TOTALLY DIFFERENT:

AN ETHNOGRAPHIC ACCOUNT OF INTELLECTUAL DISABILITY NURSING

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A thesis submitted for the award of PhD in **Disability Studies**

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Dedicated to the memory of

my husband

Barry Paech

My hero and my inspiration

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ABSTRACT

This study adopted an ethnographic approach to examine the role of the Registered Nurse (RN) in the intellectual disability sector. The research setting (The Centre) is a residential facility for clients with intellectual disability in the northern suburbs of Adelaide that opened in 1971 and was similar to a hospital with the same hierarchy of nursing. Mental deficiency nurse training was conducted there until the 1990s but that qualification is no longer recognised. The Centre is under the umbrella of a large state disability organisation that is in the process of moving clients of the service from institutions (the Centre) to community living options such as group homes.

The cessation of mental deficiency nurse training and the introduction of deinstitutionalisation were considered to impact on client health and in the late 1990s a 24 hour nursing service was commenced. There was strong anecdotal evidence the service should be evaluated. A review of the literature found some research had been conducted in overseas countries with a focus on deinstitutionalisation but with a paucity of interest in the role of the RN, particularly in Australia.

Ethnography, first used in anthropology as a way of describing different cultures, was chosen as the research methodology because the researcher wanted to discover how the culture influenced the role of the RN. The researcher is an RN employed in the area. As an ethnographer and participant observer, the researcher became the data collection instrument. The entire culture is considered to be the sample in ethnography and data took the form of hundreds of hours of field note entries and interview transcripts.

Following analysis, the findings were presented in themes answering the research question which was in two parts. The first "from the perspective of the nurse, client and other health care professionals, what constitutes intellectual disability nursing?" and secondly "what are the every day rituals, norms and patterns within the disability culture that shape and influence disability nursing for the Registered Nurse?".

"Caring for the client who is institutionalised", "The RN in the disability sector having certain qualities", "Working within a different paradigm", "Having to assume responsibility for large numbers of unregulated workers", "Having to work alongside many professional groups" and "Having different educational needs" are themes which describe the role. Themes describe the diversity of the role and in describing the registered intellectual disability nurse as "different" the role is compared with that of the nurse in other settings. The current research revealed there is a need for more health related education for unregulated workers and specific intellectual disability education for registered and enrolled nurses.

Themes that answer the second part of the research question are "hierarchical structure", "the Registered Nurse's position" and "role confusion". The non-nursing management at the top of the hierarchical ladder was found to significantly limit the role of the RN who was afforded no opportunity for leadership. Confusion over the RN's role and indeed individual workers' roles was observed at all levels. Findings suggest much stronger nursing leadership is required to provide advocacy and holistic care for the client and education for the carer. An outcome of the current research was the development of a model for intellectual disability nursing (see Table 8-1).

DECLARATION

I certify that this thesis entitled 'Totally Different: An Ethnographic Account of Intellectual disability Nursing' and submitted for the award of PhD Disability Studies, is the result of my own research, except where otherwise acknowledged, and that this thesis (or part of the same) has not been submitted for a higher degree to any other university or institution.

Signed..

Date..................................

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PROLOGUE

> What do I do now? How do I start the fieldwork that is at the heart of my profession? How do I engage the human subjects who can enliven my research and can make my theoretical ideas anthropological.....this initial ethnographic treatment produces both the context and the scaffolding of fieldwork. (Holmes & Marcus in Denzin & Lincoln, editors 2005, p.1102)

Indeed field work is a very demanding preoccupation with the culture and requires total immersion. During my breaks while conducting field work, I would drive to the north eastern boundary of the large estate and view what remains of the largest institution of its kind in the southern hemisphere, but now scattered throughout the community. I found that I could sit there quietly beneath the large shady trees, reflecting and writing field notes. One day I walked across the concrete slabs that were all that was left of two villas, in fact one was demolished during field work. It appeared demolition had taken place in a hurry leaving the roads that once led to these former villas still in place but with nowhere to go. Tiles on the floors where the bathrooms had been, and brick planter boxes, were signs these used to be homes.

I cast my eyes toward a long pathway which has pencil pine trees standing proudly down each side leading to the remaining villas. To the left are some unused buildings and directly ahead the villas where remaining clients live. On the right is the large car park and beyond that the staff development centre which was once the school of nursing. Not so many years ago, student mental deficiency nurses and psychiatric nurses sat in the class rooms and prepared for their respective roles.

If only the walls of these buildings could talk, I mused, pondering on the tales they would tell. What could this institution’s history add to the stories this researcher has been told? I can almost hear the laughter of children, playing in the courtyard after their lessons have finished for the day. I see in my mind the past charge nurses who have been described as stern women who had junior nurses trembling in their shoes.

My own journey to becoming an intellectual disability RN was to take many years, beginning in 1977, with my first nursing experience as a personal care attendant in a large institution. However it was not until 1983 that I was first exposed to people with intellectual disability. As a personal care attendant, I was assigned by an agency to work at a nursing home for people with intellectual disability and it was there that I experienced first hand the physically exhausting and emotionally challenging role of caring for people with profound intellectual and physical disabilities.

In fact that nursing home is referred to in the literature review as its closure played a significant role in shaping the future care of people with intellectual disability in South Australia. At the same time the next decade of my career saw me graduate as both an enrolled general and enrolled psychiatric nurse. Disenchanted with the enrolled nurse role, in 1990 I embarked on a bachelor of nursing degree. As a newly Registered Nurse, I completed a graduate nurse program at a large institution where I was again exposed to working with people with severe disabilities.

In 1995, I graduated as a registered psychiatric nurse with a graduate diploma in mental health. I spent the next five years employed at a psychiatric hospital which I did not particularly enjoy. I missed working with people with disabilities in a residential setting. On the advice of a colleague, I applied to The Centre. I had never even been to The Centre, I did not know anything about it, but I applied.

I immediately found the role of health care nurse to be rewarding and refreshing. I formed an easy rapport with the clients who appreciated my nursing actions. The staff seemed to value my skills. However, I felt that my knowledge of intellectual disability was lacking.

I was not long in the position when I began to notice that the RN was not included in long term planning for clients and there was limited communication between management and the nurses. The RNs, it seemed were there just to do nursing tasks. I completed a Master of Nursing Science in 2001, which sparked my interest in research. I began to ask questions such as "What is this type of nursing and where do Registered Nurses fit into the organisation?".

This research began as a result of curiosity about this very different culture and indeed totally different way of nursing. In fact a review of available literature demonstrated a need for research that will help to clarify the position of the Registered Nurse in the disability context. Research questions were posed and the answers reveal RNs continue to play a crucial role in health planning and health care for people with intellectual disability. Furthermore effective nursing leadership and research are required to facilitate change. The vision of the 1970s has changed but a challenge exists for registered intellectual disability nurses to keep abreast of trends in nursing and plan for the future needs of people with intellectual disability.

CHAPTER 1

SETTING THE SCENE - BACKGROUND TO STUDY

1.1 Introduction

This research used qualitative methodology to provide a descriptive ethnographic account of the role of the Registered Nurse (RN) in health promotion and wellness maintenance for people with intellectual disability. Strong anecdotal evidence from workers in the field indicated the need for the study. Without a clear role for the RN in the field of intellectual disability, research on the topic was timely.

As a background to understanding the role of RNs in the disabilities sector, this chapter defines intellectual disability, traces its history and provides an overview of intellectual disability nursing. Wolfensberger's (1972) groundbreaking principle of social role valorisation (originally termed normalisation) is presented and worldwide trends in deinstitutionalisation are described as they have impacted on the nursing care of people with intellectual disability in Australia. Several states have been leaders in following the example set by international standards in introducing the principle of deinstitutionalisation for people with intellectual disability. This has impacted on social and housing policies as they apply to people with intellectual disability throughout Australia and development in this area is discussed.

In particular, this thesis focuses on the South Australian experience and the history of intellectual disability nursing in South Australia in the state's psychiatric hospitals

The research setting for the study is referred to throughout the thesis as *The Centre* (or the *Organisation*). The Centre is part of South Australia's largest provider of support for people with intellectual disability, Intellectual Disability Services Council (IDSC). Innovations stemming from IDSC, in housing and health care are described in this chapter.

Changes in educational systems impacting on intellectual disability nursing are discussed. While there is currently no specific educational preparation for the role, the term intellectual disability RN is used to describe the RNs who participated in the study. As in other areas of health care, changes in the way that people with intellectual disability are cared for make it necessary to examine health care delivery and the part that RNs play in the current context and in the future.

This beginning chapter thus provides an introduction to the ethnographic study of registered intellectual disability nurses and the work they do. (Later, in chapter three, it is explained how the tenets of *interpretivism* were used to construct an ethnographic account of intellectual disability nursing.) The relevance and anticipated benefits of the research are outlined and the research questions and objectives are listed.

1.2 Intellectual Disability Defined

The terms intellectual disability, mental retardation and learning disability are used throughout this thesis as used by experts in the field. Intellectual disability is also known as mental retardation, mental handicap or learning disability (Lennox & Diggens 1999). For the purpose of this thesis, the term intellectual disability is used with the exception of direct quotations. Intellectual disability is different to mental illness. The term intellectual disability refers to a person's development while mental illness describes a disturbance in a person's normal mental state, regardless of their level of intelligence (DSM-1V 1994).

A core concept in the diagnosis of intellectual disability is considered to be an intelligence quotient (IQ) of less than 70; and there are varying degrees of intellectual disability. The Diagnostic and Statistical Manual of Mental Disorders compiled by the American Psychiatric Association (DSM-1V 1994) provides the following definition of "mental retardation":

> The essential feature of mental retardation is significantly subaverage general intellectual functioning (Criterion A) that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/ interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety (Criterion B). The onset must occur before age of 18 years (Criterion C). Mental retardation has many different etiologies and may be seen as a final common pathway of various pathological processes that affect the functioning of the central nervous system (DSM-1V 1994, p. 41).

The DSM-IV (1994) definition of intellectual disability is recognised by the Intellectual Disability Services Council, in South Australia (IDSC) as part of admission prerequisites and in determining who is eligible for its services. In December 1990, the IDSC Board of Directors adopted eligibility criteria that brought

South Australia into line with most countries around the world (IDSC 2002). Importantly, functioning and disability have many dimensions and disability, as with all human function, should be described on a continuum and not at its extremes (Australian Institute of Health and Welfare 2002).

1.3 The History of Intellectual Disability Nursing

Intellectual disability nursing has had a long, varied and interesting history, as described briefly here. People with intellectual disability have always been considered different. From medieval times in England, the "village idiot" was part of the rural scene and had a degree of acceptance and support (Ashton 1977, p. xi).

Throughout history, Christian attitudes have varied from regarding those with intellectual disability as children of the devil, to the early monasteries that gave them support (Ashton 1977, p. xi). Institutional care began in England in 1601. People with intellectual disability were banished into institutions, along with the poor, the unemployed, the infirm and the mentally ill. There was little distinction made between the person with intellectual disability and the mentally ill (Ashton 1977, p. xi).

Asylums for individuals with "mental illness and/or mental retardation" were first established in the United States of America (USA) in 1700 (Nehring 1991, p. 259). Foucault (1973) describes "the asylum" as a domain unaffected by time and the world outside, literally "protected from history and from social evolution" (p. 254). According to Foucault, asylums are religious domains without religion, "a domain of pure morality, of ethical uniformity" (p. 257). In the non-hospital domain, treatment designed to cure not only the soul, but the whole individual, continued to develop throughout the classical period from 1660 to the end of the 19th century and this period saw the birth of many of the characteristic institutions and structures of the modern world (Foucault 1973, p. 159).

In Britain, in the latter part of the eighteenth century, the medical mandate began and people with intellectual disability who were once treated as criminals and described as "offenders" began to get proper hospital treatment (Goffman 1986, p. 305). Inmates were renamed patients, training for nurses was introduced, along with the keeping of medically styled case records, according to Goffman (1986). Goffman (1986) also explained “madhouses” had been retitled “asylums” and the name was changed, yet again, to “mental hospital”. Beginning in 1756, a similar movement was led in

America by the Pennsylvania Hospital (p. 305).

In the United Kingdom (UK) the industrial revolution played a significant role in determining the future housing for people with intellectual disability. By 1830, factories had sprung up and at the height of industrial activity, people began moving from the country to the cities, taking their dependants with an intellectual disability with them. This changed society, as did the public school system in England advocating a literate work force. Intellectual disability was also on the increase, due to epidemics, measles and childbirth fever. Crime and alcoholism were rife, and this led to the creation of large institutions, mental hospitals and jails for people with intellectual disability (Hassam 2002).

Scientific study into intellectual disability began with Itard and his pupil, Seguin who founded a school in 1837 (Itard 1962, Seguin 1907 & Wolfensberger 1972). Others followed with theories of educating people with intellectual disability through intensive training programs. In 1876, Seguin was chosen as the first president of the newly formed Association of Medical Officers of American Institutions for Idiotic and Feeble-minded Persons, later to become the American Association on Mental Deficiency (Wolfensberger 1972, p. 135). The name was subsequently changed to the American Association of Mental Retardation (AAMR) (Hassam 2002).

According to Nehring (1991), members of religious nursing orders and lower class women made up the first untrained workers in USA hospital and asylums. It was not until the mid 19th century that legislation was passed that stated trained nurses should care for the "sick, mentally retarded and/or mentally ill" (p. 259).

In the mid 1800s, nurses' duties included household chores, such as laundry work and scrubbing floors. In the USA, Dorothea Dix, an untrained nurse and teacher, did much to improve the health care and living conditions for patients with "mental illness and/or mental retardation". Dix supported institutionalisation as the best environment for care, but attempted to provide "normal" routines in the institution (Nehring 1991, p. 259).

Nurses in the USA felt they could provide a "home like" environment for patients and housekeeping tasks gradually diminished in favour of time spent teaching self care skills. By the 1920s, nursing roles in caring for the mentally ill and the intellectually disabled were differentiated. Employment opportunities arose for nurses and some of the work involved identifying children with intellectual disability. By the 1940s, nurses were supervisors, administrators and staff nurses in institutions in the USA (Nehring 1991, p. 260).

Further developments took place and in 1959 Bank-Mikkelsen, head of the Danish Mental Retardation Service, was instrumental in having the principle of normalisation written into the Danish law governing services to people with intellectual disability. Normalisation is a philosophy that involves assisting the person to have an existence as close as possible to that of other members of the community (Wolfensberger 1972, p. 27).

According to Stella (1996), a Western Australian expert on deinstitutionalisation, the work of Wolfensberger, Bank-Mikkelsen and Bengt Nirje led to profound changes for people with intellectual disability (p. 93). In 1967 in Sweden, a new law was developed that had far reaching effects. The law pertained to the design and operation of residences for people with intellectual disability, and according to Wolfensberger (1972), it was stated that similar standards of health, safety and comfort should apply to systems and programs for these people "... as are applied to comparable settings for other citizens" (p. 39).

Indeed, the principle of normalisation has had profound effects on the manner of health care delivery and intellectual disability nursing in Australia. Western Australia pioneered the move away from the medical model to the developmental model in the 1970s by replacing nurses with "social trainers" and this was rapidly followed by all mainland states (Carman-Brown & Fox 1996, p. 249). In South Australia, the medical model was replaced by the developmental model in the early 1980s (Bottroff, Grantley & Brown 2000).

The principle of normalisation, which has been implemented worldwide, was conceived through the work of the German born Wolf Wolfensberger who received a doctorate in psychology and special education in the United States. Wolfensberger wrote the "first major text" dealing with the principle of normalisation (Stella 1996, p. 93). He worked as a clinician, teacher, researcher and research scientist at Nebraska Psychiatric Institute of Omaha and was interested in systematic planning of service systems, implementation of the normalization principle, and citizen advocacy.

Wolfensberger (1972) revolutionised the care of people with intellectual disability who, up to that point, were considered a "menace" to society (p. 7). He worked on the ideas of Nirje who believed normalisation meant making available to people with intellectual disability the same norms and patterns as are available to the mainstream of society. In 1983, Wolfensberger introduced the term "social role valorisation" as a better way of describing the normalisation principle (Stella 1996, p. 93).

Wolfensberger (1975) described the environment of institutions for people with intellectual disability as expressing the expectation that clients will not assume any responsibility for their actions and will act out violently (p. 2). Wolfensberger (1975) suggested that clients were portrayed as sick people and intellectual disability was fundamentally a medical question (p. 5). Males and females were also segregated to prevent "spread of the retardation" (Wolfensberger 1975, p. 41). Wolfensberger (1975) predicted that, if health services were considered a right rather than a privilege, health services of the future would "...probably undergo sweeping changes" (p. 7). He described nurses as part of a collective group of professionals who render help and their purposes as numerous, giving examples of "...case assessment, diagnosis and evaluation; correction and detention; counselling, guidance, psychotherapy; teaching and training, supervision and consultancy" (p. 1). Sweeping changes did subsequently occur, as depicted in the following section.

1.4 World Trends in Deinstitutionalisation

A significant factor affecting the care of people with intellectual disability and the role of nurses has been the worldwide trend toward deinstitutionalisation. The residential service system in developed countries, over the last 40 years has undergone significant changes. Large institutions are being replaced by smaller supported living arrangements, in community settings in line with Wolfensberger’s ideas (Felce 2001, pp. 115-121).

Braddock, Emerson, Felce and Stancliffe (2001) reviewed the living circumstances of people with intellectual disability in USA, Canada, England, Wales and Australia, and found a trend toward smaller, community houses. The USA is the most advanced in this endeavour, but in Australia, UK and Ireland, there is an increasing trend toward community based housing for persons with disability (Braddock et al 2001, pp. 503-508).

Community care is described by Titterton (1994) as "...the means of enabling people to live as normal a life as possible in their own local communities" (p. 35). Jones and Tutt (1983) state "...unfortunately, expressed public attitudes are still the greatest barrier to integration" (p. 19). They state also that different countries have developed community services at different rates and that some have been more successful than others.

As early as the 1950s, Britain began incorporating dwellings that were suitable for people with intellectual disability into mainstream society. Sweden, although the leader in deinstitutionalisation, was still slowly integrating people with intellectual disability into the community in the 1980s (Jones & Tutt 1983, p. 45). Overall, research findings indicated more positive outcomes for people living in smaller, community based homes than in large institutions (Heller 2002, p. 504). The trend toward deinstitutionalisation has had far reaching success in establishing community style living for people with intellectual disability in most developed countries of the world.

1.5 Deinstitutionalisation in Australia

The move toward community style living has had a significant impact on people with intellectual disability and their families in Australia. In 1986, a law was passed in the Australian state of Victoria, for example, stating that people with intellectual disability had a right to live in the community and clients of services for people with intellectual disability welcomed this (Community Services of Victoria 1992). It was very different from being grouped together with other people in congregate care with little or no contact with their families. In many cases inmates had been made to work in the institutions and after years of institutionalisation had lost many of their self care skills. Clients had to develop new skills and needed appropriate support. In their new homes, staff assisted them with daily living and health needs (Community Services of Victoria 1992).

The process of deinstitutionalisation in Australia is ongoing. Most institutions for people with intellectual disability have been closed in Victoria (Community Services of Victoria 1992). In 2001, a report was compiled by the Australian Housing and

Urban Research Institute to assist policy makers to understand the increasingly complex and challenging links between deinstitutionalisation, community care and housing for people with disabilities. The report revealed that in 1999 official figures showed 4340 people with intellectual disability were still living in institutional accommodation throughout Australia.

The "strategic emphasis" on deinstitutionalisation and the restructuring of housing assistance have altered social and housing policies since the late 1980s (Australian Housing and Urban Research Institute 2001, p. 7). Average deinstitutionalisation trends in Australia reveal decreasing numbers of people living in institutions and more are choosing to live in the community without ever living in an institution. Most of the increasing demand for community care is coming from those who already live in the community, making it difficult to assess how deinstitutionalisation has affected the system in terms of care provision (Australian Housing and Urban Research Institute 2001, p. 7).

1.5.1 The South Australian Context

A succinct history of the evolution of intellectual disability services in South Australia is provided to illustrate the advances the state has made in this area. Since the 1800s, when there was no distinction between intellectual disability and mental illness, there have been significant changes.

1.5.1.1 The Psychiatric Hospitals

In South Australia, the first formal step to deal with mental illness was in 1844 when the law sanctioned the placing of people with mental illness in "some gaol, house of correction or public hospital" (Adams 2003, p. 1). In 1846, a temporary colonial lunatic asylum was opened prior to patients being transferred to a permanent facility located in North Terrace, in the heart of Adelaide, in 1852. The new “Lunatic Asylum” opened in the eastern suburbs in 1870 and the name was changed to the "Hospital for the Insane" in 1873.

The years 1884 to 1885 saw the addition to the "Hospital for the Insane" of a purpose built ward for the criminally insane which was subsequently closed in 1973 (Adams 2003, p. 3). The occupants were transferred to the Security Hospital or another ward located in the grounds of a Labour Prison in Adelaide's northern suburbs (Taylor 1991, p. 16).

As patient numbers grew at the Mental Hospital, patients began being accepted at a Receiving House that was opened in 1922. Further relief for the Mental Hospital's overcrowding problem was provided by the opening of another Mental Hospital, in Adelaide's northern suburbs (Adams 2003, p. 4). That hospital became the first fully accredited psychiatric hospital in Australia by the Australian Council of Hospital Standards in 1983 and the eastern suburbs hospital followed in 1987 (Adams 2003, p. 6).

