy of further exploration, focusing more closely on the participants own lived experience.

The long time period between my interviews and the conclusion of the thesis means inevitably that some of my conclusions are based on information that has dated. In some cases participants might have moved to new jobs and /or some of the concerns expressed by them may have been addressed by service changes at local or national level. I am aware that there has been an increase in specialist services across the country to address the needs of people with intellectual disabilities and mental health problems although I think that it is unlikely that these changes have been sufficient to completely alter the lived experience of the participants.

Suggestions for Further Research

My research is intended to be an initial first step in exploring the lived experiences of nurses who work with client who have co-existing intellectual disabilities and mental health problems. The roles for nurses who work with this client group are emerging and are likely to be diverse. There is a need for further research to capture the different experiences of these nurses. By exploring the lived experiences of nurses who work in diverse roles with clients with intellectual

disabilities and mental health problems the researcher might also be able to capture that elusive thread that identifies them as a specialist group of nurses.

In closing, because there is a dearth of previous research exploring the experiences of nurses who work with clients with intellectual disabilities and mental health problems this research is important. It should be useful for other nurses to read, for education providers and employers to reflect upon, and for other researchers to compare and contrast with their findings. To this end I am grateful to the four nurses who shared their experiences of working as a nurse with people with intellectual disabilities and mental health problems.

APPENDIX 1

REQUEST FOR RESEARCH PARTICIPANTS

Request for Research Participants

My name is Michael Dorofaeff and I am a student in the MA (applied) program, Graduate School of Nursing and Midwifery at Victoria University of Wellington.

As part of a research project I want to talk with registered nurses who currently work with clients who have a co-existing intellectual disability and mental health problem.

If you:

- are a registered comprehensive, registered psychopaedic, registered psychiatric or general trained nurse;

- work predominantly with clients who have intellectual disabilities;

- are not a member of my work team; and

Are interested in volunteering and would like to discuss my research further, please contact me on (04) 237 2204. I can then forward to you the research information sheet and the consent form.

APPENDIX 2

INFORMATION SHEET FOR PARTICIPANTS

Exploring the lived experience of nurses who work with clients who have a co-existing intellectual disability and mental health problem

My name is Michael Dorofaeff and I am a student in the MA (applied) program, Nursing and Midwifery at Victoria University of Wellington.

I am inviting you to participate in my research project. I am interested in exploring nursing from the perspective of nurses who work with clients who have a co-existing intellectual disability and mental health problem. I have chosen to use the term mental health problem, rather than mental illness, because of the complexity of mental health issues relating to the population of persons who have intellectual disabilities. While terms such as mental illness, challenging behaviour, behavioural problems, or maladaptive behaviours may sometimes reflect the different philosophical standpoints of various services, they are often used interchangeably in practice.

There is a dearth of literature written by nurses who work with this client group and I believe that the work of nurses who provide care for clients with intellectual disabilities is not always acknowledged. I am offering you the opportunity to share your own stories, which I hope will help to validate your practice for you and for other nurses who work in similar specialist areas. I hope my study will encourage further research that will help to develop and strengthen the identity of a specialist area of nursing practice in New Zealand.

I am approaching you because I believe that you have the following qualities that I am looking for:

- You are a registered comprehensive, registered psychopaedic, registered psychiatric or general trained nurse.

- You work predominantly with clients who have intellectual disabilities.

- You are not a member of my work team.

Should you agree to take part, you will be one of six participants who I will interview at a place of your convenience for 60- 90 minutes. The interviews will be taped, with your permission, and transcribed. You will be invited to read, comment on and edit transcripts to ensure that your views have been accurately represented.

You will be able to keep recorded copies of your interviews and transcripts should you wish to do so.

The research will be written up as a thesis report and lodged in the library at Victoria University, and also in the Graduate School of Nursing and Midwifery at Victoria University. The research results will also written up and be submitted to appropriate scholarly journals and presented at conferences. Your permission to disseminate the results in this way will be obtained as a part of the signed consent process.

The interviews will be semi-structured and essentially conversational, and you will be asked to share your own experience of nursing people with intellectual disabilities. However, I have prepared the following questions to keep me 'on track' and provide structure for the interviews:

1/ Tell me how you came to be working with people who have a co-existing intellectual disability and mental health problem.

2/ What is nursing people with a co-existing intellectual disability and mental health problem like for you?

3/ Describe the key challenges that you experience working with people who have intellectual disabilities and mental health problems.

4/ Give me an example from your own practice that captures what nursing is for you?

I intend to protect your privacy by using pseudonyms and any names of clients or other people revealed during the study will be deleted from the submitted final research thesis. Specific information from the transcripts will not be used if you request that it be deleted. Interview data will be securely stored and accessible only to the interviewer/researcher. Research data will be retained for ten years and erased unless additional signed consent is obtained from you for further research.

While it is not my intention to explore issues which you may find personally distressing, given the exploratory nature of the semi structured interview process, it is possible that I may uncover issues which are upsetting for participants. I will be prepared to discontinue the interview at any time should it be apparent to me that participants are unduly distressed. You should feel free to contact me at any time. Should you reveal any evidence of malpractice to me during the research

study I am obliged to report this according to the protocols and policies of your workplace.

By focusing on my primary research question, I will be able to limit the risk of harm. You will be able to withdraw from the study at any time without explanation or prejudice.

I can be contacted at work on (04) 237-2204 or (04) 236-0313 home.

My supervisor for this research project can be contacted at:

Rose McEldowney
Graduate School of Nursing and Midwifery,
Victoria University of Wellington.
(04) 436 6651.
Rose.McEldowney@vuw.co.nz

This research project has been approved by the Manawatu/Whanganui Health & Disabilities Ethics Committee and the Wellington Health & Disability Ethics Committee.

Ethics committees can be contacted at:

Wellington Ethics Committee is:
Private Bag 7902, Wellington.
Email Claire.1@wec.org.nz

Manawatu/Whanganui Ethics Committee
PO Box 5203
Palmerston North.
Email mwethics@xtra.co.nz.

Yours sincerely

Michael Dorofaeff

APPENDIX 3

PARTICIPANT CONSENT FORM

Exploring the lived experience of nurses who work with clients who have a co-existing intellectual disability and mental health problem

I have read and I understand the information sheet dated 31.7.03 for volunteers taking part in the study designed to explore my experience of nursing clients who have intellectual disabilities and mental health problems. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

Although I understand that confidentiality cannot be guaranteed, I understand that the researcher will make every effort to protect my identity and that no material which could identify me will be used in any reports on this study. I understand that the investigation, will be stopped if it should appear harmful to me.

I have had time to consider whether to take part and I know whom to contact if I have any questions about the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my employment.

I understand that the researcher is obliged to report any evidence of malpractice to my employer should it emerge during the study.

I understand approval for this study has been granted by the Manawatu/Whanganui Health & Disabilities Ethics Committee and the Wellington Health & Disability Ethics Committee.

I consent to my interview being audio-taped   YES/NO

I understand that I have the right to edit transcripts   YES/NO
of my interview

I wish to receive a copy of the results   YES/NO

Alternatively, I would like the researcher to discuss the outcomes   YES/NO
of the study with me.

I .... (full name) hereby consent to take part in this
study.

Date: Signature of witness:
Signature: Name of witness:

Full name of Researcher:
Contact Phone Number for researcher:
Project explained by:
Project role:
Signature:
Date:

REFERENCES

Alaszewski, A., Gates, B., Ayer, S., Manthorpe, G., & Motherby, E. (2000). *Education for diversity and change: Final report of the ENB- funded project on educational preparation for learning disability nursing.* Schools of Community and Health Studies and Nursing: University of Hull.

Allen, D. (1994). A survey of referrals to specialist services for people with learning disabilities who have a dual diagnosis or a challenging behaviour. *British Journal of Learning Disability, 22,* 144-147.

American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders: (4th ed.).Washington DC: Author.

Baker, C., Wuest., J. & Stern. P. N. (1992). Method slurring: The grounded theory/phenomenology example. *Journal of Advanced Nursing,* 179(11), 1355-1360

Barwick, H. (1995). *Coming back: People with intellectual disabilities returning to our communities.* Wellington: Central Regional Health Authority.

Beck, C. T. (1994). Phenomenology: Its use in nursing research. *International Journal of Nursing Studies,* 31(6), 271-282.