The name of Mental Hospital was changed to Psychiatric Hospital in 1967, affecting the two psychiatric hospitals. According to Adams (2003), the opening of The Centre (the focus of the research reported here) led to the separation and transfer of clients with intellectual disability from those with mental illness and enabled the upgrading of the Psychiatric Hospital with the first sub-acute ward. For the two Adelaide psychiatric hospitals, the process of deinstitutionalisation began in the 1960s and continued into the 1970s when many residential patients were transferred to private psychiatric hostels (Adams 2003).

An informant from the eastern suburbs psychiatric hospital described the old buildings that housed people with intellectual, physical and mental disabilities prior to the opening of The Centre. She described people with severe disabilities being treated like "animals", segregated into male and female wards with male and female wardens, similar to stories that are recounted about the northern suburbs psychiatric hospital (Personal communication: "Kathy" 15.7.04).

The northern suburbs psychiatric hospital began to close its doors to new acute admissions in 1990 soon after the merger with the other psychiatric hospital was announced. When the question arose of selling one of Adelaide's psychiatric hospitals, the one in the northern suburbs was chosen due to anticipated rising land values (Adams 2003). A new organisation, the South Australian Mental Health Services (SAMHS), was incorporated in 1991 specifically to enable closure of the hospital (Adams 2003). Since that time, mental health care has become largely community based and acute inpatient facilities are provided by the general hospitals (Adams 2003, p. 7).

As recently as the late 1970s, general surgery was conducted at the eastern suburbs psychiatric hospital**,** including for those patients with intellectual disability. Wolfensberger (1972) described the practice of building expensive dental and medical suites exclusively for people with intellectual disability as "absurd". He believed that community hospitals and dental surgeries were suitable (p. 53). He also stated it was a misconception that this group of people is sick.

1.5.1.2 The Centre

In 1971, The Centre, a large residential facility for people with intellectual disability was built in Adelaide's northern suburbs in a ground breaking move intended to separate people with psychiatric illness from those with intellectual disability. Some people with intellectual disability were transferred from the northern suburbs psychiatric hospital to The Centre at that time. Although it was then acknowledged that mental illness is not synonymous with intellectual disability, The Centre was built adjacent to the northern suburbs Psychiatric Hospital, a decision that was probably based on the availability of cheap land at the time but meant the general public was unlikely to discern any difference between the two groups.

In a 2002 address to staff at The Centre, a prominent leader in the organisation explained that institutions have historically been grouped together. In Adelaide, the first asylum was situated along North Terrace, and the mental hospital was built in the eastern suburbs, and then another, close to the location of Adelaide's major prisons, in the northern suburbs. A wide circle of institutions and reformatories lay around the perimeter of Adelaide. According to the spokesperson, this was no accident as cities had been designed that way. A classic example is New York's Long Island, where the jail and hospitals are situated away from the rest of society (Hassam 2002). Placing institutions far from populated areas and towns can, in some cases be related to a controlling desire (Wolfensberger 1972, Foucault 1977).

The Centre is part of IDSC and was the setting for a large component of this research. The Centre has been the home of many people with intellectual disability since it opened over 30 years ago. The then Centre for the Intellectually Retarded was depicted as a "training centre" for children (Kent 1972, p.10).

Intellectual Retarded Services were part of the mental health system prior to the 1980s, so the 1982 formation of IDSC was a remarkable breakthrough that was greeted with enthusiasm and support by the families and carers of residents (Hassam 2002). Parent involvement was welcome and community development involved establishing new services. These new directions suggested that clients were transformed from recipients of services to people who contributed to the community.

IDSC is a member of the National Council on Intellectual Disability (NCID) which is the national association representing people with intellectual disability and their carers in Australia. Established by parents and friends over 30 years ago, NCID aims to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members (NCID 2005).

The world-wide trend toward deinstitutionalisation was not common in Australia at the time of the opening of The Centre. In South Australia, the principle has now been applied to people with a range of disabilities including psychiatric problems and physical disabilities. Indeed, another large institution in South Australia for people with various disabilities began incorporating community style living in the early 1990s.

The community move, for IDSC, began with the closure of a western suburbs nursing home in the 1980s. The home was a large institution for people with intellectual disability situated in a seaside suburb of Adelaide and the clients were mostly relocated to houses in the community. Since that time, entire Villas at The Centre comprising four units each and housing approximately 30 people, have been relocated to community houses. At the commencement of the research reported here there were 11 Villas and a total of 600 clients, 345 of whom lived in community houses. When the Centre opened in 1971, there was provision for 686 clients.

In 1995 in South Australia, Options Co-ordination was introduced as an approach to co-ordinating available services for people with disability and their families. This involved the employment of problem solving community teams, rather than the former method of case management which, in the case of people with intellectual disability, had included mental deficiency nurses (Hassam 2002). The Organisation strives to provide for clients' specialist service needs with Options Co-ordination

(IDSC 2002). This move reinforced the removal of the "medical model" (addressed in chapter 3) and nurses were relegated to the role of providing first aid and caring for people with intellectual disability only when they were sick.

1.6 The Role of the Registered Nurse

Change has impacted significantly on nursing around the world, particularly for those nurses working in the disability sector (Alaszewski, Gates, Motherby, Manthorpe & Ayre 2001). Prior to 1983, RNs in Australia completed a three year hospital based, apprentice style training. Tertiary education for RNs was slowly introduced and hospital training phased out. By 1993 the full transfer of registered nurse education from hospitals to universities was complete. Tertiary education for RNs includes psychiatric nursing, which was formerly hospital based and is now conducted at graduate diploma level.

Moreover, mental health was largely deinstitutionalised through the 1980s and 1990s. The National Review of Nursing Education commissioned by the Commonwealth Department of Education, Science and Training (2001) described the move away from institutionalised care and the effects it had on nursing practice. There have been many changes, not least an increase in the number of unlicensed personnel delivering care. There has been a significant shift away from registered nurses being employed only in hospitals to being employed in a range of other health care settings. Innovations in nursing practice include "community nurse-led care", "hospital in the home", and "case management" (Commonwealth Department of Education, Science and Training 2001).

A significant change in South Australia at The Centre was the cessation of the three year mental deficiency nurse course in 1990. The course was a separate qualification recognised by the Nurses Board of South Australia. This qualification, the mental deficiency nurse, is no longer recognised by the Nurses Board of South Australia.

Prior to its demise, the mental deficiency nurse course covered medical, intellectual, behavioural and social aspects of disorders associated with intellectual disability, theories of cognitive development and relevant pharmacology. According to the curriculum used at the time, student Mental Deficiency Nurses were also taught strategies to deal with the emotional responses of families and some medical nursing (Nurses Board of South Australia 1978).

Mental deficiency nurse training was conducted similarly to general hospital based training and psychiatric nursing. Hands on experience prepared the students for working in the Villas where their duties included every aspect of client care and medication administration. It was believed that nurses were essential to care because of their ability to observe early changes in a client's health status, often preventing serious illness (Burness 1970).

Since that time there have been major changes in staffing, as RNs no longer work directly with clients and have been replaced by unregulated workers. The Charge Nurse of the '70s has been replaced by a manager. Each "viIla" at The Centre now has a manager and a shift supervisor on each shift, most of whom, as previously stated, do not have any nursing qualifications. This is in contrast to the Centre's beginnings when it was managed similarly to a hospital incorporating the same hierarchical structure of nursing and Registered Mental Deficiency Nurses (RMDNs) cared for the residents.

In 1983, the Diploma of Developmental Disabilities, a three year full-time College-based course, became the recommended basic training course for professionals working with people with an intellectual disability in South Australia. In subsequent changes to the tertiary education system in Australia, the course moved into the university sector, and ultimately became the Bachelor of Applied Science (Disability Studies). Further changes are planned in this degree to extend it to a four year degree that provides graduates with additional qualifications in Rehabilitation Counselling (Matthews, personal communication, 9/6/05).

However, the current three year Bachelor of Applied Science (Disability Studies), and the planned four year Bachelor of Disability and Community Rehabilitation, while providing training in direct service provision, case management, and many other relevant areas, does not lead to registration as a nurse. In addition, the three year Bachelor of Nursing degree which leads to registration as a nurse in South Australia, provides very little insight into intellectual disability nursing.

1.6.1 The Nursing Service at the Centre

While prior to the 1990s much of the care at The Centre was provided by nurses (RMDNs), the 1990s saw trained nurses replaced by unregulated care workers. In response to some clients' needs for nursing care, plans were implemented to provide a visiting nursing service based at The Centre. The nursing service comprised a Health Centre and an Infirmary. At the time of writing, the Health Centre operates five days a week providing health care, medical assessments and health promotion to residential and community clients. The Health Centre also provides a dental service, and psychiatric and psychological consultations. An occupational health nurse supports the staff of the Organisation.

The manager of Health Services and the nurse manager co-ordinate the nursing team from the Health Centre. There is a RN for five days a week whose primary responsibility is to credential care workers in community houses. Credentialing is training that unregulated workers undertake to prepare them for health procedures such as medication administration, measurement of vital signs and blood glucose measurement. It is conducted by RNs and involves initial teaching followed by observation of the worker completing the task on three occasions. The worker is required to be re-credentialed annually. Credentialing is considered delegation of care and, as such, the RN remains accountable for the tasks performed (Nurses Board South Australia 2005).

The Infirmary offers short term nursing care to clients who, for example, have been discharged from hospital, or who need close supervision and are not well enough to remain in their Villas at The Centre or houses in the community. Five enrolled nurses (ENs) on rotating shifts are largely responsible for the care of Infirmary clients. Enrolled nurse supervision is provided by the RN whose main responsibility is to attend Villas when required to assess clients and conduct routine health treatments within The Centre and community houses.

Six RNs work in shift rotations to provide a 24 hour nursing service to the Infirmary. They also make daily visits to clients who are in hospital. The aim is to act as liaison persons who provide support to the clients and the hospital staff. The RN reports back to the Villa manager on the clients' condition.

At the commencement of this study, the Infirmary was a seven bed hospital-type unit for sick clients. The Infirmary was staffed by ENs and the RNs based their "on call" practice there. Changes to The Centre could mean that in years to come, this service will be based elsewhere. In June 2005, there was a trial of an alternate nursing roster which saw the majority of the RNs working a five day week based in the community. During the trial the RN on night duty was replaced by an EN.

Proposed changes to the nursing service are in line with guidelines set out by the South Australian Disability Services Office (2005) which aims to create a much more professional role for nurses. Measures which are due to be in force by 2007 will ensure a less reactive and more proactive role for nurses in the disability sector. Assessing and prioritising each client's health needs were among the tasks introduced to the role of the RN toward the end of the study.

The Centre's visiting nursing service continues to provide support for the Aged Care Service, now located in a separate purpose-built building a short drive from The Centre. The main support is the provision of a visiting RN when clients are in hospital over the weekend. The Aged Care Service only has one RN rostered on the weekend. Assistance with difficult venepunctures and venepuncture tuition to RNs working in the Aged Care Service has also been provided.

The nursing service is totally separate from the other departments. The nursing team has its own hierarchical structure based on traditions in nursing. In descending order: the Manager of Health Services (a non-practising mental deficiency nurse); the nurse manager (whose position is similar to a clinical nurse consultant at times when a clinical leader is required); and RNs, who comprise the third level and supervise five ENs There are five on call RNs, a community nurse and an occupational health RN.

The Villa managers are not RNs but they are authorised to give consent to medication administration and medical procedures. RNs are authorised to give consent to medication administration only, and may be called upon to give an explanation of a medical procedure to a manager.

All personal care is delivered by unregulated workers. This results in the RN being unable to closely monitor clients for alterations in health status. However, RNs play a significant part in teaching and credentialing unlicensed care workers in medication administration. The RN relies on the observation and reporting skills of the care workers even though they are not trained in many aspects of health care.

Unregulated workers, or care workers, have no nursing training and are not required to have any previous experience as carers. Further, they often have no knowledge of basic anatomy and physiology. They are expected to have a current first aid certificate and attend pre-employment training which teaches them basic skills in manual handling, communication and medication administration. (Literature from various sources describing the role of unregulated workers is presented in the next chapter.)

There is a large drop out rate from orientation groups and often new care workers do not remain at The Centre for long. Consequently, many of the core group of care workers are people who have been at The Centre for many years. Some of the staff members are former "mental deficiency nurses" who have remained as care workers or shift supervisors.

Because The Centre and community clients are not considered to be sick, the 24 hour service concerns health maintenance and promoting good health as much as delivering hands on nursing care. Barr (1999) suggested that the majority of people with intellectual disability are living much longer, therefore many are prone to age related diseases and conditions that can become chronic. However, as with the wider community, many of these illnesses can be prevented.

The Centre is no longer a training centre for children with intellectual disability. The current population served by IDSC is ageing, which means their health needs are changing. This research took those changes into account.

In an ongoing process, people with intellectual disability in South Australia are currently being relocated into the community. Concern for the future is rife among clients, their families and staff. Notwithstanding assurances of continued employment, the nursing staff, and in particular the ENs, are uneasy about their positions.

Of particular note are the ever changing circumstances surrounding the team of RNs in disability service delivery, such as roster and work allocation changes. I accepted these changes as part of the culture of the Organisation—it seems they did not detract from who the nurses were and what they did.

1.7 Relevance and Benefits of the Research

Patterns of care have changed since the inception of health service delivery at The Centre and the RN's role has become blurred and unclear. Societal trends have changed the face of disability service delivery and this has also had far reaching ramifications for RNs. In essence, the role of the RN in the care of people with intellectual disability has, over recent years, been eroded. From the provision of hands on 24 hour care, RNs now have a role that sees them largely credentialing untrained staff in skills that were not so long ago their tasks. Overseeing care in recuperation has, however, remained the domain of the RN.

The RN's role in disability nursing appears in danger of disappearing as the impetus to throw off the medical mantle takes effect. This research set out to explore the current role of the RN in disability care or health service delivery and to design a framework for the role in the future. The study was apt in the current context, because it sought to highlight issues pertaining to the provision of health care for people who have been largely marginalised but whose interests have been increasingly publicised in current discussions (Barr 1999, Bruggemann 2002, Crawford 2002, Hassam 2002, Higgins 1999, Rapley & Ridgeway 1998). In keeping with the aims of wider health sector research to evaluate and provide the best possible outcomes for clients, this research, while designed to clarify the registered nurse's role, will also hopefully have benefits for wider client care (Allan 1999).

The research findings should inform the practice of health professionals and educate them in the role of the RN in disability services. General hospitals and nurse education facilities will also benefit as role clarity brings enhanced understanding. It is hoped disability educators at tertiary level will find the study useful in informing curriculum about health care needs and how they can impact on other areas of clients' daily life.

In qualitative research, it is suggested that while the research has particular reference to the group studied it may also be informative to others (Denzin & Lincoln 2005). In this instance, findings could be of interest to policy makers in respect to nursing education. Indeed ethnographic work itself contributes "... descriptive and explanatory theory from which hypotheses for further study may be generated" and can "yield insights useful for examining current nursing practice" and for planning improvement (Germain 1986, p. 161). Findings of the research should prove informative to individual RNs and assist The Centre provide a better quality nursing service.

There is currently a rapid turn over of nursing staff in the disability sector. By clarifying the role of the RN, it is hoped this study might lead to increased job satisfaction among nursing staff, which could lead to an increased rate of staff retention and thus benefit client care. The research findings will also be useful to the nursing discipline as they serve as an evaluation of this important nursing role.

1.8 Research questions

Two research questions were identified from an analysis of relevant literature:

- From the perspective of the nurse, client and other health care professionals, what constitutes intellectual disability nursing? and
- What are the every day rituals, norms and patterns within the disability culture that shape and influence disability nursing for the Registered Nurse?

1.9 The Research Objectives

The specific research objectives were:

- To identify common themes implicated in the experience of providing health care for individuals with intellectual disability
- To gain a deeper understanding of, and explain the role of, the RN, and
- To produce a descriptive explanation of the role of the RN that would benefit the nursing service, the Organisation and ultimately the clients.

1.10 Summary

This chapter has provided an overview of the context of the study. Importantly, intellectual disability has been defined as different to mental illness, despite people with intellectual disability having been nursed alongside people with mental illnesses for many years.

An historical overview demonstrated the evolution of intellectual disability nursing. As explained, a significant factor has been the withdrawal of registered nurses from the residential care setting—now a common practice in most countries throughout the world. The Centre is not a pioneer in the move toward community style living for its clients. Notwithstanding recent calls for a return to institutionalisation, particularly in psychiatry, deinstitutionalisation is standard practice throughout the developed world, as exemplified by the overview here of Australia's progress in introducing community style living for people with intellectual disability.

Ethnography was considered the most effective means of exploring the research questions as it allowed me, as the researcher, to adopt the role of participant observer and study the culture first hand. (Ethnography is described in greater detail in chapter four.)

The next chapter addresses the literature relevant to the topic of the study. An important issue arsing is the impact of ageing on services for people with intellectual disability. Changes in public policy in this area have impacted on the traditional role of RNs in disability service and contributed to the need for their role to be redefined.

CHAPTER 2

HEALTH CARE AND NURSING

2.1 Introduction

The previous chapter set the scene for this ethnographic study of the role of RNs who care for people with intellectual disability. A brief history of intellectual disability was presented, dating back to a time when people with intellectual disability were "incarcerated" in psychiatric hospitals.

Literature was reviewed prior to writing the research proposal and at various times throughout the research. This chapter, and the next, presents the literature that either informed the study or demonstrated a need for further research. The literature review was conducted using documents from the IDSC library, the data bases CINAHL and Medline, the World Health Organisation and various Australian Departments of Health Services. Key words used were: NURSING, INTELLECTUAL DISABILITY, LEARNING DISABILITY, DEVELOPMENTAL DISABILITY, RETARDATION, DEINSTITUTIONALISATION. The literature was revisited throughout the research process to enable awareness of continuing trends in disability nursing. In places, dated literature is included to support more recent literature.

Literature in the field of intellectual disability is vast. For the purpose of this study, it was categorised as follows: illness in people with intellectual disability; ageing with intellectual disability; dual diagnosis; relevant studies about The Centre; the introduction of unregulated workers; worldwide trends in deinstitutionalisation and Australian perspectives; and educational preparation for RNs. This chapter presents literature about illness in people with intellectual disability, ageing, dual diagnosis and education for RNs (literature about deinstitutionalisation and unregulated workers is presented in chapter 3).

Some people with intellectual disability will have life long health problems related to the syndromes that cause intellectual disability. These are briefly presented to demonstrate the specialist nature of working with people with intellectual disability, including the need for RNs in the field of intellectual disability sector. By adopting a developmental model of service provision (and rejecting the medical model, as addressed in 3.2), The Centre has disregarded the incidence of illness in people with intellectual disability and thus the need for RNs in the disability sector.

Research findings about ageing people with intellectual disability reveal new concerns for policy makers in intellectual disability care provision. People with a dual diagnosis of psychiatric illness and intellectual disability face similar problems. Arguably, given the special health needs of people with intellectual disability, nursing education should be included in future directions planning.

2.2 Illness in People with Intellectual Disability

People with intellectual disability are "known to experience poor health" and experience "higher rates of various conditions and illnesses" than the general population (Lennox & Diggens 1999, p. 1). An overseas study found it increasingly clear that people with intellectual disability have a higher rate of illness than the general population and their special health needs may be linked to a number of factors; for example, their disability, difficulty in diagnosis, atypical presentation, unhealthy lifestyles and poor health promotion (van Loon, Knibbe & Van Hove 2005). The research, involving a postal questionnaire survey of 36 general practitioners with a response rate of 22 (61%), found it is possible to provide high quality medical care to these clients in community-based settings with specialist support (van Loon et al 2005).

Table 2-1 is a summary of health problems common to people with intellectual disability. It was compiled from relevant literature (Chaney & Eyman 2000, Community Services Commission 2001, Lennox & Diggens 1999, Reddihough & Buzio 1999, Trumble 1999), The list is not exhaustive and people with intellectual disability can have a range of health problems or, in some cases they are completely healthy.

Table 2-1. Summary of health problems more common to people with intellectual disability

Health condition	*Syndromes and aetiologies*
Neurological disorders such as epilepsy	Occurs more frequently in intellectual disability than the general population
Mental health problems	More frequently diagnosed in people with intellectual disability
Hearing and visual impairment	More common in people with Down syndrome or cerebral palsy
Diabetes	Increasingly of concern in people with intellectual disability particularly Down syndrome and Prader-Willi syndrome
Heart disease	More common in people with Down syndrome and other forms of intellectual disability, depending on aetiology.
Respiratory problems – susceptibility to infections – sleep apnoea	Particularly common in people with Down syndrome
Obesity	Common in people with intellectual disability
Eating or swallowing difficulties resulting in weight loss	Can occur in people with intellectual disability
Bowel disorders – constipation - impaction/obstruction	More common in the immobile client such as a person with cerebral palsy
Dental problems – gum disease - cavities	Commonly observed in the client with cerebral palsy or the more independent person with intellectual disability
Skin disorders – acne - potential for infection	More common in people with cerebral palsy and those who are incontinent. Skin conditions are also common in a range of syndromes including Down syndrome

While people with intellectual disability are not generally considered to be sick, they are susceptible to illnesses including epilepsy, respiratory disorders and acute infections. Chaney and Eyman (2000) conducted a large quantitative study in the USA to examine life expectancy in people with intellectual disability. The case records of 2,444 deceased institutionalised people, over a 60 year period, were reviewed by a physician and a trained psychiatric technician. The researchers found improved treatment, effective antibiotics and other medication, along with better care, had markedly increased their life expectancy. Ages at death ranged from less than one year to 88 years and those most at risk of dying at a younger age were found to be those with lower IQs and risk factors such as epilepsy, recurrent infections, a requirement for gastrostomy feedings, and a need for “maximal personal care” (Chaney & Eyman 2000, p. 293)

There is agreement it is necessary to provide health care for people with intellectual disability and that care should be relevant to their needs (Cocks & Stehlic 1996). People with intellectual disability may suffer periods of ill-health, as do other members of the community, and may require access to "more specialized health care" at times due to their complex needs (NBSA 2003, p. 33).