Berg, A., Hallberg, I., & Norberg, A. (1998). Nurses' reflections about dementia care, the patients, the care and themselves in their daily care giving. *International Journal of Nursing Studies,* 35(5), 271-282.

Bollard, M., & Jukes. M. J. D. (1999). Specialist practitioner within community learning disability nursing and the primary health care team. *Journal of Learning Disabilities for Nursing, Health and Social Care,* 3(1), 1-19.

Borthwick–Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology,* 62(1), 17-27.

Bouras, N. (1999). Mental health and learning disabilities: Planning and service developments. *Tizard Review,* 4, 3-6.

Brooke, J. (1999). Derided we fall. *Nursing Times,* 95 (4), 28.

Campbell, M., & Malone, N. (1991). Mental retardation and psychiatric disorders. *Hospital and Community Psychiatry,* 43, 374-379.

Carpenter, H. (1971). *An improved system of nursing education for New Zealand.* Wellington: Department of Education.

Central Regional Health Authority. (1995*). Coming back: People with intellectual disabilities returning to our communities.* Researched and written for the Wellington Health Authority by Helena Barwick. Wellington: Author.

Central Regional Health Authority. (1995, November). *Personal safety and people with intellectual disability. Issues & guidelines for services.* Wellington: Author.

Cook, H. (1998). Primary health care for people with learning disabilities. *Nursing Times,* 94(30). Retrieved October 12, 2006, from www.nursingtimes.net .

Cornelia, M. B., Rawlins, R. P., & Wikllimas, S.P., (Eds.), (1984). *Mental health nursing: A holistic life cycle approach.* St Louis. The C.V. Mosby Company: Hartman.

Couchman, W. (1995). Using video and conversational analysis to train staff working with people with learning disabilities. *Journal of Advanced Nursing,* 22, 1112-1119.

Crouch. D. (2003). What valuing people really means. *Nursing Times,* 99(18), 38-39.

Cutler, L.A. (2001). Mental health services for people with mental retardation: Role of the advanced practice psychiatric nurse. *Issues in Mental Health Nursing,* 22(6), 607-620.

Day, K.A. (1993). Mental health needs for people with mental retardation: A frame work for the future. *Journal of Intellectual Disability Research,* 37(1), 7-16.

Day, K. A. (1994). Psychiatric services in mental retardation: Generic or specialised provision? In N.Bouras, (Ed.). *Mental health in mental retardation. Recent advances and practices* (pp.275-292). Cambridge: University Press.

Department of Health. (1988). *Nursing Education in Transition: The Transfer of Nursing Education to the General System of Education. 1973- 1988: The Department of Health's Perspective.* Workforce Development Group, Department of Health, Wellington: Author.

Department of Health and Social Security. (1972). *Report of the Committee on. Nursing (Briggs Report).* London: HMSO.

Department of Health and Social Security. (1979). *Report of the Committee of Inquiry into Mental Handicap Nursing and Care (Jay Report).* London: HMSO.

De Santis, J. P., & Ekegren, K. (2003). Advocating for mental health services for children with depressive disorders. *Journal for Specialists in Paediatric Nursing,* 8(1), 38 40.

Edwards, A., & Talbot, R. (1994). *The hard pressed researcher: A research handbook for the caring professions.* London: Longman.

Elderly, Handicapped and Disabled programme. (1988). *Guidelines for standards for people with intellectual handicaps.* Department of Health. Wellington New Zealand: Author.

Gabriel, S. R. (1994). The developmentally disabled, psychiatrically impaired client: Proper treatment of dual diagnosis. *Journal of Psychosocial Nursing,* 32(9), 35-39.

Gilbert, T., Todd, M., & Jackson, N. (1998). People with learning disabilities who have mental health problems: Practice issues and directions for learning disability nursing. *Journal of Advanced Nursing,* 27(6), 1151-1157.

Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation.* Newbury Park, California: Sage Publications.

Guba, E., & Lincoln, Y. (1995). Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (Eds.). *Handbook of qualitative research,* (pp.105-117): Thousand Oaks: Sage.

Hallas, C. H., Fraser, W. I., & MacGillivray, R. C. (1982). *The care and training of the mentally handicapped.* (7th ed.). Bristol:Wright. PSG.