The theory that people with intellectual disability have a greater chance of having illnesses than other people is supported by Allan (1999) who explained that this is partly due to the syndromes that may have caused the intellectual disability but also due to life style and economic factors. The illnesses they are likely to experience include: epilepsy, mental health problems, hearing or vision impairment, heart disease, speech difficulties, obesity, hypertension, skin disorders, spinal deformities and dental problems (Lennox & Diggens 1999).

As the person with intellectual disability ages, increasing life expectancy brings with it a greater incidence of ill health, and the likelihood of requiring specialised nursing care. This view is substantiated by a New South Wales review of disability, death and responsibility of care. This review examined the circumstances of 211 "disability deaths" between 1991 and 1998 using a reliable method of extracting data primarily from client records and by referring to existing research on morbidity and mortality. It was recommended that regular health reviews be conducted by health professionals experienced in the area of intellectual disability. The review states:

> ...for people who are unable to communicate or have limited communication, health screening and review and early detection are important, due to the difficulty they may have in identifying or describing symptoms for conditions that may otherwise go unrecognised (Community Services Commission 2001, p. 26).

In this review, the most common cause of death was found to be respiratory disease, followed by diseases of the circulatory system. The study identified the following functional limitations contributing to ill health of people with intellectual disability: immobility, the need for feeding assistance, and incontinence. Anticonvulsant therapy, specifically toxicity, sub-therapeutic levels and failure to administer correctly, were also identified as contributing factors (Community Services Commission 2001, p. 19).

According to the New South Wales Council for Intellectual Disability (2004a), recent Australian research has shown that people with intellectual disability have a 20 year lower life expectancy than the general population. The report disclosed that a large percentage of medical conditions go undiagnosed or are poorly managed. It was also found there is a high incidence of dental disease and of people being either underweight or obese. Reasons for the statistics were explained as the population's vulnerability to various health conditions, poor communication, lack of funds for proper care, and stigma. Another explanation suggested was that genuine health related symptoms are often attributed to the disability.

Disability services' move away from the medical model and the replacement of trained nursing staff with unskilled workers could also play a part in the shorter life span of people with disability (New South Wales Council for Intellectual Disability 2004a). Studies assessing medical care of people with intellectual disability by general practitioners have found an "excessive number of unrecognized or poorly managed medical conditions" and "inadequate health screenings and preventative care" (van Loon et al 2005 p. 175).

Indeed, according to Parmenter (2000) the health needs of people with intellectual and developmental disabilities have been "severely neglected", particularly in the adolescent and adult range. Historically, people with intellectual disability were placed in institutions at an early age, where their health needs were met. The gradual deinstitutionalisation of people with intellectual disability is thought to have "thrown increased demands on the general health services" (Parmenter 2000). Moreover, according to Parmenter (2000) people with developmental and intellectual disabilities who remain in institutions are not receiving adequate health care due to the reduced number of medical officers and limited replacement of these positions when medical officers leave.

2.3 Syndromes and Common Conditions

As some health conditions are common to people with intellectual disability due to the syndromes that may have caused their disabilities, some relevant syndromes and resulting health problems are described below, although the list is not exhaustive.

2.3.1 Epilepsy

Epilepsy affects 25%–35% of people with intellectual disability compared to approximately 2% of the general population. Epilepsy is often more severe and more difficult to control in people with intellectual disabilities. Trumble and Berkovic (1999) predict most will need "some degree of specialist overview of their management" (p. 131).

2.3.2 Cerebral Palsy

Another cause of disability, cerebral palsy, a persistent disorder of movement and posture, occurs in about two out of every 1000 live births. Cerebral palsy is caused by a defect or lesion of the developing brain. Most children born with cerebral palsy live to adulthood and can experience a range of health problems including premature ageing. Management can be complicated by the person's inability to communicate. Health problems common to people with cerebral palsy are epilepsy, musculoskeletal, gastrointestinal and other problems related to poor mobility, and people with cerebral palsy are also prone to hearing and vision deficits and lung disease. For many years people with cerebral palsy were nursed as invalids, but they are now enabled to be participating members of society (Reddihough & Buzio 1999).

2.3.3 Autism Spectrum Disorders

Autism spectrum disorders are lifelong neurodevelopmental disabilities with onset before 36 months of age. They are characterised by impaired reciprocal social interactions, impairments in verbal and non verbal communication skills and stereotyped behaviour, interests and activities. Autism spectrum disorders include Autistic disorder, Asperger's syndrome, atypical Autism or pervasive developmental disorder not otherwise specified (PDDNOS), Rett syndrome and childhood disintegrative disorder. The clinical picture varies from person to person (Curran & Tonge 1999, p. 201).

2.3.4 Down Syndrome

Down syndrome is the most common identifiable cause of intellectual disability and affects approximately one in 660 live births according to Trumble (1999, p. 171). Prenatal screening has reduced the incidence of Down syndrome which is common in the offspring of older mothers (Trumble 1999).

Down syndrome is also discussed in the next section due to the client's potential for premature ageing. Healthier living conditions have increased the life expectancy of people with Down syndrome who can suffer cardiac problems if undiagnosed. Preventative screens for mitral valve prolapse should be conducted routinely. A healthy diet and sensible exercise will assist the fight against obesity, another common problem for people with Down syndrome (Trumble 1999, p. 171).

2.3.5 Communication Issues

A problem common to all of these disorders can be difficulty in communication. Symptoms of illness, often characterised by a deterioration in behaviour, can be missed due to the client's inability to communicate pain, for example. Illness could also be dismissed by care workers as bad behaviour or attention seeking (Curran & Tonge 1999, p. 201).

2.3.6 Gaining Client Consent

Nurses can also experience difficulty in communicating the necessity for health interventions to clients who have limited understanding of health issues. Intellectual disability nurses can face an ethical dilemma when providing care for people who do not have the capacity to give consent to treatment as RNs are required to reflect on their own practice (Holloway 2004). Citing the example of a nurse who needed to assist a client who could not consent to oral hygiene, Holloway (2004) stated there is also a necessity for nurses to act within the legal framework of "consent, capacity and decision making" (p. 285).

An important contextual issue that affects what constitutes intellectual disability nursing is the client's understanding (or lack of understanding) of the need for health interventions. Clients are sometimes described as "non compliant" or "difficult"; for example, "the removal of a compression bandage almost as soon as the nurse leaves the room" (Selim, Lewis & Templeton 2000: online) and some simply refuse treatment. There is a paucity of literature addressing this issue; however, Prasher and

Janicki (2002) describe behaviour that is classed as "challenging" as an obstacle to the provision of health care (p. 255).

Indeed, some people with intellectual disability can only be examined by a doctor after "supportive measures" such as pre-medication or pre-visits for desensitization (Prasher & Janicki 2002: Online). Designing programs for managing behaviour is not the role of the nurse (Personal communication B. Matthews: 2006), however improved communication with clients can assist in developing caring relationships. The avoidance of "technical words or health jargon" is suggested and the complexity of language should vary according to clients' verbal abilities (Keane & Dixon 1999). Also, it is argued that the use of restraint (force to control the actions of another person) is a sign of therapeutic failure (Breggin 1999) and that, when conducting any intervention with a client, the least intrusive method of intervention should be used (Cocks & Stehlic 1996).

Harchik and Putzier (1990), for example, outlined a non-intrusive method of encouraging a client with severe disabilities to take oral medication. The client/participant in this research was prescribed medication twice daily to control seizures. There was a long history of refusal: saying "No", turning her head away, pushing medication away, spitting it out and episodes of self induced vomiting. The second author knew the client well and compiled a list of "high probability requests", such as "touch your nose" or "clap your hands", so named because of the likelihood that the client would comply (p. 41). The client was then given a token as a reward for complying with requests and medication was subsequently taken more often with less "prolonged undesirable and disruptive interactions" between staff and client (Harchik & Putzier 1990, p. 41).

Beauchamp and Childress (2001) developed a four-principle framework that could be used to resolve an ethical dilemma. The principles are: respect for autonomy; beneficence; non-maleficence; and justice. The client’s autonomy is respected when he/she can make reasoned informed choices. Beneficence considers risks and costs with the benefits of the health care. Non-maleficence involves the principle that no harm should come to the client or health care consumer. The principle of justice is an expectation of equality of care and indeed these four principles should be reflected in the practice of all health care professionals (Beauchamp & Childress 2001).

The Nurses Board of South Australia (2003) has a standard in place for the use of restraint and the setting for the study described here has stringent policies on the use of such measures. Disturbing evidence based research suggests that people admitted to hospital from residential settings were most likely to be subject to physical restraint (Joanna Briggs Institute 2002). This practice is unacceptable in the 21st century.

2.4 Mental Health Issues

There is agreement on the high prevalence of psychiatric disorder in adults with intellectual disability and that psychiatric disorder can be masked by poor communication and language skills (Chan, Hudson & Vilec 2004). Two case studies described by Chan et al (2004) clearly demonstrate the difficulties in assessing the mental health needs of an "invisible" group of people with intellectual disability. Interestingly, in relation to mental health disorders, people with intellectual disability are more likely to present with aggression, self injury or physical complaints, while people who do not have intellectual disability are more likely to present with depression or anxiety (Davis 1999).

The presenting symptoms of psychiatric illness may be different in people with intellectual disability from those shown by members of the general community "especially as the level of disability increases" (Davis 1999 p. 102). People with intellectual disability can suffer a range of psychiatric disorders including depression, bipolar affective disorder, psychoses and anxiety disorders (Priest & Gibbs 2004).

2.4.1 Dual Disability

Dual disability is the term used in South Australia to describe diagnoses of intellectual disability and psychiatric disorder. Although, as stated earlier, intellectual disability should not be confused with psychiatric disorder, the rate of psychiatric disorder in people with intellectual disability is two to three times more prevalent than that in the general population (Tonge, Einfeld & Mohr 2006).

A range of medical disorders, if unrecognised or poorly managed, can contribute to a psychiatric disorder. These include brain injury/epilepsy, poor communication, genetic and physical factors, and excess medication. It is also thought that life experiences, including abuse and hostile environments, feature as triggers to psychiatric disorder (Davis 1999, p. 101).

One of the major obstacles to the diagnosis of mental illness in people with intellectual disability is that instruments used in the general community are not suitable assessment tools for this population (Tonge et al 2006). A recent initiative in Australia, the Lifespan Project, has been started to ensure people with intellectual disability receive appropriate mental health assessment and treatment. The aim of the Lifespan Project is to assess the mental health of people with intellectual disability throughout their life. Tonge et al (2006) describe a tool developed through the Project, the Developmental Behaviour Checklist (DBC). First developed for young people, the DBC was so successful the chief investigators have developed a similar assessment tool for adults with intellectual disability. Furthermore, due to the success of the Lifespan Project at Monash University, funding has been obtained to further extend this research in South Australia, the state that has the best data base of people with an intellectual disability in Australia.

2.4.2 Schizophrenia

In the case of Schizophrenia, intellectual disability may arise from the Schizophrenia or both may result from a common brain impairment/damage (Schizophrenia Fellowship of New South Wales 2004). Symptoms of Schizophrenia, which is thought to affect around 3% of people with intellectual disability, include hallucinations and delusions. Thus it is difficult to diagnose Schizophrenia in a person with an intelligence quotient (IQ) of less than 50, or when the person is mute or unable to communicate (Priest & Gibbs 2004).

2.4.3 Depression

Depression in the person with intellectual disability is likely to be perceived as behavioural disturbance, according to Davis (1999). Crying episodes, aggression toward self or others and somatic complaints are among the symptoms of which the health professional needs to be aware (Priest & Gibbs 2004).

2.4.4 Bipolar Affective Disorder

Bipolar affective disorder is described as extreme mood swings that can be accompanied by psychoses in the manic phase. During a hypomanic episode, there is greatly increased activity (Myers 1999). The client may at other times present with recurring depressive episodes displaying the symptoms of depression. Symptoms can be observed and reported by carers (Deb, Matthews & Holt 2001).

2.4.5 Anxiety Disorders

Anxiety disorders, which are common in the general population as well as people with intellectual disability, may produce significant levels of functional disability and handicap, according to Davis (1999).

2.4.6 Assessment of Psychiatric Problems

Comorbidities affect the presentation of psychiatric problems and make diagnosis difficult. These include epilepsy, cerebral damage, physical illness, medication effects, autism, chronic pain, endocrine disorders, sensory deficits and behavioural disorders (Davis 1999, p.104).

Thus, optimally, assessment should be conducted by specially trained staff (Tonge et al 2006). Unfortunately, services specific to people with intellectual disability are often not available and the task is left to general practitioners. Reporting on findings of a study conducted in Victoria, Lennox and Chaplin (1995) used a questionnaire to survey psychiatrists and trainee psychiatrists (N = 116). This research revealed that psychiatrists and psychiatric trainees, although interested in the psychiatry of intellectual disability, felt that they were inadequately trained and the authors concluded that more research into dual disability was necessary.

According to Mohr, Curran, Coutts and Dennis (2002), there is a tendency for mental health practitioners to see presenting challenging behaviours as a result of the intellectual disability rather than a symptom of mental illness. There is a lack of specialised training in this area. Furthermore there appears to be an "us and them" demarcation issue between mental health and disability services regarding roles in assessment, treatment and on-going management of people with intellectual disability and mental health problems (Mohr et al 2002). This often results in a lack of coordination and inadequate services for these people.

2.4.7 Providing Appropriate Care

It is difficult to find treatment for people with dual disability as services tend to relate to one condition or the other; that is, intellectual disability associated conditions or mental health issues. There is a need for skilled professionals who are able to treat both conditions, according to the Schizophrenia Fellowship of New South Wales (2004).

The move toward mental health deinstitutionalisation in NSW commenced in the 1960s and was completed by the late 1970s (Richmond 2003). The devolution of mental health institutions that commenced in South Australia in 1990 impacted on health care and accommodation for people with psychiatric disorders. Mental health has been largely deinstitutionalised and nursing care is provided by community mental health nurses and multi-disciplinary mental health teams (Commonwealth Department of Education, Science and Training 2001).

The closure of South Australia's psychiatric hospitals has resulted in a greater demand for support from intellectual disability services for those with dual diagnoses. Furthermore deinstitutionalisation has highlighted special needs as clients face different lifestyles and risks (Gibbs & Priest 1999). For this reason, knowledge of psychiatric disorders and their treatment is considered crucial for intellectual disability nurses because of an increase in the presentation of dual disability (Gibbs & Priest 1999). These authors report the success of a program identifying nurse educational needs in the UK, introducing training in dual disability and observing enhanced practice.

2.5 Meeting the Health Needs of an Ageing Population

Much current research into intellectual disability focuses on the needs of people who are ageing with a lifelong disability. Their health and accommodation issues, including those of people with Down syndrome, are presented here, as expounded by various authors.

The increasing number of older people with intellectual disability can be attributed to several factors. The introduction of adequate health care and deinstitutionalisation have meant an increase in the life expectancy of people with intellectual disability (NSW Council for Intellectual Disability 2004). In addition, as for the general population, developments in pharmacology have enhanced longevity (Commonwealth Department of Education, Science and Training 2001).

2.5.1 The Statistics

In the disability sector, due to the premature ageing experienced by some groups, those 55 years and older are classified as aged (Bigby 2002, p. 235). Barr (1999) stated "...the majority of people with learning disabilities now live into their 60s and 70s and some much longer" (p. 1482).

Australia is experiencing a rapid increase in the number and proportion of aged people with intellectual disability. This has been explained as a "relatively new phenomena" confronting service providers and is due to increased life expectancy and that longevity, combined with the "demographic bulge" of the baby boom generation, will significantly increase the numbers over the next 15 years (Bigby 2002, p. 231). To illustrate this point Bigby (2002) cited statistics that show changes over the past 50 years. The average age of death for people with intellectual disability was 22 years in 1931, 59 years in 1976 and 66.1 years in 1993 (p. 231).

2.5.2 Ageing and Down Syndrome

Similar statistics apply to people with Down syndrome who, in 1900, had a life expectancy of 9–11 years. Now the average is above 50 years, with one out of ten living to 70 years of age (Brown, Taylor & Matthews 2001).

Brown et al (2001) conducted pilot qualitative research on a small (number not specified) sample of people with Down syndrome who were in the upper age group, 45–70 years. The research, which utilised a questionnaire, found there was a need to recognise the principles of variability, perception and choice. People needed support to maintain active but dignified lifestyles. It is "generally conceded that people with Down syndrome age earlier than most people" (Brown et al 2001, p. 111).

An earlier decline in leisure activity than others with intellectual disability can begin around the mid 20s, but studies of ageing and Down syndrome do not usually start until about 45 years of age (Brown et al 2001). The extra chromosome in Down syndrome also makes the person susceptible to some "biochemical negatives" which are associated with Alzheimer's disease (Brown et al 2001, p. 112). In fact most people with Down syndrome over the age of 50 years experience neuropsychiatric problems associated with Alzheimer's disease (Rasore-Quartino 1999).

2.5.3 Health Issues

An entire community of people with intellectual disability is ageing which means their health needs are changing. The National Review of Nursing Education found that Australia's population is ageing and there have been gains in life expectancy in the middle-aged to older group (Commonwealth Department of Education, Science and Training 2001).

However, a longer life makes the client more susceptible to chronic illnesses associated with age. As in the general population, age and particularly advanced age are considered to be significant predictors of poor health and disability. Health promotion and health education should be priorities for people with intellectual disability, as they should for the general aged population, because many illnesses can be prevented (Barr 1999 p. 1482).

Health problems more common to older than younger people with intellectual disability include incontinence, reduced mobility, hearing impairment, arthritis, hypertension and cerebrovascular disease (Bigby 2004, p. 71). Bigby (2004) also pointed out that it is important to be sensitive to additional needs related to disability, such as environmental and medication usage histories, lifestyle, exercise and diet (p. 61).

The clinical management of ageing individuals with intellectual disability can be complicated by several factors, not least communication impairment, which can prove an obstacle in obtaining an accurate history; health problems could, therefore, be attributed to the disability (Balandin & Kerse 1999, p. 62). The guidelines suggested by Balandin and Kerse (1999) were compiled for medical practitioners but the recommendations of keeping good records and building a good rapport with the client could be useful to nurses who have more contact with the client, placing them in an optimal position to observe changes.

2.5.4 Accommodation Issues

Bigby (2002) described the aged care system as "a specialist one", used only by the minority of Australia's aged population because most do not require services designed for the frail elderly (p. 235). This is where the needs of aged people with intellectual disability vary from other ageing people. They are more likely to have a need for assistance with the activities of daily living and they may have chronic health problems, but there is less chance they will be classed as "frail aged" (Bigby 2002, p. 236). The focus of aged care organisations is on the frail aged or the over 80 group and it is in this age group that the largest growth has occurred in the past decade (Bigby 2004).

In the UK, as Thompson (2003) revealed, the demise of institutional settings has produced a much more "complex and uncertain picture of later life" for people with intellectual disability (p. 2). Older people with intellectual disability largely live in the family home, in residential services for people with intellectual disability or in residential services for older people. There is evidence showing many people with intellectual disability who live with older family carers have been neglected; on this point, Thompson (2003) referred to UK Department of Health statistics (p. 3).

While the placement of older people with intellectual disability in services for the aged might be seen as positive inclusion, it is far from optimal because staff members are untrained to work with people with intellectual disability and there is little contact with the "disability professions" (Thompson 2003, p. 4). The poor quality of life perceived to be experienced by people with intellectual disability who are forced to live in aged care residential facilities in the UK is explained in terms of the cost of care. United Kingdom residential facilities for older people cost about only a third of what is considered to be good quality support for people with intellectual disabilities (Thompson 2003).

A NSW study of over 200 people with long standing disabilities found people with intellectual disability would like to stay in familiar surroundings as they get older. While many hoped to remain living independently in the community, some had a preference for specialised supported accommodation. A widely held position was that people did not want to live in aged care facilities. The conclusion drawn from this qualitative study (involving "consultation") was that "flexible models of service provision" are needed to bridge the gap between aged care and disability services (Gething 2001, p. 3).

2.5.5 Carers

The closure of institutions has meant that the care of people with intellectual disability often involves family members. Organisations such as Carers Australia understand that caring can be physically and mentally exhausting and offer respite services. Acknowledging, from anecdotal evidence and observation, that carers receive little or no assistance from other family members, the respite offered by Carers Australia can take many forms. In-home and residential care is available as well as day care options and recreation activities in the community (Carers Australia 2004).

The National Disability Administrators (NDA) are responsible for the funding and administration of disability support services throughout Australia. Since the Commonwealth/State Disability Agreement (CSDA) was signed in 1991, governments have increased funding to disability services. A major reform has been decreasing institutional care in favour of community based and in-home support options. Recognising the needs of carers, the NDA provides funds for respite, designed to give the carer a break. It is also acknowledged that respite should provide the person with intellectual disability with a positive experience (The National Disability Administrators 2002).

An important issue is that of older carers, usually parents, who are likely to be outlived by a middle aged "child" with intellectual disability. People with intellectual disability who have lived at home with their parents will have a high need for supported accommodation in late adulthood due to loss of parents, rather than infirmity related to age (Bigby 2002, p. 232). Carers' needs are changing and it is suggested that carers need support and plans should be in place for the transition from parental care to alternative arrangements (Bigby 2002).

2.5.6 Areas of Need

Notwithstanding the many efforts to promote positive images of the aged and people with intellectual disability, Gething (1999) stated that societal stereotypes are particularly negative for older people and aged care workers are seen to be "at the bottom of the barrel" (p. 2). This is seen to be due to the high value placed on finding a "cure" and the high status afforded those who work with "high tech" equipment (p. 2). Gething (1999), who proposed a framework of principles to stimulate debate to redress the situation, suggested education at undergraduate, postgraduate and in-service levels could assist in dispelling stereotypes and attract health professionals to aged care.

It has also been suggested that ageing issues could be introduced to the curricula of the health professions, and information provided on healthy ageing. In addition, a variety of clinical placements could be offered in both institutional and community settings and the same principle could be applied to the education of health care professionals who want to specialise in intellectual disability (Gething 2001).

The position of ageing people with intellectual disability within the system and the services available to them was analysed by Bigby (2002) who concluded that neither intellectual disability services or aged care services adequately address their needs (p. 231). Similarly, Gething’s (2001) study, involving over 200 participants, considered issues for people ageing with a life long intellectual disability and found that "aged care disability policy and practice have not evolved to meet their needs" (Gething 2001, p. 2). The study, conducted in NSW, included a forum, working party and focus groups. Participants were largely consumers of aged care services and data analysis found their responses "strikingly consistent" (Gething 2001, p. 2). Moreover Gething's (2000) research indicated that attention is needed to the "special needs" of people ageing with an intellectual disability (p. 58). The study found a lack of knowledge and expertise in ageing among personnel and this is supported by recent local research in South Australia (McPhail 2005).

It is agreed that much work is needed in the area of ageing with a lifelong intellectual disability. The UK and Australia are in the early stages of policy and program development to address the needs of older people with intellectual disability (Bigby 2004). The USA is further ahead but there are significant differences between the states. The problem of disparity in service development can also be seen across the Australian states (Bigby 2004, p. 249).

The organisation to which The Centre belongs responded to the need for an aged care service by providing a separate purpose built nursing home in 2002. Supporting adults with intellectual disability in the nursing homes provided for the general population has been deemed "highly inappropriate" by the NSW Council for Intellectual disability (Position Paper 2004 b). Reasons for this opinion include the undermining of basic human rights and because placements are often driven by saving money. Other considerations are social isolation and the significance of previous institutionalisation in de-skilling people with an intellectual disability. Ideally, people with intellectual disability should expect to remain in their own homes with support services, for as long as possible.

2.6 Educational Preparation of Nurses

Tertiary education for nurses is now standard in many English speaking countries. According to Nehring (1991) curricular content on intellectual disability in the USA in general nurse education is minimal, but there are post graduate courses in "mental retardation" (p. 263). In 1960, university affiliated training began in the USA. At the same time, plans in the USA were in place to discontinue hospital based psychiatric nursing training (Nehring 1991, p. 262). However mental retardation nursing, as it is known in the USA, has developed and is now considered a nursing specialty.

In England, according to Jones (1999), specialist training is incorporated into the RN's three year education, so one can elect to undertake studies in a certain branch of nursing. Alternatively, in England, there are post graduate courses in this field of nursing and Jones attributes the successful moves toward deinstitutionalisation in the UK to nurses skilled in intellectual disability nursing.

Because of the possible clinically isolated or remote locations of the nurse's practice in England, community nursing training is also a requirement and a post graduate degree or diploma is available (Tidby 1999, p. 59). Similarly in Ireland, "mental handicap nursing" is still a career option for nurses and training is available at tertiary level (Parahoo 2000, p. 608).

In Australia, there are a small number of registered intellectual disability nurses specialising in intellectual disability but the nurse registering authorities no longer have registers for the speciality. However in NSW, registered and enrolled nurses have the option of undertaking post-basic courses at Technical and Further Education (TAFE) colleges to enable them to specialise in intellectual disability nursing (per telephone, Department of Health and Ageing personnel 10.3.03). Developmental disability nurses in NSW work in family homes, private and government subsidised residences, hostels, nursing homes, hospitals and clinics in the community (NSW Chief Nursing Officer 2003). However, the NSW Nurses' Registration Board does not register any post-registration qualifications.

Likewise in South Australia, there is currently no formal education for intellectual disability nursing, as the Diploma and Bachelors degrees in disability have replaced this training. People interested in disability are able to undertake studies in disability as part of their nursing degree, but there is no disability or intellectual disability speciality acknowledged.

The introduction of the Health Service, the focus of the South Australian research being reported here, has altered the way that clients' health needs are met. Moreover, the cessation of mental deficiency nurse training, and the introduction of tertiary courses, have meant nurses no longer receive education in intellectual disability specific disorders. Interventions for epilepsy, behavioural disturbance and long term bowel management tend to be learnt on the job. It is often the case that long-employed care workers and supervisors have more knowledge of the needs of the client with intellectual disability than the nurse does. The important questions of how intellectual disability nurses will be educated in the future, and indeed if these nurses are needed, or whether they will be phased out, warrant consideration.

There is a new generation of nurses approaching careers in intellectual disability nursing—nurses who have had no training or experience with people who have intellectual disability. The Bachelor of Nursing course offered by South Australian universities provides little preparation for intellectual disability nursing, yet there are graduate nurses seeking employment in the disability sector. There is also no in-service training provided by IDSC specifically for nurses.

However, one major South Australian institution for people with disabilities, not previously mentioned because the focus of services is on people with acquired disabilities, has re-entry programs for RNs who wish to work in aged care and disability nursing. The program is for RNs who wish to re-enter nursing after up to 10 years absence and it aims to help participants regain their confidence. It is described as being "practice orientated" with a holistic focus and as teaching RNs to work with trained and untrained staff. Placements are available within the institution and private homes that are part of the Australian Nursing Home and Extended Care Association. The focus is on aged care and disability nursing because the organisation acknowledges that not every nurse wishes to work in the acute setting. There are no fees and participants are paid as RNs for clinical placements of 10–16 weeks. The course is an overall refresher with more emphasis on neurological problems due to the institution's clientele. (per telephone: Chris Firth CEO, Julia Farr Services 17/12/02)

The National Review of Nursing was commissioned in April 2001 by the Minister for Education, Training and Youth Affairs. There is a focus on the skills and knowledge required to meet changing needs of nurses and mechanisms for recruitment as well as encouraging a commitment to lifelong learning of those already in nursing. It was found that education is a paramount concern for nurses and needs to be appropriate, ongoing and accessible (Commonwealth Department of Education Science and Training 2001).

The Review (2001) suggested that there should be a national curriculum that allows for specialisation in particular areas of practice and more contribution from the workplace in developing the nursing curriculum. Support, mentoring and preceptorship are called for to facilitate the personal and professional growth of nurses as lifelong learners and it is argued that nursing education should be addressed along with that of other health workers and professions (Commonwealth Department of Education Science and Training 2001).

Training in intellectual disability is currently missing from the curricula of medicine, psychiatry and psychology training in South Australia, although a disability "major" is available in one course that may lead to registration as a psychologist. The IDSC (2002) submission to the Generational Health Review suggested that this lack of input on intellectual disability in professional courses should be remedied. IDSC's health team philosophy provides the flexibility to update old ideas and introduce new initiatives as required. Their mission statement suggests that a policy should be developed and implemented that promotes nursing research and continuing education in order to enhance knowledge and skill development (IDSC 2000).

In articulating a role for disability nurses it is important to consider the level of training. In the UK where care of people with intellectual disability is mostly community based and nurses provide a visiting service, a diploma of learning disability nursing followed by a degree to work in the community are minimum essential criteria (Tidby 1999, p. 59). The UK University of Luton offers a two year part-time Bachelor of Arts with honours (Learning disabilities).

Intellectual disability nursing is described by some authors as a nursing speciality and Mitchell (2000) described it as "a discrete branch of the nursing profession" (p. 78).

However, intellectual disability nursing is not mentioned in the curricula of any South Australian university offering the bachelor of nursing course with the exception of Flinders University, which offers a disability option.

Borbasi (1995) observed that mental deficiency nursing was afforded lower status compared to psychiatric nursing, which in South Australia continues to be a recognised post basic qualification. Psychiatric nursing is in turn often believed to be inferior to general nursing (Borbasi 1995, p. 8).

In 1982, Sturt College of Advanced Education (SACAE) introduced the Diploma of Applied Science (Developmental Disabilities). This award eventually became the Bachelor of Applied Science (Disability Studies) and SACAE became part of Flinders University. This created an academic pathway for many mental deficiency nurses, leaving few RNs who were trained in intellectual disability.

Flinders University now offer a combined program that enables students to qualify for the Bachelor of Nursing and the Bachelor of Applied Science (Disability Studies) in four years. The Bachelor of Nursing course is a three year course. The University of South Australia is the only other South Australian university to offer undergraduate nursing courses.

2.7 Summary

This chapter has presented literature examining the specific health needs of people with intellectual disability. There is much literature on the subject of intellectual disability, however very little research has been done into the role of RNs who care for people with intellectual disability. There is literature about the role of RNs working with people with intellectual disabilities from the UK and USA, and some literature on this role in NSW. However, no literature could be found to suggest that any recent Australian study has been conducted into the role of the RN in caring for people with intellectual disability. The role of health care and in particular nursing care is also seldom addressed in the intellectual disability literature. This is despite many authors expounding the special health care needs of people with intellectual disability.

There are particular concerns when people have more than one major disability because services are usually in place to treat specific conditions rather than combined conditions. The literature highlights the dilemma of people who have both intellectual disability and psychiatric disorder and there appears to be an increasing number of people who are presenting with dual diagnosis. Similarly, due to increased longevity in people with intellectual disability, there is a growing need to address the issues associated with ageing in this population.

The literature also suggests that the health needs of people with intellectual disability can be complex and should be treated by health care professionals who specialise in the field and who have experience in communicating with people with intellectual disability and their care workers. It appears timely that the role of an important health professional—the RN—is explored in disability service. Further, arguably, this role requires definition and a model for practice designed.

Available literature on educational preparation for intellectual disability nurses has been discussed in this chapter. Australia, and specifically South Australia, where this study was conducted, has very little to offer neophytes RNs wishing to enter the field of intellectual disability nursing. They require a diverse range of skills and there are currently no post basic courses for RNs to prepare them for the role.

Notwithstanding the array of literature addressing the accommodation needs of people with intellectual disability and some mention of health needs from a medical perspective, the role of nurses is unclear, thus indicating the need for this research. If there is a role for the RN in the care of people with intellectual disability, a nursing model for practice is a pressing need (please see example: Table 8-1).

Literature on intellectual disability nursing in Australia is scarce. No literature could be found to suggest that the areas of need discussed here have been researched from a nursing point of view. Most of the literature has its origin overseas where intellectual disability nursing is considered to be a speciality in its own right. Australian and overseas initiatives, such as community living and the introduction of unregulated workers, impacting on intellectual disability nursing are addressed in the next chapter.

Chapter 3

HEALTHY COMMUNITY LIVING

3.1 Introduction

The previous chapter highlighted various health issues that might be relevant to people with intellectual disability. It was explained that people with intellectual disability are now living longer and a longer life makes them prone to illnesses associated with ageing. The literature also demonstrated a higher incidence of psychiatric disorder in people with intellectual disability. Moreover, it was highlighted that despite an obvious need for health care professionals who specialise in intellectual disability, there is no specific training in this area of care for nurses.

This chapter begins by examining literature that describes The Centre’s move from the medical model to the developmental model, which has significantly altered the RN's role. The journey of The Centre in South Australia (the setting for a large part of this research) from an institutional model to a community based model is described. Comparison is drawn between nursing at the time of The Centre's opening and the current service, and the trend toward employing unregulated workers explored.

The principle of deinstitutionalisation, previously outlined, has impacted on the care of people with intellectual disability throughout the world. Literature related to the health care of people with intellectual disability in the community is now presented from worldwide and Australian perspectives.

3.2 The Move from the Medical Model to the Developmental Model

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The most significant factors affecting the health care of people with intellectual disability over the last 20 years in South Australia have been the changes from the medical model to the developmental model and the removal of institutional living as a primary option. The principle of deinstitutionalisation is referred to throughout this thesis as it impacts on health care and is, in many ways, linked to changes in the model of care. The model of care delivery undeniably impacts on the health of a group of people. Some believe this to have had a negative impact; indeed one senior manager at The Centre described the removal of the medical model as 'throwing the baby out with the bath water'.

The impetus for moving from an institutional to a community based model came from studies such as that conducted by Miller and Gwynne (1974). Examining six institutions in the UK between 1966 and 1969, the study found that the physical and psychological dependence of "inmates" was an important issue and that enriching the environment could be of benefit (p. 213). Interestingly, the study was initiated by a resident of an institution who was concerned about quality of life. A qualitative methodology, action research, was used and a theoretical framework enabled the researchers to compare the institutions in the study. It was concluded that the ideology of institutions tends to "stunt and distort the personal development of inmates" (Miller & Gwynne 1974, p. 20).

Goffman (1986), who conducted an ethnographic study into the experiences of psychiatric patients in institutions, described a focus on "the medical-like therapeutic services the hospital supplies patients" (p. 307). Goffman (1986) suggested the medical model, when used in psychiatry, assumes that all cases fit neatly into the framework used by the medical model for assessment. A medical model is no longer recommended in the care of people with intellectual disability but it is a difficult model to break and there are some institutions that still cling to it (Hassam 2002).

Hassam (2002) explained that the medical model is no longer recommended because intellectual disability clients are not considered to be sick, although Gallagher (2002) suggested it is still useful in order to inform practice and diagnosis. Moreover, the role of medical science in keeping many people with disabilities alive and reducing their pain and discomfort should not be denied (British Film Institute 2005).

In contrast, the developmental model, as the name suggests, addresses the fundamental need for growth and development of competencies (Cocks & Stehlic 1996). Advocates and leaders of the developmental model argue against the former medical model claiming that citizens’ ordinary daily activities are "nothing to do with health care" (NBSA 2003, p. 32). Notwithstanding that the organization involved in this study worked at developing a best practice model of health care, its leaders have been opposed to the “remedicalisation” of disability services and felt this would result should the Nurses Board attempt to regulate care workers (NBSA 2003, p. 33).

The assumptions underpinning the developmental model are "intrinsically positive" and utilise a range of educational and developmental technologies (Cocks & Stehlic 1996, p. 20). Benefits of the developmental model were clearly evident in the setting of the research reported here, including empowerment of clients to make decisions about their lives. For example, many of the clients were employed in jobs that they enjoyed and this elevated self esteem and provided some regular additional income. As the researcher, I also observed a range of available activities at The Centre such as a regular supper dance and other outings. Clients were taken on holidays by their care workers and most days they had the option of attending activities such as pottery, art, music, grooming and various sporting pursuits.

3.2.1 Deinstitutionalisation

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Although a relatively recent concept in South Australia, the 1980's concept of deinstitutionalisation originated in the 1950s and became a reality in many countries in the late 1960s and early 1970s. This is probably the most important change in "policy and the pattern of service provision" in intellectual disability in the last 50 years (Mansell 2006, p. 65). Deinstitutionalisation has become a "focus of disability policy" in many countries although outcomes for clients are not always uniformly better, according to Mansell (2006, p. 65). Mansell (2006) reported on the results of a large study to determine the effects of deinstitutionalisation. The research drew on data collected over the 25 years since the commencement of deinstitutionalisation in most developed countries of the world. Data are presented as rates per 100,000 total population, to "permit international comparison" (Mansell 2006, p. 66). The report is descriptive and emerging problems are identified; overall findings suggest community-based services are superior to institutions. While many recommendations have little to do with health or nursing, it was found that there is a need for "enabling support of individuals", especially those with severe and complex disabilities (Mansell 2006, p. 65). The research methodology in Mansell's study is not described and a limitation is that much of the analysis was based on the British experience.

Also from the UK, Read (2004) examined the results of an 18 month "prospective evaluation" of the effects of deinstitutionalisation on 111 older people with intellectual disability moved from a long-stay hospital to care in the community (p. 299). The gender of the client participants is not provided. Observations were made prior to discharge, at six months and 18 months following discharge. These included health and medication, staffing, mental health and behaviour. As would be expected, there was an increase in the involvement of non-registered staff and Read (2004) suggested additional training was required for workers. Unfortunately, the results showed a decrease in client mobility and a higher rate of mortality but this is explained as being relative to the ages of the clients. Overall, based on clients’ general health, the study found an improved life style in community based living (Read 2004).

Similarly, Young and Ashman (2004) described a deinstitutionalisation research project in which 57 males and 47 females were relocated to the community from Challinor Centre in Queensland. The respondents were staff members involved in direct care and who assisted in developing assessment tools for data collection. The areas examined were adaptive and maladaptive behaviour, choice making, and objective life quality as well as the implications for service provision. The researchers found that "life circumstances improved" and deinstitutionalisation " accompanied by a lifestyle that fosters individual development" is suitable to meet the needs of people with intellectual disability and those who are ageing in Australia (Young & Ashman 2006, p. 409). Again, while not related directly to nursing, the study has implications for client health.

Some concerns have been expressed about the outcomes of deinstitutionalisation. In particular, questions about the practical implications of deinstitutionalisation and whether the best interests of people with intellectual disability are being served have been raised (Rapley & Ridgway 1998).

3.2.2 Inception of The Centre

The impact of deinstitutionalisation is also reflected in literature about The Centre and the changes in health care delivery, and nursing in particular, are considerable. Much of the historical data required to paint a picture of the 30 year history was found in the IDSC library. This section provides an overview of the evolution of the disabilities sector nursing service.

3.2.3 The Vision

The 1971 opening of The Centre marked the end of an era in the care of people with intellectual disability in South Australia. They were finally able to break away from the state's psychiatric hospitals and enjoy a new purpose built home. The Centre was hailed as "an outstanding example of the modern approach to the treatment and training" of people with intellectual disability (Dibden 1970, p. 2).

3.2.4 The Journey

Prior to the 1970s, the field of intellectual disability was dominated by the medical model which assumed that people with intellectual disability were sick and in need of treatment. The medical model was "displaced by a developmental model which accompanied the new policies of normalisation and integration" (Carman-Brown & Fox 1996, p. 205). The introduction of developmental approaches were considered to be "major advances", creating lifestyles for people with intellectual disability that would be unrecognisable to past generations (Carman-Brown & Fox 1996, p. 205).

The manner in which the care of people with intellectual disability has been constructed by the disciplines of medicine, psychology and education as a "field of knowledge" requiring exclusive authority was discussed by Carman-Brown and Fox (1996, p. 248). They described the shift away from the traditional medical model, which "prescribed nursing care for people with disabilities", and suggested that the model has been replaced with one of social training (1996, p. 249). Gallagher (2002), a Victorian psychologist and family therapist with an interest in disability, stated that use of a medical model "assumes a clearly defined and diagnosable 'syndrome'" and is hardly ever admitted to in the disability field (p. 202). Despite this he described the medical model as being "alive and well" beneath the surface (p. 202).

Service delivery provided at The Centre has evolved from the medical model of care to one of offering clients lifestyle choices. In the times when the medical model was used, Ashton (1977) stated that people with intellectual disability had a right to proper medical care and physical restoration. He described the service provided by the Centre as "second to none" (p. xi). A former nurse educator at the Centre, Ashton (1977), stressed the importance of training for health care providers (p. 77).

Kent (1972), the former medical superintendent of The Centre, suggested there was a need for a multidisciplinary approach and emphasised the importance of recognising the skills of other members of the team. About 400 nursing staff and "home assistants" were employed to care for up to 684 people with intellectual disability. The home assistants had a similar role to the care workers as they are now known. Kent (1972) described the improved conditions as "a far cry from the days of human storage" when 150 people were cared for by a few nurses (p. 10).

It was suggested initially, by unknown parties, that the role of the nurse be confined to caring for "sick" clients. However, McElwaine (1970) suggested that was not in accordance with The Centre's concept of the Mental Deficiency Nurse. Rather, the nurse should take a holistic approach and provide "residential care and training" (p. 4).

The school of nursing at The Centre commenced "educational activities" in 1971. Its purpose was to educate nurses from a psychiatric hospital and The Centre in psychiatric and mental deficiency nursing. The training was for a period of three years in either psychiatric or mental deficiency nursing. Graduates were then entitled to register their qualification with the Nurses Board of South Australia. A general nursing registration was not a prerequisite, but could be obtained by completing a further two years and three months of study (Hardwick & Ashton 1970, p. 6).

The 1978 final exam paper for registered Mental Deficiency Nurses gives valuable insight into the former role. The training incorporated medical, intellectual, behavioural and social assessment. Students were required to display an understanding of diagnoses and methods of training the children in their care. They were taught relevant pharmacology and how to relate to families and other staff; the curriculum also contained some medical nursing (Nurses Board of South Australia 1978).

Major change affecting the staffing structure at The Centre began in the early 1980s. A 1981 study was commissioned to detail how nursing hours were spent and this study concluded that the number of RNs was excessive. At that point, policy began to direct that much of the care could be delivered by unqualified care workers without detriment to the clients (Community Systems Foundation 1981).

The decision to reduce the number of RNs and introduce more unqualified care workers impacted significantly on Mental Deficiency Nurses. In 1990 in South Australia, career restructuring resulted in Mental Deficiency Nurses becoming Developmental Educators. As a result of these changes, the *Nurses Act 1999* does not include a mental deficiency register (correspondence, Nurses Board of South Australia 2002).