Heidegger, H. (1925). *History of the concept of time.* (T. Kisiel, Trans.). Bloomington: Indiana University Press.

Heidegger, H. (1967). *Being and time.* (J. Macquarie & E. Robinson, Trans.). Oxford: Basil Blackwell.

Heidegger, H. (1962). Being and Time. In A. Friedman. (Ed.). *The worlds of existentialism: A critical reader.* (pp.94-100) Chicago 1964: The University of Chicago Press.

Holbrook, S. H. (2000). Psychopathology and behavioural problems in mental retardation. *Journal of Psychosocial Nursing, 38*(3), 23-25.

Howie, D., & Cuming, J. (1986). *Self advocacy by mentally retarded persons: A New Zealand study.* Wellington, New Zealand: New Zealand Institute of Mental Retardation.

Husserl, E. (1929). The Paris Lectures. (P. Koestenbaum, Trans). In Robert C Solomen. (Ed.1972). *Phenomenology and Existentialism.* (pp.43--77) Harper and Row, New York.

Husserl, E. (1931). *Ideas.* (W. R. Boyce-Gibson, Trans). Collier Books, New York.

Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. Retrieved 22 January 2007 from www.moh.govt.nz .

Jacobson, J. (1999). Dual diagnosis services: History, progress and perspectives. In N. Bouras. (Ed.). *Psychiatric and behavioural disorders in developmental disabilities and mental retardation.* (pp.329-357) Cambridge: Cambridge University Press.

Jack, A. (1985). Deinstitutionalisation and the intellectually handicapped. *Community Mental Health in New Zealand.* Vol 2(1), 45-51.

Jarmen, G. (2002). Caring for all a persons mental needs. *Kaitiaki Nursing New Zealand,* 22-23, 45-51.

Jay Committee. (1979). Report of the Committee of Enquiry into Mental Handicap Nursing and Care. CMND 7468. London: HMSO.

Jenkins, R., & Northway, R. (2002). Advocacy and the learning disability nurse. *British Journal of Learning Disabilities,* 30(1), 8-12.

Jones, C. (1998). Social work and society. In: L. Adams, L. Dominelli & M. Payne (Eds.). *Social work; themes, issues and critical debates.* (pp.34-43) Macmillan: London.

Jones. A. (2003). Palliative care and people with learning disabilities. *Learning Disability Practice,* 6(7), 30-37.

Jones, S. (1999). Learning disability nursing-holistic caring at its best. *Nursing Standard,* 15(52), 61.

Jukes, M., & Bollard. M. (2002). Health facilitators in learning disability are important roles. *British Journal of Nursing,* 11(5), 297.

Kay, N. B., Rose, S., & Turnbull, J. (1995). Continuing the commitment. *The report of the learning disability project.* London: DOH.

Koch, T.; Marks, J. & Took., E (2001). Evaluating a community nursing service: Listening to the voice of clients with an intellectual disability and/or their proxies. *Journal of Clinical Nursing,* 10, 352-363.

Koch, T. (1994). Establishing rigour in qualitative research: The final decision trial. *Journal of Advanced Nursing,* 19, 976-986.

Lau, V. M. H., & Mackenzie, A. (1996). Attributes of nurses that determine the quality of care for mentally handicapped people in an institution. *Journal of Advanced Nursing,* 24(6), 1109-1115.

McCray. J. (2003). Interpersonal practise and learning disability nursing. *British Journal of Nursing,* 12(22), 1335-1344.

McGill, P., & Emerson, E. (1992). Normalisation and applied behaviour analysis: values and technology in human services. In Brown H & Smith H. (Eds.), *Normalisation: A reader for the nineties* (pp.60-83). London: Routledge,.

McHaffie, H. E. (1996). Ethical issues in nursing research. In D.F.S Cormac. (Ed.). *The research process in nursing.* (3rd ed.). (pp.30-39). Oxford; Cambridge, USA: Blackwell Science.

McMillan, I. (1996). Independent means. *Nursing Times,* 92(9), 59-61.

Mann, R. (1994). Imbalance of power. *Nursing Times,* 90(49), 54-56.

Mathieson, A. (2001). Arena harsh lesson for our teachers. *Nursing Times,* 97(34), 32

Mathews, D.R. (1996). Learning disabilities: The challenge to nursing. *Nursing Times,* 92 (27), 36-38.

Menolascino, F. J., Gilson S. F., & Levitas A. S. (1986). Issues in the treatment of mentally retarded patients in the community mental health system. *Community Mental Health Journal,* 22(4), 314-327.

Mental Health Commission. (1997). *Blueprint for mental health services in New Zealand.* Wellington: Author.

Ministry of Health. (1994). *Planned Deinstitutionisation: Papers prepared for CHEs, RHAs and the PHC.* Wellington, New Zealand: Author.

Ministry of Health. (2001). *The New Zealand Disability Strategy: Making a Difference - Whakanui Oranga.* Wellington, New Zealand: Author.

Ministry of Health. (2001 August). *Preferred Service Provision for the Residents of the Kimberley Centre.* Prepared for the Minister of Health and Minister of Disability Issues. Wellington, New Zealand: Author.

Mitchell, D. (2000). Parallel stigma?: Nurses and people with learning disabilities. *British Journal of Learning Disabilities,* 28, 78-81.

Mitchell, D. (2003). A chapter in the history of nurse education: Learning disability nursing and the jay report. *Nurse Education Today,* 23(5), 350-356.

Minto, C. (2001). Contemporary issues in learning nursing-a UK perspective. *Hong Kong Journal of Psychiatry,* 11(1), 25-28.

Mobbs,C., Hadley, S., Wittering, R., & Bailey, N. M. (2002). An exploration of the role of the community nurse, learning disability, in England. *British Journal of Learning Disabilities,* 30, 13-18.

Mollett, J. (2002). *Deinstitutionalisation: Issues and challenges for people with an intellectual disability discharged from Tokanui Hospital between 1996-1998.* Research undertaken for the Waikato District Health Board in Association with the Ministry of Health, Disability Support Link and Life Unlimited.

Moore, M. K. (1986). Nursing the developmentally disabled. *Michigan Nurse.* December, 4.

Morrison, A. A., Beasley, D. G. M., & Williamson, K. I. (1976). *The intellectually handicapped and their families: A New Zealand survey.* Wellington Foundation of New Zealand Society for the Intellectually Handicapped.

Munro, R. (2000). Vibrant nurses in from the cold. *Nursing Times,* 96 (28), 14.

Naylor, V., & Clifton, M. (1994). People with learning disabilities-meeting complex needs. *Health and Social Care,* 1, 343-33.

New Zealand Elderly, Handicapped and Disabled Programme, Department of Health. (1988). *Guidelines for standards for services for people with intellectual handicaps.* Wellington Zealand: Author.

New Zealand Health Information Service. (1999). *New Zealand nurses and midwives 1997.* Ministry of Health. Wellington, New Zealand: Author.

New Zealand Health Information Service. (2002). *New Zealand nurses and midwives 2000.* Ministry of Health. Wellington, New Zealand: Author.

New Zealand Health Information Service. (2006). *New Zealand nurses and midwives 2004*. Ministry of Health. Wellington, New Zealand: Author.

New Zealand Herald. (2004, June). More allegations of abuse at mental institution. Retrieved 20 January, 2007, from www.nzhearld.co.nz

New Zealand Herald. (2006, September). Lake Alice patient's payout up to $34,000. Retrieved 20 January, 2007, from www.nzhearld.co.nz

New Zealand Hospital Design and Evaluation Unit. (1980). *Accommodation for severely physically disabled persons. A study of the requirements for those in Need of 24 hour care: A report prepared by the Hospital Design and Evaluation Unit, Department of Health*. Wellington, New Zealand: Author.

New Zealand Ministry of Health (April 2001). *The New Zealand Disability Strategy*. Wellington NZ: Author.

Nottestad, J. A., & Linaker, O. M. (1999). Psychiatric health needs and services before and after complete deinstitutionisation of people with intellectual disability. *Journal of Intellectual Disability Research, 43*(6), 523-530.

Nursing Council of New Zealand. (1980). *An exploratory study of the competencies expected of the psychopaedic nurse at the time of sitting the State Examination*. Wellington: Author.