Many factors have impacted on the delivery of health care at The Centre in recent years, not least the move toward primary health care. The IDSC, of which The Centre is a part, aims to balance the "inclusion of people with intellectual disability within the mainstream life of the South Australian community" (Intellectual Disability Services Council 2002, p. 1). This includes the use of services available to the general population as well as special services for those with special needs.

3.2.5 The Reality

Changes in healthcare, and nursing education and practice, have been anecdotally reported, by staff and significant others, to impact significantly on The Centre, its clients and its staff. Now the RN is visible only when health problems arise and is not trained in the field of intellectual disability. Moreover, the past three decades have taken their toll on buildings that were considered ahead of their time in design when first built. As a result, the community move is a timely one considering the poor state of repair of The Centre's buildings and roads.

A Family Newsletter reported findings of a consultant's report confirming the condition of The Centre had deteriorated, including the buildings, roads and underground services (IDSC 2004). The Newsletter (2004) described plans to upgrade some of the Villas to last for five to seven years. As reported, it was also planned for five Villas to be closed and 150 clients to be relocated into the community, leaving 99 clients remaining in upgraded Villas. Services at The Centre will decrease as clients move from the site, but services and buildings such as the pool, gymnasium, chapel, canteen, laundry and kitchen are likely to remain as there is no urgency for use of the land.

3.3 The Nursing Home

The 1990 closure of the Nursing Home, a large residential facility for people with intellectual disability in Adelaide's western suburbs, impacted on disability care in South Australia by removing the nurse as central to client care. The former Nursing Home residents were the first large group of people with intellectual disability in South Australia to move to houses in the community.

3.3.1 Nursing Care

Prior to the closure of the Nursing Home it was determined that the clients had healthcare needs that required nursing expertise. A review was conducted, which set the scene for Royal District Nursing Service (RDNS) nurses to enter the field of disability nursing as the Nursing Home closed its doors and clients were moved into the community (Flett 1992). It was anticipated that RDNS nurses who provided care to people with intellectual disability, would be clinical nurse consultants (Level 3). The current health care nurses at The Centre are Level 1 RNs, the first level of registered nurses, therefore the rate of pay is significantly lower than the RDNS nurses who continue to provide care for a number of clients.

Flett, Ellis and Masters (1989) also examined the role of RNs in caring for those with intellectual disability in South Australia. They described the formation of a task committee set up to plan the move by the Nursing Home to the community. RDNS nurses, it was proposed, would have "clinical autonomy as consultants, advisors and educators and would not be accountable for the quality or quantity of care delivered by the Developmental Educators or Direct Care Workers" (p. 23).

Horsfall (1990), one of The Centre's medical officers at the time of the Nursing Home closure, suggested that people with intellectual disability have a need for specialised medical care because of their "physical conditions" (p. 27). He did not mention nursing care, and to the present time the RNs report feeling that nursing does not seem to rate much importance. This is in accord with Borbasi's (1995) suggestion that the medical profession have always been the dominant culture that influences government policies relating to health and illness (p. 7).

The professions of medicine and nursing were considered to be skilled in "inservicing and recertification of competency" (Flett et al 1989). The health needs of the ex Nursing Home clients were considered to be their bowels, epilepsy and "pressure sores". Drugs were administered by credentialed Direct Care Workers and doctors and nurses were the only staff permitted to give injections. Continence management was primarily the role of Direct Care Workers in consultation with RDNS (Flett et al 1989, pp. 23-24).

3.4 Future Directions

Since the closure of the Nursing Home, many people with intellectual disability have made a relatively uneventful transition into the community. The draft of the South Australian Disability Services Planning and Funding Framework (2000-2003), which takes into consideration all forms of disability, stated there will be further reductions in institutional places and the "credentialing model of health care" will be supported with the development of appropriate standards (Department of Human Services 2000, p. 7).

The plan is being continually assessed and the government of South Australia Department for Families and Communities Draft Framework (2004-2007) subsequently set out the state's future plan for people with disabilities. The social inclusion of people who have previously been excluded was promoted and the goals included enhancing and valuing the participation of people with a disability, identifying their needs and being accountable for the services provided to people with a disability.

The Framework (2004-2007) suggested that medical advances are "saving and prolonging lives" resulting in more people with more severe disabilities (Department for Families and Communities 2004, p. 11). This calls for a skilled and experienced workforce, staff development, training and a focus on client satisfaction. It is suggested that mainstream services should be available to people with disabilities as they are to the rest of the community but this has proved a contentious issue among the disability community and services and a Centre for Intellectual Disability Health has recently been established at one of the metropolitan hospitals (IDSC 2005).

Other points stressed in the Draft Disability Services Framework (2004-2007) include the need for a focus on prevention and early intervention. Strategies suggested include primary health care, health promotion and offering choices on recreational activities. It is also suggested that improved information should be made available on such things as health, diet, lifestyle and physical activity and that there is a need to maximise South Australia's capacity to attract government funding for disability (Department for Families and Communities 2004, p. 25).

In 2002, the South Australian Department of Human Services called for interested parties to develop submissions for a Generational Health Review to evaluate health services throughout the state's public hospitals and health care provision agencies. IDSC's submission to the Review described the issue of "balancing the inclusion of people with intellectual disability within the mainstream life of the South Australian community (including the use of services accessed by other citizens) and the provision of special services for a client population with special needs" (IDSC 2002, p. 1).

The submission suggested there is a need for coordinated health care to ensure people with special health needs have these met. The specialist nature of intellectual disability organisations is emphasised but, it is acknowledged that there was a conscious shift away from the medical model in the 1980s. The submission states that over one third of IDSC's clients have significant health issues. It is suggested nurses with core competencies in working with people with intellectual disability should be included in the skill mix of staff (IDSC 2002, p. 25).

3.5 Unregulated Healthcare Workers

Cost is a factor in determining the number of qualified nurses (RNs) in the healthcare sector. There is significant growth in healthcare expenditure and labour is the largest item. There has been a decrease in the number of full-time RNs employed in recent years according to the National Review of Nursing Education (Commonwealth Department of Education Science and Training 2001). This has placed demands on the flexibility and adaptability of nurses as more unskilled and semi-skilled workers are introduced.

The cessation of Mental Deficiency Nurse training meant that the primary responsibility for day-to-day care of people with intellectual disability shifted to care workers with no nursing training. The withdrawal of RNs from the residential setting means that the nurse does not know the client as well as the care worker does which can make it difficult for nurses to develop a rapport with clients, generally considered to be essential in the therapeutic relationship. Literature from the Nurses Board of South Australia and others' comments on unregulated care workers follow.

3.5.1 Advantages of Unregulated Healthcare Workers

The change from a medical model to a developmental model has meant that the nurse is not central to the client. Unlike nurses in other health settings, intellectual disability RNs have very little contact with clients of The Centre and are largely not involved in their personal care, making it difficult to assess alterations in their health status. Foley and McCutcheon (2004) conducted a small (number not specified) qualitative study, using interviews and focus groups of carers, that examined ways of assessing pain in people with intellectual disability who present to the emergency department of a general hospital. They found that self-reporting measures were unreliable and emergency nurses "must therefore rely on the person who knows the person with an intellectual disability" (p. 196). That person is often the care worker, or unregulated worker, who has daily contact with the client but, due to high staff turnover and shift work, often people are accompanied by a worker who has little direct knowledge of the client. It was recommended that people with intellectual disability should be accompanied to hospital or other medical appointments by a familiar carer or care worker and, as this is not always possible, documentation is therefore very important.

Authors Lennox and Diggens (1999) stated that alterations in health status are readily recognisable and can be managed in the primary care setting; they cited communication difficulties as barriers to providing quality health care (p. 1). While the RNs at The Centre have expertise in communicating with people with intellectual disability and skills in assessment of health issues, the care workers who know their clients well are also a great asset.

3.5.2 The Nurses Board's Position

The Nurses Board of South Australia, the statutory authority established to regulate nursing in that state, acknowledges changes in the health needs of people with intellectual disability. The community care environment has meant an increase in the demand for RNs to work closely with unregulated care workers to ensure the provision of effective, safe and ethical care. In 2002 the Board undertook an inquiry to gain information regarding the role and function of unregulated workers across all health care sectors of South Australia (NBSA 2003). In addition to calling for submissions from key professional and government bodies, the inquiry examined international literature and Crown opinion was sought with regard to the Board's mandate pursuant to the *Nurses Act 1999* (NBSA 2003). The *Nurses Act 1999* is in place to ensure the public receives the highest standard of competence and conduct by regulated health care professionals (NBSA 2005, p. 4).

The inquiry assisted in defining the duties and role responsibilities of unregulated workers, which can vary but are broadly categorised into: "community access and inclusion", activities of daily living (ADL) and personal care support, home assistance, health care and technical support (NBSA 2003, p. 4). A range of available training and education was described as appropriate to the care worker role, however this is not mandatory and the IDSC submission to the Board's inquiry explained that a qualification such as Certificate III in Community Work would entitle a care worker to a salary above that of an Enrolled Nurse (NBSA 2003, p. 32). While recognising the role played by unregulated health care workers within an appropriate skill mix and framework of services, the NBSA emphasises the importance of the role of regulated health care professionals in improving client outcomes (2005, p. 3).

In issuing guidelines for the delegation of duties by RNs to care workers, the NBSA cited research by the Harvard School of Public Health (2002) indicating that a higher ratio of RNs in health services is consistently associated with higher quality care, lower morbidity and mortality rates, improved outcomes for clients and fewer adverse incidents (NBSA 2005, p. 2). The large study involved analysing the discharge records of 6.2 million patients from 799 American hospitals (Harvard School of Public Health 2002).

However, examination of this and other related research revealed that it pertained to hospital nurse staffing and adverse patient outcomes (Needleman & Buerhaus 2003). This arguably indicates a need for further research into the role of unregulated workers specific to intellectual disability, as improved client outcomes clearly relate to nursing competencies such as diagnosis, problem solving and leadership skills (NBSA 2005, p. 2).

According to the NBSA (2005) safety should be a consideration and issues such as accountability, delegation, supervision and complaints mechanisms should be identified and addressed. Role distinctions between regulated and unregulated health care workers should also be clear to both clients and the public (p. 7). In addition, the Board proposed that unregulated health care workers should not be placed in positions outside of their competence or skill base and, while tasks may be delegated to unregulated workers, they should not be required to make any decisions in relation to any health care intervention and they should receive appropriate competency based training to ensure the health care needs of clients are met (NBSA 2005, p. 6).

The NBSA argued that as members of the nursing profession, nurses are responsible for ensuring clients receive quality care. Nurses, as leaders in health care are seen to be contributing expert knowledge to maximise health outcomes and, as such, nurses "should be recognised and acknowledged as a *value add* to any and all models of care" involving unregulated health care workers (NBSA 2005, p. 9).

3.5.3 Adverse Events

The National Review of Nursing Education (2001) cited USA research that established clear links between the use of qualified nurses and reductions in adverse events associated with the mortality rate and nosocomial infections (those acquired in a hospital). The Review suggested that there is a need to capture the specific contributions of nursing to patient care in every nursing setting. With patients spending less time in hospitals, the National Review of Nursing Education stressed that there is a need for more qualified nurses, stating that care rather than cure distinguishes nursing from medicine (Commonwealth Department of Education Science and Training 2001).

Care workers are not nurses; indeed the IDSC submission to the NBSA (2003) inquiry into unregulated workers described "in a general sense a number of differences" between professional nurses and care workers (p. 32). The differences, "frequently commented on across the sector" need to be noted according to the respondent (NBSA 2003, p. 32). A generally more transient level of worker, the care worker is less inclined to take on the role "as a vocation" with a resultant higher turnover rate (NBSA 2003, p. 32). Furthermore, of concern was the unregulated worker’s work ethic, which is "less obvious in some of these workers" requiring managers to be very creative in pursuing optimum performance (NBSA 2003, p. 32).

Gleeson (1998) discussed the contentious issue of unregulated workers performing nursing care, describing the workers as the third level of nurses who usually learn on the job, without formal instruction or demonstration. In the 1980s, in the USA, nurses were replaced with care workers who made so many dangerous mistakes that employers came to realise that nurses are cost effective because they prevent complications (Gleeson 1998). Some indicators of the quality of nursing care are skin integrity, the incidence of urinary tract infections and falls, and nurses' level of job satisfaction. "Employers do get optimal value for money by employing Registered Nurses - the longer term benefits override the short term profits" (Gleeson 1998, p. 21). However, from June 2008 it will become mandatory for care workers in South Australia to have achieved Certificate III in Community Services (Disability Work) to prepare them for their role (South Australian Disability Services Office 2005a).

3.5.4 Guidelines

The South Australian Disability Services Office (2005) has issued guidelines for RNs in the training of unregulated workers who provide complex health support to people with disability. RNs will be required to have Certificate IV in Workplace Training and Assessment, an Australia wide qualification that is required in order to train other staff in most industries. The RN is described as remaining responsible and accountable for the competency based training and assessment of unregulated workers. It is anticipated that RNs will accept referrals and develop programs of training.

3.6 Intellectual Disability Nursing in other Parts of the World

A significant factor underpinning the research reported here has been the withdrawal of nurses from the residential setting which is now common practice in the developed world.

3.6.1 Standard World Practice

Deinstitutionalisation is standard throughout the developed world according to Felce (2001) who described the move away from accommodating people in "large segregated and geographically isolated institutions" in the USA, Canada, England, Wales and Australia (p. 115). Scandinavia has also replaced institutions with community style living (Felce 2001, p. 115). In Sweden, people with intellectual disability began moving from large institutions in the 1970s and in the UK, most people with intellectual disability now live in the community (Jones 1999, p. 15).

3.6.1.1 Israel

Merrick, Arda and Kandel (2004) described nursing aspects of the care of people with intellectual disability in Israel where most people with intellectual disability live in small institutions or community settings. However, there is a shortage of nurses willing to work with people who have intellectual disability. The nurse's duties include psychosocial support, physical care and advocacy. There is currently no university training for the speciality of intellectual disability nursing in Israel (Merrick et al 2004).

3.6.1.2 England

Most of the available literature on intellectual disability nursing has its source in the UK where several authors have described the role; however, not based on research findings. Seal (1998) stated that "learning disability nurses have developed their profession" alongside changes that have occurred in the system of care (p. 45). He stressed the importance of nurses determining the exact function of their roles (in keeping with the research reported here). Seal described Learning Disabilities Nurses as having a wide range of skills. They care for people of all ages and differing levels of disability, and carry out simple and complex tasks in both social and health care settings (1998, p. 46).

The UK National Network for Learning Disability Nurses Foundation of Nursing Studies Award (2003) was granted to a project titled the Health Review Project in Primary Care for People with Learning Disabilities (led by Ruth Denny, a Primary Care Liaison Nurse). The project was a response to government reports highlighting the increased health needs of people with intellectual disability (Department of Health 1998, 1999a, 1999b, 2001). Results of a six month pilot study, involving three medical practices and using a questionnaire and short interview, were to be analysed and used to design a person-centred plan for each client. Denny anticipated primary care services would provide the opportunity for people with intellectual disability to improve their health by identifying health needs and strategies for health facilitation. These included staff training and providing an evidence base for practice.

In similar findings from Coventry, also in the UK, Bollard reported the results of research that tested a theory of providing routine health checks for people with intellectual disability. The checks "highlighted unmet social and health needs" and provided evidence of gains pointing to the clinical effectiveness of the health checks. The research involved a postal survey of 25 general practitioners on the health issues of people with intellectual disability. Bollard suggested that nurses can provide the link between disability services and health services (1999, p. 1218).

A study conducted in the UK (Alaszewski et al 2001) examined the ways in which learning disability nursing has developed within a multi-professional, multi-agency context. A qualitative method involving questionnaires, case studies and focus groups was used. In evaluating the educational provision for such practice the researchers identified four main components of the nurse's role: direct care, management and administration, liaison work, and education. It was acknowledged that there had been major reconceptualisation and restructuring of the field of practice in the years prior to the study and that taking these changes into account, courses of training aimed to produce competent practitioners. Participant numbers were not provided, however the research is interesting in view of the paucity of studies into the role of the intellectual disability RN.

Another study by Holloway (2004) reported on the results of a postal questionnaire sent to 171 community learning disability services that assessed the support systems available to newly graduated community Learning Disability Nurses in England and Wales. There was a disappointing 16.7% return rate from 684 individual questionnaires. The focus of the research was resolving ethical dilemmas which sometimes arise from choices made by people with learning disabilities (Holloway 2004, p. 283). Holloway (2004) found that respecting a client's autonomy can pose difficulties in such areas as nutrition, sexuality, dental care and consent and that community Learning Disabilities Nurses were expected to draw on a number of resources. These included agency and government guidelines and policies; participants also reported finding it helpful to talk to colleagues (engage in reflective practice). Clinical supervision and training was also reported as helpful.

Since the completion of the study reported here, a compilation of care plans specific to intellectual disability RNs has been published (Gates 2006). The nature of care planning and delivery in intellectual disability nursing is examined and nursing care plans suggested for a range of nursing situations that may occur in the care of people with intellectual disability. This is a much-needed resource that has a person centred focus, and provides an evidence-based framework for the practice of intellectual disability nurses (Gates 2006).

3.6.1.3 Ireland

In Northern Ireland, Barr's (1999) study into the need for health screening for people with intellectual disability found that carers felt the screening should be conducted by the specialist community nurse. The study involved 373 clients (221 male and 152 female; 20% had Down syndrome) who used a health screening clinic for people with intellectual disability over a 31 to 32 year period. Predetermined indicators of health such as blood pressure, weight and urinalysis were used to screen the health of the participants and a postal questionnaire was sent to 124 randomly chosen clients and their carers (Barr 1999). Respondents were asked about their perception of the health screening clinic. The carers highlighted the RN's communication skills, and their clinical knowledge of conditions and behaviours of people with intellectual disability (Barr 1999, p. 1487). Furthermore, Barr's (1999) study found many people with intellectual disability lead unhealthy lifestyles and are at risk of physical and mental health problems. Barr (1999) emphasised that these problems are preventable and Barr's study resulted in the instigation of new health developments.

Barr (2004) described the UK and Ireland as different from most other countries in that they provide specific intellectual disability nursing education at pre-registration level. The course outline defines expectations of the role of the RN for people with intellectual disability who live in the community. In more recent literature, Barr (2006) described research conducted over an 11 year period, that examined changes to the community intellectual disability RN’s role and work practices. A survey was used involving the entire population of intellectual disability community nurses. Forty nurses completed questionnaires, providing information about 1559 people with intellectual disability (Barr 2006). Results showed an increasing caseload with a predominantly monitoring, rather than active, clinical role. Not surprisingly, participants reported they had less involvement with children and that there was more focus on adults with physical and mental health problems (Barr 2006). This large, longitudinal study indicated a need for revision of the role of the intellectual disability nurse, and educational preparation for the role (Barr 2006).

In another reported study from Ireland, Sheerin (2004) revealed that the role of nursing in intellectual disability services has not been "constructively debated" in the Republic of Ireland (p. 159). Her study, aimed at identifying the foci for nursing intervention within residential intellectual disability care, found that nurses may not be prepared for, or even aware of, the challenge of intellectual disability nursing and she feared that intellectual disability nursing's contribution to the "broader profession" could be lost (Sheerin 2004, p. 170). A Delphi study was used to examine the specific input of eight intellectual disability nurses who completed questionnaires, and participated in interviews and focus groups (Sheerin 2004).

Another large-scale survey conducted in Northern Ireland revealed a need for research that focuses specifically on learning disability nurses (Parahoo 2000). The sample comprised general, psychiatric and intellectual disability nurses employed by 23 hospitals. In all 2600 questionnaires were distributed and 1368 returned, a response rate of 52.6% (Parahoo 2000). The increasing emphasis in recent times on evidence based practice has given rise to the need to "assess the value of nursing interventions and their outcomes" (Parahoo 2000, p. 607). The objectives of the study were to determine the nurses' perception of the extent to which they utilise research in their practice and assess attitudes to research. The findings revealed that learning disability nurses need to demonstrate that their practice is "effective, efficient and worthwhile", that it enhances client care and adds to nursing's body of knowledge", making professional practice "more sound" (Parahoo 2000, p. 607).

According to Turnbull (1997) "a review of the contribution of the learning disability nurse has never been commissioned and published" and, to date, this would appear to be the case (p. 187). However a 1997 commission to examine the role of the nurse in the Irish health service produced a report titled *Blueprint for the Future*. In discussing this report, which has had significant impact, McKeon (2002) explained that the distinct identity and unique working environment of intellectual disability nurses needed to be highlighted. As a result of the report, changes have occurred and a new four year degree course in intellectual disability nursing was introduced in 2003.

The introduction of the degree course has also meant a review of the syllabus for intellectual disability nurse training in Ireland. The revised syllabus allows for continuing development of new knowledge to meet emerging trends in intellectual disability nursing and research-based nursing practice. The report acknowledged that changes are driven by the economy, politics and technology (McKeon 2002). The cessation of hospital based training is acknowledged as a significant change affecting nursing and hope is expressed that graduates of the new nursing degree program will be:

> ....professional nurses who are safe, caring, competent decision makers, willing to accept personal and professional accountability for evidence-based practice... flexible adaptable and reflective practitioners, integral members of the multidisciplinary team, with a life-long approach to learning (McKeon 2002).

Nurse-led research in Northern Ireland investigated the impact of health promotion classes for people with intellectual disability in relation to weight reduction (Marshall, McConkey & Moore 2003). Twenty people, 14 male and six female, participated in the research which was conducted over a six week period and involved health promotion classes. Weight was monitored at each two hour session, and pre and post weight and body mass index (BMI) were compared; topics included healthy eating and exercise. The participants’ mean weight was reduced significantly from 85kg to 81.6 kg (Marshall et al 2003). The participants in this study were identified as being overweight through a larger study of 503 people who were invited to take part in a special health screening program led by two registered nurses specialising in intellectual disability nursing (Marshall et al 2003).

3.6.1.4 Scotland

Allan (1999) suggested that the health needs of people with intellectual disability in Scotland are "less well met" than the rest of the population, and explained that there has been a shift in disability care from a medical focus to a social focus, but that one should not lose sight of the health needs of people with intellectual disability (p. 35).

Allan's (1999) research examined the benefits of nurses providing a "pop-in" health clinic for clients with intellectual disability. Data were collected from two centres (A & B) with the use of an interview, recording age, gender type of consultation and the outcome. The data underpinned recommendations for change, the aim being a greater integration of people with intellectual disability into the primary health care system (Allan 1999). The researchers found that participants think about and value their health. They appreciated seeing health professionals other than doctors, and each had "at least one health need identified" (Allan 1999, p. 35). This useful research identified a need for a service such as a pop-in clinic to facilitate health gain and health maintenance although the number of participants is not included in the research report.

3.6.1.5 United States of America

In the USA, where the majority of people with disability live in the community, family support, accommodation and health care are ongoing issues. Tyler and Bourguet (1997) described the trend in the USA to deinstitutionalise adults with intellectual disability (p. 45). They studied 21 such people for one year following deinstitutionalisation with regard to their medical needs and concluded that these clients have special health needs and require careful monitoring, including diagnostic and therapeutic reassessment. Although these are all tests that could be conducted by nurses, the role of the nurse was not discussed.

Other literature from the USA suggests that nurses play an integral part in meeting the health needs of individuals with intellectual disability. Nehring (1991) described the evolution of nursing in the USA, as typical of the way the profession has evolved in most countries of the western world and gives an historic account of the evolution of intellectual disability nursing, then described the tertiary preparation available in the USA. She could find little documented about intellectual disability nurses but stated they should possess greater skills in assessment than general nurses because the patients were often unable to describe their symptoms (p. 260).

However, more recently Nehring (2004) reported that the American Nurses Association, in 1997, recognised intellectual disability nursing as a specialty. Nehring stated this would seem appropriate as intellectual disability is broad in context and content, incorporating holistic aspects of client care, not restricted to health (2004). Indeed, in recent years, efforts have begun in the USA to include education in this nursing specialisation in university nursing curricula (Nehring 2004). Hahn (2003), also from the USA, described a need for greater integration of curriculum about nursing care of people with intellectual disabilities in basic nursing education at all levels.

3.7 The Australian View

In Australia the role of health care, and in particular nursing care, of persons with intellectual disability is seldom addressed in the literature. This absence is particularly evident in that Australian long range plans for community style living fail to address the reality that institutions provide health care as well as accommodation.

The history of deinstitutionalisation varies between each state and territory. There is no centralised source of information on state/territory deinstitutionalisation policy and future plans to close institutions and/or reduce bed numbers, hence there is no accurate way of assessing patterns of change across Australia (Australian Housing and Urban Research Institute 2001).

It is evident, in keeping with world trends, that people with intellectual disability across Australia are slowly being integrated into the community. For example, the Victorian Department of Human Services stated that their 2001 Draft Disability Plan "...is consistent with a number of international statements and declarations on human rights, as well as social policy developments in a number of countries, including

Canada, England, Ireland, New Zealand, South Africa and Sweden" (Victorian Government Department of Health Services 2001, p. 9).

Since 1988, Victoria has closed most of its institutions and relocated many people to the community (Victorian Government Department of Human Services 2001, p. 3). The Victorian 2004-2005 budget aims to enable people with disabilities to live more independently in the community and reduce the need for residential care (Disability Services Division Victoria 2004). Furthermore, the government recognises the changing nature of disability, with technological advances and treatments enabling people with intellectual disability to participate in community life and prompting society to view disability differently. The State Disability Plan (2004) reaffirms the rights of people with disability to live and participate in the community and predicts total closure of institutions by 2012 (Disability Services Division Victoria 2004).

According to Western Australian authority Stella (1996), it was the growth of "human and civil rights movements", in the 1960s, across the Western world and in Australia that underpinned changes in the field of disability (p. 93). Hamilton, the Physician Superintendent of the Western Australian Mental Deficiency Division appointed in 1964, supported and was able to influence government's policy on normalisation (Stella 1996, p. 97). Subsequently, Western Australia closed all large scale institutions for people with intellectual disability between 1987 and 1998 (Australian Housing and Urban Research Institute 2001). Clients were chosen carefully for placement in community houses and given "considerable support"; consequently few adjustment problems were encountered (Stella 1996, p.103).

In Queensland, people with intellectual disability started leaving institutions and moving into the community in the early 1970s (Disability Services Queensland 2001). An Alternative Living Service (ALS) was established when people were relocated from institutions such as the Challinor Centre (Ipswich) and the Basil Stafford Centre (Brisbane). The ALS consists of small groups of people who live in the community with the support of Disability Services Queensland staff. The households typically comprise four or five people. Across Queensland, there were 550 people living in 140 shared or single houses in 2001 (Queensland Government 2001). The 2004 budget allocated more funds to support community moves and acceptance of people with disabilities in Queensland (Disability Services Queensland 2004).

Changes have also occurred leading to deinstitutionalisation in New South Wales (NSW). While most people in NSW live in the community, there are still "about a dozen" larger institutional type care facilities known as large residences. Plans are being implemented to move all residents to the community and this project has been underway for approximately two years. In 2004, funding was provided for the purchase of 15 group homes as part of the first stage of the devolution of large institutional residences. The current timetable for full devolution is by 2010 (Disability Services NSW 2004).

While staff changes have taken place in the community houses, nurses have been employed in the large residences in NSW. Specialist Developmental Disability Nurses, as they are known, work with other professions to assist people with intellectual disabilities and their families to live as normal a life as possible, in the community. The RNs support clients by assessing their needs and wishes, helping them to access appropriate resources, advocating on their behalf when necessary, and assisting with everyday tasks that clients are unable to perform themselves (NSW Chief Nursing Officer 2003).

Tasmania closed all its large-scale institutions for people with intellectual disability in November 2000 and The Australian Capital Territory and Northern Territory do not have large-scale institutions (Australian Housing and Urban Research Institute 2001).

The ideology of governments impacts on disability service provision and "can determine changing policy priorities" (Australian Housing and Urban Research Institute 2001, p. 9). For example, government inquiries concerning abuse in institutions which contributed to the process of deinstitutionalisation and institutional reform have been conducted in several states, but not South Australia. Social pressure from interested groups, such as family members, is also a factor and those opposed to deinstitutionalisation include workers whose jobs could be affected (Australian Housing and Urban Research Institute 2001).

The policy makers appear to assume that people with intellectual disability will have their health needs met by public and private means as other members of the community do. The role of the RN is not explicitly considered in the planning for services for people with intellectual disability in Australia, which is arguably a major oversight—considering the health needs of a large population and the importance of the role in other countries.

3.8 Summary

This chapter extended the literature review of the previous chapter to a focus on community living. There is much literature on the subject of intellectual disability, but very little research has been done into the role of nurses who care for people with intellectual disability. The Centre has adopted a developmental model of service provision and, in doing so, rejected the medical model. The consequent neglect of the incidence of illness in people with intellectual disability has been highlighted as justification for the research reported here.

The principle of deinstitutionalisation has impacted on the care of people with intellectual disability throughout the world. Social and political trends have influenced the care of people with intellectual disability; today many live in supported homes in the community and it is considered they are more "empowered" than at any previous time in history. It is clear from the literature that the philosophical underpinnings of intellectual disability service are acceptance and inclusion in the general community. Deinstitutionalisation is discussed in the Australian literature but efforts seem to have concentrated on the accommodation needs of people with intellectual disability. Documented evidence suggests that other countries have been leaders in deinstitutionalisation and that Australia is slowly following their lead.

Plans to integrate people with intellectual disability into the community are to be found across Australia. But the limited mention of health care is particularly evident in the Australian long range community living plans, notwithstanding that the literature reveals a number of factors that have impacted on the care of people with intellectual disability over the past 30 years—principally the move away from institutionalised care and the increase in community care, family provided care, and care provided by unlicensed personnel. Impact has been considerable on the mode of health care delivery to people with intellectual disability and provided in large part the impetus and justification for the research reported here: an examination of the role of RNs in disability service.

Ethnography, the methodology used for the research, is described in the next chapter.

CHAPTER 4

ETHNOGRAPHY: METHODOLOGY AND METHOD

4.1 Introduction

In previous chapters an historical overview of intellectual disability has been given, including explanations of some common causative factors. From worldwide and Australian perspectives the far reaching effects of the ideas of "normalisation" have been explored. Current trends in the care of people with intellectual disability, and healthcare in particular, have also been presented. Moreover I have argued that health is an issue that needs further research for people with intellectual disability and that there is a need to examine the role of RNs in caring for people with intellectual disability. .

The purpose of this chapter is to describe the methodology used in this research. A range of research methodologies are briefly described to build a case for the use of ethnography as the most appropriate qualitative methodology to answer the questions posed.

This thesis began with a *reflexive* account of my nursing career and an explanation of the notion of *reflexivity* is included in this chapter. Reflexivity as an important consideration in work of this kind pertains to the personal significance the research might have for the researcher. Examples of similar research using ethnography are provided through analysis of extant literature.

4.2 Why Qualitative Research?

The most common research model used in health and therefore the one with which most people are familiar is quantitative or positivist research. "Research in this (reality - based) paradigm is normally quantified numerically" (Bailey 1997, p.18). Qualitative research however is based on "different ontological and epistemological beliefs" (Bailey 1997 p. 18). Ontology, the study of being, informs the theoretical disposition and is the "what is", of reality and with it the nature of existence (Crotty 1998, p. 10). Crotty describes epistemology as a certain way of understanding what it means to know, and states that ontological and epistemological issues tend to "emerge together" from the data (1998).

A qualitative methodology was chosen for this study rather than a traditional positivist method. Ethnography was considered the most appropriate methodology for examining the role of the RN in disability service because it allows for an understanding of human behaviour within a specific context (Baillie 1995). A quantitative research methodology was not considered suitable to answer the research questions, which did not imply any manipulation or control of participants.

The aim of the current research was to produce a detailed, descriptive account of a way of being, rather than an objectified account of measurable parameters that could be generalised. Generalisation is not seen as the issue in qualitative research; what is more important is to gain rich data to describe the situation and provide answers directly from experience (Koch 1998).

4.2.1 Qualitative Research

The word *qualitative* implies an emphasis on the qualities of entities and on processes and meanings that are not experimentally examined or measured (if measured at all) in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry as in the current study (Denzin & Lincoln 2005, p. 10).

The qualitative model of research has evolved as an alternative to the quantitative model as a way of describing and analysing human behaviour (Crotty 1998). The goal of qualitative research is to provide a way of understanding lived reality from the point of view of those who live it (Bailey 1997). Indeed qualitative social research investigates human phenomena that do not lend themselves to quantitative methods (Carspecken 1996) and can be considered "a field of inquiry in its own right" (Denzin & Lincoln 2005, p. 2).

Qualitative research poses the question of how to turn an "informed hunch or nagging concern" into something that can "drive a legitimate and purposeful inquiry" (Schram 2003, p. 17). Studies can be conducted to fill gaps in understanding or to provide interpretation of situations and do not necessarily imply that something is wrong (Schram 2003, p.19).

Qualitative research methods are considered to be essentially interpretive or critical. Interpretive research methods aim to make meaning of human experience. Of the various qualitative approaches, interpretive examples are grounded theory, phenomenology, historical research and ethnography (Denzin & Lincoln 2005). Ethnography was chosen for this study as it has the potential to provide impetus for positive change. Ethnography allowed the researcher to gain entry and collect data as a participant observer. As the researcher, I was particularly interested in the culture of the social unit under research and the purpose of ethnography is to examine culture (Atkinson, Coffey, Delamont, Lofland & Lofland 2001).

4.2.2 The History of Ethnography

Ethnography is one of the oldest qualitative research methods and the history of ethnography dates back to the beginning of last century. Ethnography was first used in anthropology to study cultures that share a common core of beliefs (Denzin & Lincoln 1994).

Ethnography is said to have arisen in the 15th and 16th century as a result of problems encountered with Columbus', and later explorers' voyages to the western hemisphere, the so called New World and South Sea island cultures (Denzin & Lincoln 1994, p. 25). Before the professionalisation of ethnography, descriptions of races and cultures were provided by Western missionaries, explorers, buccaneers and colonial administrators. Some 17th, 18th and 19th century explorers and missionaries have provided "thick descriptions" of other cultures' practices (Denzin & Lincoln 1994, p. 26).

The concept of the "intensive" fieldwork used by ethnographic researchers emerged out of the framework of cultural anthropology and is believed to have originated with British anthropologist Bronislaw Malinowski (Roper & Shapira 2000, p.2). However his systematic methodology was believed to have been influenced by W.H.R. Rivers, a physician-anthropologist-psychologist who undertook fieldwork in the Torres Straits, in the late 1800s (Roper & Shapira 2000, p.2).

During the traditional period, from the early 1900s to World War two, early qualitative researchers wrote "objective" accounts of field experiences. The "other" who was studied was considered alien, foreign, and strange (Denzin 1997, p. 17). According to Denzin (1997) the modernist phase built on canonical works from the "traditional period" which extended through the post war years to the 1970s and can still be found. Many texts attempted to formalise qualitative methods and, for example, rigorous qualitative studies attempted to explain important social processes such as deviance and social control in the classroom and society (Denzin 1997, p.17).

At the beginning of what Denzin (1997) calls the "Blurred Genres" stage, the evolution of qualitative research (1970 - 1986), qualitative researchers had a full complement of "paradigms, methods, and strategies" to employ in their research (p. 17). Denzin (1997) describes a number of theories ranging from symbolic interactionism to constructivism, naturalistic inquiry, positivism and postpositivism, phenomenology, ethnomethodology, critical (Marxist), semiotics, hermeneutics, psychoanalysis, structuralism, feminism, and "various ethnic paradigms" (Denzin 1997, p. 17). At that time, Geertz (1973) suggested all anthropological writings were interpretations of interpretations. The observer had no privileged voice in what was written and making sense of local situations was the central task of theory (Denzin 1997, p.17).

In the mid 1980s, Denzin (1997) suggests, a rupture occurred which has been termed a "crisis of representation" and the production of works that made research and writing more reflexive. In fact anthropological writer Geertz (1973) had already called for a more transparent research process particularly in American anthropological circles. Such issues as the researcher's gender, class, and race were called into question. It was felt that the world of real lived experience could not be captured in the writer's "memoirs, fictitional experimentations, or dramatic readings" (Denzin 1997, p.18).

Grounded in anthropology, ethnography has "held sway" in educational circles for years (Schram 2003, p. 3) and has been used successfully by others for health orientated studies. Researchers in the health disciplines have found that a new or different understanding can influence client care (Koch 1998, p. 1184). Ethnography is being increasingly adopted by social scientists in education, health care and human geography (Atkinson et al 2001).

4.3 Ethnography

Ethnography is the indepth study of the members of a culture. Rice and Ezzy (1999) define it as the art and science of describing a group or culture. The researcher, using participant observation, attempts to "tell the story" of people's daily lives, and describe the culture (Burns & Grove 1987, p. 40).

> Culture is not to be called into question; it is not to be criticised, least of all by someone from another culture. Instead, one is to observe it as closely as possible, attempt to take the place of those within the culture, and search out the insider's perspective: Herein lies the origin of ethnography, born to anthropology but adopted (and adapted) by sociology (Crotty 1998, p. 76)

Germain (1986) describes the aim of ethnography as to examine the implicit (implied) as well as the explicit (clearly expressed) aspects of culture. An example from this research within the culture of the setting (at the time of writing) might be the explicit request by an unregulated care worker for the presence of an RN "immediately". Yet further probing reveals the request has an underlying implicit "it is alright, I just need to 'cover my back'". This example can be interpreted as delegation of accountability, as the unregulated worker passes the problem to the RN.

Nurse theorist Leininger (1985) categorises ethnographies as "maxi" or "mini" depending on whether they are comprehensive large scale studies or smaller-scale with a narrow focus of enquiry. Behaviours, such as those observed in this study are studied from "an insider's point of view" using an "emic" approach (Hoey n d). This is in contrast to the "etic" approach used across cultures from an "outsider's perspective" (Roper & Shapira 2000, p. 4). Qualitative researcher, Morse (1992) describes an emic perspective as "eliciting meaning, experience or perception" from the participant's point of view, rather than the researcher's point of view (p. 1).

Ethnographic enquiry seeks to uncover meanings and perceptions on the part of the people participating in the research, viewing these understandings against the people's "overall world view or 'culture' " (Crotty 1998, p. 7). The essence of ethnography is the discovery of the "way of life and the meaning of events and relationships to the people", from their point of view (Germain 1986, p. 156). The researcher attempts to see things as the participants do. Hammersley and Atkinson (1995) describe ethnography as resembling the way people make sense of "the world of every day life" (p. 2). Ethnography recognises everyday life as an ongoing achievement worthy of study.

Qualitative research conducted in this manner has a holistic perspective according to

Morse (1992), "considering underlying values and the context as part of the phenomena" (p. 1). A characteristic described by Morse (1992) is the "inductive process of inquiry" between researcher and data (p. 1). The researcher drives the analysis as he or she gains comprehension and insight about the culture by seeking further explanation. Alternatively, the deductive method has a predetermined conceptual framework and hypotheses may be tested, but results are not known until data collection is complete and all data have been analysed (Morse 1992, p. 2).

Madeleine Leininger, a noted American nurse anthropologist defines ethnography as:

> ..a systematic process of observing, detailing, describing, documenting and analysing the life ways or particular patterns of a culture (or subculture) in order to grasp the lifeways or patterns of the people in their familiar environment (1985, p. 35).

Ethnography refers to social research that emphasises exploration of phenomena, rather than the testing of hypotheses (Atkinson et al 2001). The method of data collection, analysis and interpretation share "...certain components with other qualitative designs" (Germain 1986, p. 81) and these are discussed later in this chapter.

4.3.1 Examples of Ethnographic Research

Today the focus for many ethnographers has shifted from remote communities to those closer to home. Most ethnographers would agree that ethnography may be used for any small scale research carried out in everyday settings and focusing on individual's interactions (Savage 2000, p. 1400). This section will deal with examples of the ways in which ethnography has been used in everyday settings.

Examples of ethnographies resulting from doctoral dissertations are Germain's *The Cancer Unit*: *An Ethnography* (1982) and Kayser - Jones' *Old, Alone and Neglected* (1990), a comparative study of a nursing home in Scotland and one in the United States. Walker (1993) used an ethnographical approach to make an overtly political interpretation of "everyday moments" for five nurses (p. iv). The focus of Walker's study was the network of discourses that make up nursing. Kanitsaki (1989) studied the importance of family to Greek people in Australia. Kanitsaki's work has provided insight for nurses who care for Greek people, for others, it heightens the awareness of the need for cultural sensitivity (p. 112).

Recent examples of nursing research using an ethnographic approach are the studies of Harrington (2003), Yamaguchi (2004) and Goopy (2005). Harrington's (2003) PhD research resulted in a new model identifying the important role of the palliative care nurse in spiritual care giving. Yamaguchi's (2004) research, examining the nursing culture of an operating "theater" in Italy, found that nurses were directed in nearly all activities by physicians (p. 261). Findings suggest improved patient care outcomes and that there may be gradual recognition of the contribution of nurses by medicine, management and the public (Yamaguchi 2004). Goopy (2005) builds a picture of the "working world" of a group of intensive care unit nurses in Rome (Italy) and emphasises the value of acknowledging local culture (p. 144). In light of this, the universality of the current paradigm of professionalism and professional identity is brought into question (Goopy 2005).

Using a critical ethnographical method, Shui-Kang (1998) examined three rituals in nursing, "tidying", "handover" and "teabreak". Carspecken's (1991) framework for data collection and Foucault's (1975) theoretical framework of power / knowledge were used to inform the analysis in Shui-Kang's study. Critical ethnography was also the methodology chosen by Manias and Street (2001) to examine the relationship of doctors and nurses in a health unit in Melbourne, Australia and an ethnographic approach was also used by Maggs and Rapport (2000) to investigate district nursing work in England. The latter authors claim that ethnography studies the ordinary, routine daily lives of people and data are collected through "... an intensive period of observation, discussion or ideally a mixture of the two" (Maggs & Rapport 2000, p. 221). The findings could be used to predict changes in nursing roles and to make recommendations to ensure quality patient care. McIntosh et al (2000) report on a similar study conducted in Scotland where ethnography was used to examine the skills mix in a district nursing team.

In the field of intellectual disability, an ethnographic study was conducted in England (Allan 1999). The project had a dual purpose, to explore whether people with intellectual disability attending a training centre would benefit from a pop-in health clinic, and to encourage them to think about their health and access appropriate services. The interview survey found that people with intellectual disability would like time to discuss their health concerns with health practitioners other than doctors.