O'Brien, A. J. (2001). The therapeutic relationship: Historical development and contemporary significance. *Journal of Psychiatric and Mental Health Nursing, 8*, 129-137.

O'Brien, L. (2000). Nurse- client relationships: The experience of community mental health nurses. *Australian and New Zealand Journal of Mental Health Nursing*, 9, 184-194.

Orlando, I. J. (1961). *The dynamic nurse-patient relationship*. New York: G.P Putnam and Sons.

Paltridge, A. (2001). Long wait nearly over. *Evening Post*, June 20, p 7.

Parrish, A., & Styring, L. (2003). Learning disability nursing. Nurses' role in the developments in learning disability care. *British Journal of Nursing*, 12(17), 1043- 1047.

Parrish, A., & Sines, D. (1997). Future directions for learning disability nursing. *British Journal of Nursing*, 6(19), 1122 - 1124.

Parsons, C. (2002/2003). Advocating for mental health patients in a system under stress. *Kaitiaki Nursing New Zealand*, 24-25.

Patterson, T., Higgins, M., & Dyck, D.G. (1995). A collaborative approach to reduce hospitalisation of developmentally disabled clients with mental illness. *Psychiatric Services*, 46,3.

Pennington, S. (2000). Learning curve. *Nursing Times*, 96(50), 47-49

Plager, K. (1994). Hermeneutic phenomenology. In P, Benner, (ED), *Interpretive phenomenology: embodiment, caring, and ethics in health and illness* (pp.65-83). Thousand Oaks, CA: Sage Publications.

Polit, D. F., & Hungler, B. P. (1993). *Essentials of nursing research: Methods, appraisal and utilisation*. Philadelphia: Lippincott.

Prentice, C., & Barnett, P. (1983). *Census and service use of the intellectually handicapped in North Canterbury.* Christchurch, New Zealand: Health Planning Research Committee.

Raghavan, R. (1996). Confusing diagnoses…learning disabilities, mental illness. *Nursing Times,* 6(23), 59-63.

Rawlings, R. P., Williams, S. R.., & Beck, C. K. (1993). *Mental health-psychiatric nursing: A holistic lifestyle approach* (3rd ed). St Louis: Mosby Year Book.

Reiss, S. (1982). Psychopathology and mental retardation: Survey of a developmental disabilities mental health programme. *Mental Retardation,* 20(3), 128-132.

Report from the Mental Health Service Committee to the Wellington Hospital Board. (Oct 1988). *1989–1994 Plan for the mental health service for the Wellington Area.* Wellington: Author.

Research Report Commissioned Jointly by the Central and Midland Regional Health Authorise. (Aug 1995). *Needs, supports and services for people with intellectual disabilities who have challenging behaviour.* Wellington: Author.

Roberts, K & Taylor, B. (1997). *Nursing research process: An Australian perspective.* Melbourne: An International Thomson Publishing Company.

Rose, S., & Kay, B. (1995). Significant skills. *Nursing Times,* 91(36), 63-67.

Rutter, M., Graham, P., & Yule, W. (1970). *A neuropsychiatric study in childhood.* London: Heinemann.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Archives in Nursing Science,* 8(3), 27-37.

Schapiro, N. A. (2005). Bipolar disorders in children and adolescents. *Journal of Pediatric Health Care,* 19, 131-141.

Singh, N. N., & Wilton, K. W. (Eds.). (1985). *Mental retardation in New Zealand: Provisions services and research.* Christchurch: Whitcoulls Publishers.

Singh, N. N., Sood, A, Sonenklar, N., & Ellis, C. (1991. Assessment and diagnosis of mental illness in persons with mental retardation. *Behaviour Modification,* 15(3), 419-443.

Smith, A. P. (2004). Patient advocacy: Roles for nurses and leaders. *Nursing Economics,* 22(2), 88-90.

Sorrell, J. M., & Redmond, G. M. (1995). Interviews in qualitative nursing research: Differing approaches for the ethnographic and phenomenological studies. *Journal of Advanced Nursing,* 21(6), 1117-1122.

Sovner, R., & Hurley, A. H. (1983). Do mentally retarded people suffer from an affective illness? *Archives of General Psychiatry,* 40(1), 61-67.

Statistics New Zealand. (2006).Retrieved 15 January, 2007 from www2.stats.govt.nz.