It is important to note that qualitative researchers do not always achieve closure by answering research questions, but can raise other questions that generate awareness and understanding of problems (Schram 2003). In some instances this can lead to further research, as in the case of Harrington (2003), who used an ethnographical approach in her Masters and later Doctoral research which culminated in the development of a Model of Spiritual Caring for the use of nurses in hospices.

4.3.2 Focused Ethnography

Unlike traditional (or classical) ethnography which describes an entire system of a culture (Roper & Shapira 2000), in the current study the researcher used a focused ethnographic approach examining the organisational culture broadly, while focusing on the nursing service. Observations of the nursing service within the culture of the organisation and the effects of each on the other were made. Focused ethnography emphasises a smaller group or specific culture such as a nursing culture and is appropriate when the researcher already possesses insider cultural knowledge (Buncuan 1997).

Most nursing ethnographies today tend to focus on "distinct problems within a specific context" studying small groups (Roper & Shapira 2000, p. 7). The questions are formulated prior to entering the field and the knowledge gained is expected to be useful and have practical application in the health setting. Pioneer nurse anthropologists used focused ethnographic methods to study the way health practices and beliefs were integrated into the lives of people of various cultures (Roper & Shapira 2000).

Roper and Shapira (2000) cite examples of focused ethnography which include Brink (1982) and Morse (1984). Pamela Brink used a focused ethnographic approach in her study of the practices of traditional birth attendants among the Annang of Nigeria, comparing them with the practices of hospital-based obstetrical teams in America and Nigeria. Brink discovered most of the strategies were effective, but made recommendations about the use of clean techniques (p. 7). Similarly Morse described and compared infant feeding practices in the Fijian and Fijian-Indian cultures. The study revealed lack of knowledge, on the part of hospital staff, regarding the infant feeding practices of these cultures (Roper & Shapira 2000, p. 8).

A classic example of focused ethnography is Street's (1992) examination of nursing culture. Street adopted a critical approach and the study resulted in positive changes to nursing practice. Street, who is not a nurse claims that "...nurses need to put their role as nurse, their nursing actions, and the clinical perspective in which they practice under close scrutiny as a basis for critical analysis and reflection" (p.15). Buncuan (1997) also adopted a focused ethnographical approach to examine mother's knowledge, attitudes and practices of child feeding in Kampung Sampun Kelil in Sarawak, Malaysia.

My position as both an insider, an RN employed by the Organisation, and an outsider, a newcomer to the setting, enabled exploration and analysis of an issue not previously attempted for that particular culture.

4.3.3 The Scope of Ethnography

Ethnography can be used to examine the culture of any group of people and does not require an ethnic flavour. It can answer questions, for example about the way the people and cultural practices in a ward or unit relate to nursing and health. Indeed the scope of ethnography can be as broad, as in a complex society, or can be limited to a "subunit of a single institution, such as a nursing unit" (Omery 1988, p. 17). The current study was an exploration of one organisation and the nursing service based at its residential facility, known as The Centre. The culture was examined as to how it impacted on nursing care that is prescribed to clients associated with The Centre and vice versa.

Moreover, the study examined the social milieu/ culture where the RNs within the organisation practice and provides a descriptive account. Healthcare nurses, as the RNs at The Centre are known (at the time of writing), provide services that cover a large geographic area, which extends into the community, and their role often sees them visiting general hospitals. Ethnography was considered a suitable choice of research methodology because it has been shown to be useful wherever nursing and health care take place (Germain 1986).

4.4 Ethnography and Nursing

Several questions are posed by Omery (1988, p. 17) that illustrate the potential of ethnographic research for nursing situations. For example, an examination of expectations of the nurse-physician relationship for a nurse who has only worked in intensive care. Omery asks if the expectation would be different if the nurse had worked exclusively in a psychiatric setting. The term "culture shock" springs to mind, as it did many times during the early days of the current research as I often struggled in an unfamiliar area of nursing. Omery (1988) urges nurses wishing to understand "some actual or potential human response to illness, that is, some health belief or practice" from a social or cultural viewpoint to undertake ethnographic research. (p. 17).

Although ethnography is a relatively recent tool being used by nurses in their research, nurses are very familiar with reflective practice which is a vital component of ethnography (Koch 1998). Feally (1997) states that reflective practice is widely espoused as an essential feature of professional nursing and is used as a problem solving tool on a daily basis in nursing education (p. 1062). According to Koch (1998) who describes reflective practice, "stories can make nursing practice visible" (p. 1182). Koch states that care activities of nursing are taken for granted and can be undervalued by the nursing profession. Stories can show us where we went wrong, give us ideas for improvement, "facilitate change, [and] can also give minority groups a voice" (Koch 1998, p. 1182).

Furthermore, Roper and Shapira (2000) draw a parallel between ethnography and the nursing process. The nursing process "begins and ends with observation". Nurses are both observers and participants in the health care environment (p. 26). Nurses also practice an intentional use of self, or reflexivity. Nurses are "naturals" at ethnography, asking questions, considering all sources of information (Roper & Shapira 2000, p.27) and, with suitable training, are in a good position to conduct ethnographic studies.

4.4.1 Reflexivity

Reflexivity is described as intentional use of "self" and is a skill that nurses use in their practice (Roper & Shapira 2000, p. 26). Reflexivity in this context involves deliberate awareness of oneself, one's responses, and one's internal state in relation to a specific situation, at the same time attempting to understand the patient's situation. Reflexivity allows nurses to be aware of their role in ethnographic research, "to identify biases and their potential influence on the data and the interpretation of the data" (Roper & Shapira 2000, p. 26).

Therefore reflexivity also describes the struggle between being the researcher and becoming a member of the culture (Streubert & Carpenter 1999). Furthermore, unlike other approaches, the ethnographer experiments with the participants, rather than on them and consequently the ethnographer should be aware that "just being present in the culture on some level affects its character" (Streubert & Carpenter 1999 p. 150).

Ethnographic research includes the researcher in all stages of data collection and Atkinson and Hammersley (1994) believe that the impact of ethnographic research could be greater if practitioners were themselves involved in the research process because they could make it more practically relevant. They could also be more inclined to draw on the research due to their involvement (p. 253). After all the reflexive aspect assumes the researcher is "a part of the world being studied" and that the experiences and relationships encountered have significant meaning (Roper & Shapira 2000, p. 4).

Indeed there are different schools of thought on how well the researcher should know the field and the extent to which the researcher should be a participant, but Street (1992) states this differs from researcher to researcher, and from discipline to discipline. All fieldwork skills are built on basic participation skills and for the current study, I adopted the role of RN within the setting.

Because reflexivity pertains to the personal meaning and significance the research questions have for the researcher, as the researcher in the current study I kept a diary. Diary entries were a daily activity and served to "locate self in the research process" (Koch 1998, p. 185). Unlike the objective field notes, diary entries were reflective and personal. Keeping a daily diary (or journal) can "help clinicians address some troublesome practice-based issues" (Koch 1998, p. 184).

4.5 The Research Process

The processes of qualitative research are multiple; they are linked and interactive to each other and to the human being who is the research instrument (Meloy 2002, p. 145)

The previous sections in this chapter described ethnography and explained why the research methodology was chosen for this study**.** This section describes the method used to explore the role of the RN in disability service.

4.5.1 The Literature

The first stage of the research process was a thorough literature review conducted over an eighteen month period prior to commencement of data collection (see chapter 2). This provided me with a deeper understanding of people with intellectual disability. The literature review also helped identify gaps in the existing body of knowledge. Examining other authors' work in addition assisted with the choice of methodology and study design. Clare and Hamilton (2003) describe the literature review as a way of gleaning information that assists in the study design, choice of approach, and definition of concepts.

4.5.2 Participant Observation

Ethnography and participant observation are uniquely humanistic interpretive approaches compared to "scientific" and positivist positions (Denzin and Lincoln 1994, p. 249). Observation plays a fundamental part in all qualitative research and ethnography is no exception. Inquiry into the social world calls for "attentiveness to particulars" (Schram 2003, p. 9).

When conducting an ethnography, description is "the most basic form of interpretation" (Shank 2002, p. 74). Likewise Schram (2003) states that the qualitative researcher aims to describe what is happening. Interpretation gives meaning to, uncover and generate questions or hypotheses for further research. Explanatory or theoretical aims "identify and analyse patterns and identify plausible relationships" (Schram 2003, p. 25).

Notwithstanding the value of observation, the ethnographer cannot rely on observation alone. The ethnographer needs to become "immersed" in the culture (Roper & Shapira 2000, p. 15). That is, "looking at" does not constitute understanding and the ethnographer who wishes to understand another needs to build up an understanding based on a deep involvement in the subject's world of experience (Denzin 1997, p. 35).

Ethnography relies substantially on participant observation according to Atkinson and Hammersley (1994) and ethnographers must commit themselves to being as close as possible to the people (Rice & Ezzy 1999). Closeness to the people of interest in order to facilitate that deep involvement can be achieved through participant observation because it involves total immersion in the culture (Rice & Ezzy 1999).

The guiding assumption of participant observation is that only through direct personal experiences in real-world settings can we gain understanding of the social world. This involves "being there and getting close to people" (Schram 2003, p. 7). There is no predetermined course established or manipulated by the researcher. "Qualitative methods work through you" (Schram 2003, p. 7).

As participant observer, I was the data collection tool and participated overtly (this can be done covertly) in the daily lives of the culture for an extended period of time, in this case, for one year (Hammersley & Atkinson 1995). Various methods were used to collect data, including watching what happened, listening to what was said, asking questions - in fact, collecting whatever data were available "to throw light on the issues that are the focus of the research" (Hammersley & Atkinson 1995, p.1).

There are four levels of participant observation: participant, participant-as-observer, observer-as-participant and observer. Most researchers "move back and forth among these levels" but most information is collected when the researcher is in the role of participant-as-observer, as in this study, or observer-as-participant (Roper & Shapira 2000).

The period of participant observation is known as fieldwork and can last for six months to two years or longer, but is usually over a year as the amount of time spent in the field can make a difference to the findings (Rice & Ezzy 1999). A longer period of fieldwork will gain the researcher insights that may not be obvious in a shorter time. Moreover Maggs and Rapport (2000) state that prolonged engagement in the field offers the researcher the opportunity of building up trust with participants (p. 2). In the current study the gathering of data or field work was conducted, mostly during my off duty time, over a twelve month period. In addition to conducting interviews, a professional journal was kept and field notes made of observations. These were made unobtrusively during the course of my work or during visits for research purposes with the approval of my employer. The ethnographer is however never "off duty" (de Laine 2000, p.146).

Fieldnote entries were made at the earliest opportunity to ensure an accurate recall of events. Data were entered onto my computer to be coded and sorted later. Data, in the form of audio tapes and computer discs will be held for a period of five years in a locked office at Flinders University.

4.5.3 The Field of Study

This section provides a picture of the research setting known as The Centre (at the time of writing) which sits under the umbrella of a larger disability services organisation, Intellectual Disability Services Council (IDSC). A succinct description of the organisational structure of The Centre is given in order to explain the position of the RN within The Centre's hierarchical structure. Table 4-1 depicts the positions and numbers of employees at The Centre (at the time of writing) related to the categories of staff discussed in the current research.

The structure of leadership within IDSC begins (at the time of writing) with the chief executive officer. It is important to note that IDSC is divided into two main areas, the Community Services Division and the Accommodation Services Division. Included in the Community Services Division are such services as Early Childhood Service and Community and Family Support Services. The Centre is a part of the Accommodation Services Division, which also includes Community Accommodation Services. (DHS 2001, p.14)

The leader of the Accommodation Services Division (at the time of writing) is the Director who is assisted by Area Managers who are in charge of the divisions within the organisation. Each Villa has a manager and two shift supervisors. Some of the managers and shift supervisors have a background in nursing due to having been former Mental Deficiency Nurses but most of them have limited medical background as their role is to care for the clients' accommodation needs. In the absence of a responsible family member, the Villa Manager acts as guardian to the affairs of most clients, including health. The Shift Supervisors represent the Villa Managers in their absence, particularly on weekends and at night when there are two "floating" Shift Supervisors in charge of the whole centre. This is in addition to the Shift Supervisor appointed to each Villa. The Villa Managers are also on call for emergencies.

The care workers, who form the largest number of The Centre's employees, are unregulated workers, some who have been there for many years and some have TAFE qualifications in Aged care or Disability and Community work. The care workers are a mixture of age groups, and people from different social circumstances. Throughout The Centre in the units, care workers work in pairs, while in the community houses they often work alone.

Table 4-1. Positions and numbers of employees related to the categories of staff at The Centre that are discussed in the current research.

Position	Number employed
Director of the Centre (responsible to the Chief Executive Officer and responsible for all Community Accommodation Services as well as The Centre)	1
Area Managers	2
Villa Managers	8
Manager Health Services	1
Nurse Manager (RN Level 3)	1
Clinical Nurse (RN Level 2)	1
Nurse Specialist (RN Level 1)	1
RNs (RN Level 1)	5
Enrolled Nurses	5
Shift Supervisors	20
Care Workers (including casual staff)	450

The Centre sits within the Northern suburbs of Adelaide. Around The Centre where the research is based there are numerous "community houses" for people with intellectual disability. The Centre itself comprises separate houses called Villas and during the research period, 4 Villas have been demolished and the clients relocated to community houses.

There are 8 existing Villas at The Centre (at the time of writing) which cater for a clientele of around 300 people with a range of intellectual disability diagnoses including Down syndrome, autism and cerebral palsy. Clients’ ages range from 18 years to 65 years. The clients' needs, which vary depending on their level of intellectual disability, are taken into account when they are grouped so that people who have similar support requirements are located in the same Villa. For example, some Villas specialise in catering for the needs of clients who have behavioural problems. In addition to the Villas there are also 5 self contained flats (originally onsite accommodation for nursing staff) where "higher functioning" clients live largely independently with minimal support from staff.

Each Villa has four units, with the exception of one Villa that houses the Infirmary and three units. The Villa units are situated at the corners of the Villas and joined by utility rooms, offices, a laundry and a kitchen. Each Villa has a central courtyard, where many of the clients spend their day. Some of the courtyards have lawn and plants growing, while others are bare and the dirt surfaces tell the story of clients who pull up gardens and eat the grass.

The units have five or six bedrooms each and provide sleeping areas for about seven clients. Each unit has a kitchen, lounge area, an office that acts as a dispensary for medications and houses the communication books and health care plans. Each unit has a large bathroom that is fitted appropriately for people with a disability. There is ample room for a "Pacific" bath which is a mobile bath the client lies on. Consideration has also been given to the use of shower chairs and bath chairs in the bathroom.

The units are furnished according to the clients who live in them. Some are very sparse with furniture bolted to the floor, to prevent it being thrown or pushed over. In such units, television sets are out of reach, bolted to the shelves that hold them and have protective covers to prevent breakage, should clients throw objects at them. Window dressings are sparse in units where clients tend to pull down the lace curtains that adorn many of the other windows around The Centre.

Articles for washing, including clients' personal laundry, are sent to a central laundry within the grounds that also provides a mending service. The Centre also has its own pharmacy and a canteen. There is a dining room and the kitchen provides nutritious meals for all clients and staff, at a reasonable cost.

The Centre was completed in 1971 and, although it was then considered a "modern" facility, it is well known that inadequate attention was paid to providing foundations that were appropriate to the soil type (Bay of Biscay) in that area and this has led to premature cracking of the buildings (Personal communication: B. Matthews 16.1.02). The buildings also show clear signs of accommodating people with challenging behaviours and poor understanding of the need to care for living areas.

The Villas are joined by a road and internally there are paths and "covered ways" joining them. They are all within walking distance of each other and situated on a large piece of land adjoining a housing estate near to the site of the former psychiatric hospital referred to in earlier chapters. The complex has an oval in the centre, a swimming pool, administration block, health services building, physiotherapy and psychology buildings, and day therapy buildings, along with a staff development centre, and a well stocked library containing up to date publications on intellectual disability.

Most clients attend activities during the day and some are employed in Business Services (sheltered workshops) outside of The Centre. The complex has a garden where some clients work and the work crew provides employment for others. The work crew is a group of residents, community clients and volunteers, led by a staff member, who do gardening within the grounds and in the wider community.

Clients who live in the community also have programmed activities and some go to work. Some community clients will visit the Infirmary for blood tests or dressings and others are visited by the RN in their home. Community clients share group homes with 3-4 other people with intellectual disability. Depending on their needs they have care worker(s) assisting them, often 24 hours a day.

On Fridays (at the time of writing), the RN goes to two community houses where clients who have diabetes live and refills their insulin syringes for the week. Some community clients visit the doctors at The Centre's health service while others see general practitioners out in the community. Medication is dispensed for all Centre clients by The Centre's pharmacy and some community clients. There are currently three psychologists on staff and a physiotherapist supported by a number of physiotherapy aides.

4.5.3.1 The Health Centre

The Health Centre is separate from the Infirmary and (at the time of writing) is the hub of the health service. The Manager, Nurse Manager, Occupational Health and Community Nurses are based there. The Health Centre has a fully equipped dental suite with capacity for general anaesthetics. Dentists and a dental nurse visit once a week, as does a podiatrist and opthalmologist. A speech pathologist and dietitian are employed part time. The RN who works in the Health Centre assists the visiting allied health professionals.

Notwithstanding the need for education and research in the field of intellectual disability, the presence of such an array of health care support would suggest that the organisation has experienced difficulties with clients with severe disabilities accessing external private or public services of this kind. Types of difficulties I became aware of during the current study include clients who do not like going to a mainstream dental surgery, for example, and can become very agitated in the waiting room. There are also other staff, experienced with people with intellectual disability, available to assist with supporting clients at The Centre's health service. Behaviour problems, from resistance to aggression, can become an issue when caring for people with intellectual disability, however experienced staff can often avert "situations" by offering support and reassurance.

The door of the Health Centre is fitted with a combination lock to deter entry by clients as some tended to enter this area and cause noisy disruptions. All other doors at The Centre are locked with a key and most staff are provided with a key for the duration of their shift. Experienced staff have learnt to enter Villas by the tea room door, to reduce the risk of a client charging past and "escaping" from the Villa while they are entering.

4.5.3.2 The Infirmary

Currently (at the time of writing), the Infirmary consists of a large day room surrounded by four bedrooms and an office that is too small for the number of health professionals who need to sit and write reports. One bedroom in the Infirmary unit serves as a treatment room with a barouche and a stock of dressings. Other equipment is not in good supply and there is often a shortage of thermometers and sphygmomanometers. Unfortunately, the treatment room has no facility for hand washing which is an inconvenient oversight, considering the room is often used by doctors for suturing and by nursing staff for dressings.

4.5.3.3 The Medical Practice

In 2005, IDSC opened a medical practice to cater for the medical needs of community clients. The Clinic is located at a nearby public hospital and provides a range of consultant services. In addition it is anticipated there will be an education focus offering placements for nursing, allied health and medical students and "training posts for registrars in general practice and psychiatry" (IDSC 2005, p. 7). The clinic will also have a Research Arm "to significantly expand the current level of research in South Australia" as part of a collaborative program with the State's universities (IDSC 2005, p. 8).

4.5.3.4 The Volunteer Service

The description of the services offered by The Centre would not be complete without mention of the Volunteer Service. The Centre is assisted by a large group of people who offer their services as volunteers. This service is valued by clients who, in many instances, have limited contact with their families. By contributing their time and skills, the volunteers assist in combating the social isolation otherwise experienced by clients (DHS 2001, p. 31). Volunteers are often seen after hours, accompanying clients to theatre productions and concerts. Indeed, much of the success of the client's social activities can be attributed to the volunteer service.

4.5.4 The Culture

Beliefs about what constitutes culture are changing and Savage (2000) suggests that culture is no longer viewed as a matter of shared beliefs and practices. Recognition is given to the differences existing between social groups and some, according to Savage (2000), say culture demonstrates a process of struggle like a power play. This can be observed in the acknowledgement of individual's ideas and input without the focus on what the group has in common "... and in identifying who had the power to impose their particular practices on staff" (Savage 2000, p. 1401).

The current research explores the role of RNs who care for people with intellectual disability. Specifically, the RNs within The Centre's nursing service were the culture of interest, but their role was examined within the context of being part of the larger culture of the organisation (IDSC). The nursing service is an integral part of the health service that The Centre relies on, but the practice of the RN extends beyond the confines of the health service and indeed beyond The Centre itself. In fact (at the time of writing) RNs are based at The Centre and their practice extends to Northern community houses. Nurses also visit clients in general hospitals during periods of acute illness. In order to study the role of the RN in disability service, it was necessary to make observations of the entire culture within which nursing takes place. It was only by observing the culture that I could grasp the nature of the group, who they are, what they do, and how they do it.

4.6 Gaining Entrance

Gaining entrance to the field did not pose a problem, as the research was prompted by my employment in the area. Rice and Ezzy (1999) explain that ethnographic fieldwork does not usually commence on the researcher's initial entrance to the field, as permission needs to be sought from the "gatekeeper" (p. 159). Ethical approval was sought and duly received from IDSC's ethics committee, Flinders University ethics committee and the department of Disability Studies at Flinders University.

4.6.1 Cultural Immersion

Omery (1988) states that the researcher should be able to build "trusting relationships with the members of the culture under investigation" (p. 22). Cultural immersion is described as:

> ...gaining increased familiarity with such things as language, sociocultural norms, traditions and other social dimensions such as family, communication patterns (verbal and nonverbal), religion, work patterns and expression of emotion. Immersion also involves gradually increasing acceptance of the researcher into the culture (Burns and Grove 1987 p. 92).