Steadham, C. I. (1993). Role of professional nurses in the field of developmental disabilities. *Mental Retardation,* 31(3), 179- 181.

Stewart, D., & Todd, M. (2001). Role and contribution of nurses for learning disabilities: A local study in a county of the Oxford-Anglia region. *British Journal of Learning Disabilities*, 29(4), 145-150.

Street, M. R. (1980). *An exploratory study of the competencies expected of the Psychopaedic Nurse at the time of sitting the State Examination: For the Nursing Council of New Zealand.* Wellington: Author.

Taylor, P. (1986, May). *Barriers to community care of the severely mentally handicapped in New Zealand.* This is an unpublished paper that was presented at the ANZSERCH conference in Wellington.

Turnbull, J. (1995). Services do need specialists. Specialist services for people with learning disabilities. *Nursing Times,* 91(49), 54.

Turnbull, J. (1999). Who will lead the way? *Learning Disability Practice,* 2(2), 12-16.

van Manen, M. (1984). Practising phenomenological writing. *Phenomenol. Pedag,* 2, 36-69.

van Manen, M. (1990). *Researching lived experience: Human science for action sensitive pedagogy.* London: State University of New York Press.

van Manen, M. (Ed.). (2002). *Writing in the dark. Phenomenological studies in interpretive inquiry.* Canada: The Althouse Press.

van Manen, M. (October, 2003). *From Hypomneis to Anamnesis: Doing phenomenology and the demands of writing.* Draft Paper, Seminar Presentation: Auckland University of Technology, Auckland New Zealand.

Vessey, J. A. (1988). Care of the hospitalised child with a cognitive developmental delay. *Holistic Nursing Practise,* 2(2), 48-54.

Waizkin, H. (1991). *The politics of medical encounters.* London: Yale University Press

Walsh, K. (1999). Shared humanity and the psychiatric nurse-patient encounter. *Australian and New Zealand Journal of Mental Health Nursing,* 8(1), 2-8.

Walters, A. J. (1994). The comforting role in critical care nursing practice: A phenomenological interpretation, *International Journal of Nursing Studies.* 31(6), 607-616.

Walton, J. A. (1980). *Nursing practice in New Zealand hospitals. Staff Nurses and Enrolled Nurses: An investigation into the nature and organisation of nursing practice.* A report of a study undertaken for the National Action Group, with assistance from the Health Workforce Development Fund.

Watson, J. E., Singh, N. N., & Woods, D. J (1985). Institutional Services. In Singh, N.N., & Wilton, K.W. (Eds.). *Mental Retardation in New Zealand:* (pp 47-59). Provisions Services and Research. Christchurch: Whitcoulls Publishers.

White, P., Chant, D., Edwards, N., Townsend C., & Waghorn, G. (2005). Prevalence of intellectual disability and co-morbid mental illness in an Australian community sample. *Australian and New Zealand Journal of Psychiatry,* 39, 395-400.

Wellington Department of Education. (1972). *Nursing education New Zealand. Report of the committee set up to consider and report to the Minister of Education in recommendation 1.6 of the report of Dr Helen Carpenter.* Wellington: Author

Wellington Department of Health. (1983). *Survey of occupied hospital beds and psychiatric day and outpatients*, 1981, Special Report No 66. Wellington: Author.

Wellington Hospital Board. Mental Health Service Planning Committee. (October 1988). *Plan for the mental health service for the Wellington area.* Wellington, N.Z: Author.

Wolfensberger, W., & Tullman, S.A.(1982). A brief outline of the principle of normalisation. *Rehabilitation Psychology,* 27, 131-145.

Wright, E. C. (1982). The presentation of mental illness in mentally retarded adults. *British Journal of Psychiatry,* 141, 496-502.

Wanganui Area Health Board: Service Development Unit. *Community care for people with an intellectual handicap.* P.O. Box 649 Wanganui.

Manawatu Wanganui Area Health Board (November, 1992). *Draft Strategic Plan Services for Persons with an Intellectual Disability* 1992-1997.

Wellington Hospital Board. Mental Health Service Planning Committee (1988). *1989-1994 plan for the mental health service for the Wellington area/report from the mental health service planning committee to the Wellington Hospital Board.*