Despite my being an employee of the Centre, cultural immersion was not an easy process as I had only been employed at the Centre for a short time prior to commencing the current study. It was noticeable that not having been a part of the culture's past set me apart from other staff. Memories appeared very important to this group of people. Staff would often share memories of past staff members and clients and many remember the clients as children and would often reminisce about "the way things used to be". While I was caught up in the camaraderie by just listening, there was no doubting my outsider status as I had no stories to contribute.

Indeed (at the time of writing) there are whole families of people working at The Centre, husbands and wives, brothers and sisters, and parents. A young female care worker remembered when her grandmother worked there. Even non-familial bonds are strong as many staff have never known any other job. Change seems to be very frightening to them and on entering the field, I was treated very much as a newcomer by the staff.

Notwithstanding my separateness from the culture being observed, within the nursing unit there was a certain bond, nursing being the common link. A rapport quickly developed with the nursing staff as I knew about nursing. It took much longer for trust to develop with the staff in other areas as the "culture" seemed very strange and the ways of doing things unfamiliar.

At the outset of the fieldwork the nursing service was in its formative stage and the RNs had unwittingly taken something away from the former Mental Deficiency Nurses and long time care workers, or so it seemed. The cessation of mental deficiency nursing meant a career change for many and they were not prepared to let go of their status without letting me know at every opportunity that things were different not so long ago. They spoke of what they had lost and it seemed as though RNs had to prove themselves worthy of the title.

However, the clients were almost immediately accepting of myself and within a short time many knew me by name. *"I still get a buzz when I am doing my rounds and a client calls out my name* (11.03). RNs who "know their stuff" are valued by the clients. There were also staff who were immediately warm, trusting and accepting and *"...most people are friendly, they soon realise that you know what you are doing and they trust and confide in you* (09.02).

Borbasi (1995) experienced the culture of The Centre first hand in the 1970s. In her treatise on nursing practice, Borbasi describes her early days of working at The Centre as a trainee mental deficiency nurse. She states:

> ...initially it was the camaraderie amongst the staff that cushioned the effects of this introduction to nursing, but later it was the residents themselves that sustained me. I became accustomed to their institutionalised ways of being and discovered many of them to be personable individuals (pp. 4-5)

I agree with these sentiments. The camaraderie amongst the staff was noticeable immediately and after the initial testing time, trust was established and I became privy to the humour and confidences they shared.

4.6.2 The Orientation

Orientation to The Centre was in two parts, firstly to the night shift and then the day shift, and these were conducted after having been given a comprehensive tour prior to interview. The night shift orientation commenced at 7pm on a Tuesday and lasted until around midnight. The orientation was conducted by an RN who works mostly night shift at The Centre, a middle aged man who has worked there most of his working life. His knowledge of The Centre and level of comfort with his role was impressive.

I had already seen the inside of the Infirmary, but was introduced to the clients. The nurse explained that numbers can vary from one client to seven and that night there were four clients, all male. They had various medical disorders and one was on a palliative care order. He lay quietly in his bed and the nurse stated that he was on two hourly positional changes to prevent pressure areas. Another sat in a wheelchair until it was time to go to bed and two of the clients were ambulant, one with standby assistance. They were all unable to communicate verbally, but one responded to the introduction with the most delightful smile.

I was then ushered into the office. The office is central to all activities in the Infirmary. It has a "fish bowl" effect, surrounded by windows, so nothing escapes the notice of the nurses who sit at the long desk to write their notes. At orientation, I was handed copious amounts of paper work to read. There was a nursing orientation folder and Standing Orders which were to become very familiar over the duration of the study. The long time RN was also able to answer a battery of questions.

After the clients had settled for the night, the other RN asked the care worker in an adjoining villa to keep an eye out for them while a tour of the community houses was conducted. To this day, I recall the other nurse's tip to locating a house; "they all have ramps and a government car in the driveway”.

The half day orientation to the day shift commenced at 7am on a Thursday and was conducted by a then Community RN who also had a role to play within The Centre. Accompanying the other nurse on her rounds that morning, I observed the easy rapport that she had with the clients and staff, who were very welcoming to myself as well.

The tasks required of the position seemed a bit overwhelming for one who needed to brush up on her general nursing skills. Much could be learnt from the other nurse who, although she had been employed at The Centre for less time, displayed similar knowledge and confidence as the night RN.

Of concern was the geographical layout of The Centre and I wondered if I would ever find my way around. There were also a large number of staff and it was to take more than two orientation sessions to work out who they all were. My first impressions of The Centre were of friendliness, comfort and "homeliness". Unlike any residential facility I had ever visited, The Centre had an air of being the client's home and this feeling extended to the community houses.

4.7 The Client

How to describe the typical client? This would be difficult as there is no text book client; they are all unique. Clients range from those who have severe physical and intellectual disabilities, totally dependent on care workers for feeding, continence management, in fact every basic need, to those who are known as "higher functioning". Some higher functioning clients are able to live independently with support systems in place. This latter group is largely accepting of nursing actions and will seek out health intervention when they are unwell; in fact some develop somatic complaints to gain the attention of the nursing staff.

However most of the clients belong in a group between the two, people who are able to ambulate freely, with varying levels of communication and self care skills. Most are able to feed and toilet themselves. These people require constant supervision because they have limited insight into safety issues and some display unusual behaviours such as head banging, biting and slapping themselves. At the same time aggression is hardly ever directed toward others and then usually as a defence mechanism when others enter their personal space. Clients like this prefer to be left alone and the most simple of nursing procedures, like taking a blood pressure, can be a lengthy ordeal for the client and the RN.

The clients also vary in that each has his or her own personality. Indeed these are seen in a smile, or a "temper tantrum", and in the manner in which they relate to their care workers and families. It is in recognising these distinctive qualities and idiosyncratic means of communication that the intellectual disability RN is assisted in delivering optimal care.

4.8 The Participants

In ethnography, the entire culture under observation is considered to be the sample. Furthermore it is common in ethnographic work to obtain blanket consent for the purpose of fieldwork and informal interviewing as was the case in this study. However, to inform the staff about the research, two participant information sessions were held at The Centre. All staff were invited by way of a notice posted in all departments. The notice, which also appeared in two copies of The Centre's weekly publication was an announcement in itself that prompted many questions and comments from staff curious to find out more detail.

The actual meetings were not well attended by Villa staff, although most of the nursing staff attended, some on their day off. The meetings had the effect that those who attended returned to their Villas and talked about the research. On the whole the meetings had a very positive outcome, with many questions asked and much support offered.

The meetings provided an opening to begin enlisting participants for interviews. I was also invited to briefly present the research proposal at a Health Services team meeting and received further support. While any person not wishing to be included in the study, could be excluded, no such requests were received. In the case of formal interviews, informed consent was obtained from participants who were given a written explanation of the research and asked to sign a consent form. They were assured of confidentiality and told that they could withdraw at any time without prejudice.

During the data collection phase of the research, as the researcher, I collected perspectives on the role of the intellectual disability RN from a range of other stakeholders however it was undeniably the nurses themselves who provided a description of their current role, the organisational structure and how they might view the future. The culture of the organisation was thought to impact on the nurse’s role and the culture was created by many players. Therefore the role of others in the setting was explored.

The views of all people, from the Director to the newly employed care worker are included in this ethnographic account of intellectual disability nursing. The culture that was examined included medical and allied health staff, Managers, Enrolled and Registered Nurses, clients’ care workers and family members and representatives from other agencies and general hospitals.

Research participants were invited to participate depending on my contact with them during field visits. Some participants, representing a cross-section of the culture, were invited to be interviewed. However, interviews were kept to a minimum due to my desire to capture a naturalistic view of the setting and its people (see Table 4-2 for information on participants who were interviewed). A pilot interview was conducted to assist in question design and interview technique.

Clients were not selected for interview because it was anticipated that, those who were verbal, would make relevant comments to myself during their treatment or on visits to their homes.

Interviews were open ended, asking the subject to talk about their experience "Tell me about....", giving the subjects the opportunity to describe their perceptions of what the nurses do, for example. "How do you see the role?" "What skills are required?" "Are the client's needs being met?" Positive and negative feedback was invited.

A total of fourteen formal interviews were conducted and the participants were given pseudonyms (See Table 4-2). The first, Dorothy is a care worker with 17 years experience at The Centre. Larry, an RN in The Centre's nursing service for 5 years completed Mental Handicap Nurse training in the UK, worked as a Shift Supervisor at The Centre for many years, and gained general nursing experience through working for an agency. The third participant, Angela, an RN at the Centre for 2 years spent the previous years, from 1988 working as a care worker at The Centre. The fourth participant, Colleen, similarly started as a care worker 16 years ago and is now an EN.

The fifth participant, Verna, is the parent of a Centre client and has a long association with the Centre and the next, Sarah, has 20 years experience as a care worker and is now a Shift Supervisor. Number 7, Karen, is a former care worker in her first Enrolled Nurse position, and she is currently a student nurse. Number 8, Bevan commenced in 1983, became a Registered Mental Deficiency Nurse and has been a Shift Supervisor since 1992. Number 9, Ron, has a similar background, with insights to add from his lengthy experience of being Shift Supervisor in charge at night.

Table 4-2. Information on the position and length of service of interview participants

Participant	**Position**	**Length of service**
Dorothy	Care Worker	17 years
Larry	Supervisor/RN	23 years
Angela	RN	2 years
Colleen	Care Worker/Enrolled nurse	16 years
Verna	Parent	Long association
Sarah	Care Worker/supervisor	20 years
Karen	Enrolled nurse	2 years
Bevan	Former MD nurse/ Supervisor	22 years
Ron	Former MD nurse/ Supervisor	28 years
Laura	Agency RN	6 months
Dean	Former MD nurse/ RN	20 years
George	Former MD nurse/ Manager	25 years
Heather	Enrolled Nurse	3 months
Mick	Medical officer	12 months

An agency RN, Laura, who has worked often at The Centre is participant 10. She was able to add valuable insight because as a student she did a placement at a general hospital emergency department which is used by The Centre clients. Number 11, Dean, is a Centre RN, a former mental deficiency nurse of many years. Number 12, George, a senior manager at The Centre for many years, is also a former Mental Deficiency Nurse who completed a bridging course to qualify as an RN. Participant 13, Heather, had the shortest service with The Centre, 3 months as an Enrolled Nurse. Finally, participant 14, Mick, was a part time Medical Officer employed by IDSC. The Centre has one full time medical officer.

Interviews were audio taped and transcribed verbatim using a word processor. Participants were given the opportunity to view their transcripted interviews, but most were happy to give verbal confirmation of concepts. The interviews formed an important part of the data collection process as analysis usually takes the form of interpretation of meanings from verbal descriptions (Atkinson & Hammersley 1994).

4.9 Analysis

The purpose of this section is to describe the process of interpretation and analysis of the data used to answer the research questions. In ethnography, data analysis is not a distinct stage of the research, it begins in the pre-fieldwork phase as research problems are formulated and clarified and continues through to the writing stage (Hammersley & Atkinson 1995). Analysis formally takes shape in analytic notes and memoranda and is informally embedded in the researcher's "ideas and hunches", feeding into the research design and data collection (Hammersley & Atkinson 1995, p. 206).

Subsequent data collection is guided by emergent theory and aims at descriptions and explanations (Hammersley & Atkinson 1994). It is customary, with an ethnography, for a certain amount of analysis to take place before the completion of data collection. This was found to be the case, because as themes began emerging, I was sent in different directions seeking more information and confirmation of emerging themes. The guiding principles of Hammersley and Atkinson (1995) and Clifford (1997) were utilised in the analysis which was informed by other tenets of qualitative research drawn from studies in the field.

4.9.1 Organisation of the Data

Data analysis in qualitative research is described as a "hands-on process" in which the researcher must become deeply immersed in the data, sometimes referred to as "dwelling" with the data (Streubert and Carpenter 1999, p. 28). An ethnographical study is very detailed and descriptive. An enormous amount of data were received and examined.

Ethnographers deal with unstructured data that are not coded at the collection point. Data are open-ended verbal descriptions in field notes, interview transcripts, documents et cetera, and the process of analysis involves developing a "set of categories" that capture relevant aspects of the data (Hammersley & Atkinson 1995,

p. 208). Data are then grouped into those categories.

Data collected from interviews were transcribed verbatim using pen and paper first and then transformed into a workable text using a word processor and saved onto a disk. It was considered best to transcribe the interviews within 24 hours of conducting them, while they were still fresh in my mind and this practice aided transcription of the tapes. Clifford (1997) describes transcribing the interview as the first step of data analysis as the data are displayed in a "visual form which enables you to look at it in more detail" (p. 61).

Similarly, as described previously, the field notes were recorded by hand in a diary and word processed at a later date. During the word processing stage, all hospital names and other identifying comments were removed from the text. All the lines on the text were numbered and sufficient space allowed in the margin for analytical comments. Page numbers and line numbers formed the data codes for interview transcripts and my field notes, and the first initial of the participant's name was used where the full name was not relevant. An example of the method used is, *Larry, a RN and former shift supervisor, said that RNs "do a lot of care" (6. 41).* Verbatim quotations from my diary have the date included, for example, *A manager was called and he gave the client money in exchange for a promise that she would behave (Fieldnote entry: 3.3.02).*

The data were read and re-read many times. Data need to be read several times according to Hammersley and Atkinson (1995) who suggest data should then be coded according to concepts. Coded data are compared for differences and similarities.

However I chose a method described by Clifford (1997) which emphasises reducing the data to make it more manageable. When I had become very familiar with the data, key concepts were extracted from the text, thereby removing that which was not relevant to the research. Clifford (1997) describes this process as content analysis, summarising responses to questions and grouping similar ones together. It is a time consuming, yet effective method of reducing the data.

An excerpt from Sarah's interview transcript illustrates the researcher's perception of content analysis. Some of the content was irrelevant and content analysis helped me focus on answering the research questions (Clifford 1997):

> *I rely on them. I know there's somebody there, just a phone call away. In my Villa we don't have anyone that's trained, medically trained, I mean my knowledge come from 20 years of service, but it's good to know that there's someone just a phone call away, and I have been in a situation where I needed someone like 10 minutes ago and they have been there like that. I can't fault them, they are very positive.* (S: 1,16)

The concepts drawn from this text are that the RNs are reliable, prompt and needed, positive and faultless in the eyes of staff who are not trained. Despite her 20 year service with the organisation the participant felt that only the RNs were appropriately trained to make health decisions.

Clifford (1997) suggests "collating" the responses or collecting all the responses to the same question together (p. 61). This was achieved by transferring the questions and answers to a word processing file where similarities and differences were identified in the data. The coded field note entries were managed in a similar way. Clifford (1997) suggests presenting a summary of similar responses in tabular form and discusses different methods that can be used to display the summary of data at this stage, but for the purpose of this research, concepts were given headings and listed using a word processor.

4.9.2 Clustering Similar Data

Streubert and Carpenter (1999) describe the data analysis as taking the form of "clustering similar data" (p. 28) They describe the "clustered ideas" as themes or the "structural meaning units of data" (1999, p. 28). Germain (1986) explains that themes can be "shared knowledge, norms (rules of behaviour), values, belief systems, language, rituals, economics, role behaviours, or patterns of social interaction" and the list is not exhaustive (p.148).

In order to cluster the data, the coded data were printed, then cut and separated into concepts. The common features that emerged from studying the text were groups of concepts or thematic phrases that described the role of the RN in disability service. Some examples of concepts are similar to those drawn from the interview transcript on the previous page; the concept of RNs being faultless, prompt, needed, reliable and positive. The previously examined interview excerpt along with the other data also suggests a lack of confidence on the part of the workers and a need to be recognised

"...my knowledge comes from 20 years of service" (S 1.16).

The data were thick with rich descriptions of the many tasks the nursing role entails and the cultural behaviours which either assist or impede the role of the RN. These also took on a different meaning depending on from whose perspective I explored them, (nurses, other care providers or the client). Among other nursing agencies and general hospitals there was found to be yet another variation of the perceived understanding of the role. For example, the belief that RNs at the Centre "know what to do" and use skills that other nurses do not, was important in answering the first part of the research question.

Accordingly, concepts which formed subthemes answering the first part of the research question are about the diverse range of tasks that form part of the RNs' role. Issues around clients' beliefs about nursing tasks, and the experience and confidence of nurses undertaking the role were important observations. Subthemes or thematic phrases emerged around the caring role of the RN, the importance of knowing the client, and the expectations of other workers.

Being both supported and supportive was considered to be a concept of teamwork and includes the nursing team as well as the extended team of staff, care workers and professionals. Indeed attitudes of agency nurses and general hospital nurses were significant to the theme “other aspects of the RN's role".

The question is asked, how well do we work together? Indeed the nursing service seemed to be on an island within the larger organisation, albeit a crucial "cog in the wheel". Furthermore the lack of training for the job is described by the theme "education" which highlights a need to address the issue of the continuity of nursing knowledge in the field.

Subthemes tended to fall into two categories, most answered the first part of the research question: *From the perspective of the nurse, client and other health care professionals, what constitutes intellectual disability nursing for the RN?* Concepts that did not describe the role of the RN in disability service were grouped together. These form the remaining group of subthemes that answered the second part of the research question: *What are the everyday rituals, norms and patterns within the disability culture that shape and influence disability nursing for the nurse?* Concepts include "back covering", the term used by RN for some of the unnecessary calls they receive, and the jealousy of other workers. The emergent subthemes formed the theme of "confusion over the role".

The issuing of Standing Orders (Internal Memoranda of instructions stating consequences of non-compliance) and the use of casual staff are concepts of power which emerged from the perspectives of the nurse, the Villa manager and the organisation's management. Subthemes emerged around the concepts of power, cooperation and communication. Table 4-3 summarises the themes and sub-themes that emerged from the current study.

Table 4-3. Thematic summary of the research

PART ONE THEMES

- Caring for the client who is institutionalised
- The RN in the disability sector having certain qualities
- Working within a different paradigm
- Having to assume responsibility for large numbers of unregulated workers
- Having to work alongside many professional groups
- Having different educational needs

PART TWO THEMES

- Hierarchical structure
- The RN's position
- Role confusion

4.9.3 Finding Common Themes

After I, as the researcher, had become very familiar with the data, common features became evident and themes began to emerge, but these themes clearly depend on both the researcher's and the reader's interpretation of the data presented (Clare and Hamilton 2003). Nonetheless, Hammersley and Atkinson (1995) suggest useful analytical concepts can arise "spontaneously" and that these are worth following up (p. 213).

Notwithstanding the value of reducing the data and organising it into concepts, I needed to examine the data in terms of how it answered the research questions. In analysing the data, I remained constantly mindful of the research questions, and asking how does this culture impact on the role of RNs? The data were analysed to determine the relationship of the entire culture to the role of the RN.

> The aim, though is not just to make the data intelligible but to do so in an *analytical* way that provides a novel perspective on the phenomena we are concerned with or which promises to tell us much about other phenomena of similar types (Hammersley & Atkinson 1995, p. 209)

In order to produce a written report describing the role of the RN in disability service, I attempted to reduce the data to a number of themes without losing its authenticity (see Table 4-3).

4.10 Rigour

The chapters that follow describe the themes in detail, but this study would not be complete without addressing the issue of rigour, or validity. The goal of rigour in qualitative research is to accurately represent the experiences of study participants (Streubert & Carpenter 1999, p. 28). Cutcliffe and McKenna (2004) describe the quest for truth in qualitative research as a “contested area” that can leave an opening for “additional theoretical and methodological discussion” (p. 126) when compared with quantitative research. The researcher acknowledges it can be difficult to establish credibility when conducting a qualitative study.

The observations made and the interview statements are representative of what was happening at the time. There is no guarantee that the opinions stated would always be the same. This research is an ethnographic account and tells the story of the role of the nurse in disability service as seen through the eyes of myself as the researcher and as confirmed by many participants.

Ethnographic research is considered to be story telling and, as such, researchers in interpretive traditions are often called "journalists or soft scientists" according to Koch (1998, p.1186). Research methodologies that utilise story telling are sometimes described as "unscientific, full of bias or entirely personal". The research is considered credible though when co-researchers or readers confronted with the experience can recognise it (Koch 1998, p.1186).

According to Koch (1994), a major threat to the trustworthiness of any qualitative study lies in the closeness of the relationship between the investigator and the subject. When researchers describe their own behaviour and experiences in relation to those of the subjects, credibility is enhanced (Koch 1994, p. 977). For this reason, throughout the display of findings, I have included verbatim field note entries. Furthermore participants became collaborators in the reflexive process, sharing in their own experience which combined with the researcher's insight and understanding gave rise to "self-critique and ideology critique" (Street 1992, p.12).

In order to be rigorous, qualitative research should have credibility, fittingness, auditability and confirmability (Koch 1998 & Streubert & Carpenter 1999). Credibility is demonstrated by the extent to which concepts of the research findings can be recognised by co-researchers and other readers according to Koch (1998) who also stresses the need for conclusions to be firmly grounded in the data. Fittingness, also known as transferability, refers to the ability of the study findings to fit other contexts outside the study setting and also relates to the meaning and relevance that the research has for the participants (Streubert & Carpenter 1999).

To achieve auditability, the researcher needs to produce an "audit trail" which would enable another researcher to arrive at the same or a comparable result (Cutcliffe & McKenna 2004 p. 126). When credibility, fittingness and auditability can be demonstrated, confirmability of rigour is achieved.

In the current study, on completion of data analysis the results were sent to the research participants to determine if the findings reflected their understanding of the culture. This is a means of ensuring confirmability of the research findings (Cutcliffe & McKenna 2004 p. 126). Additionally I as the researcher maintained a journal to ensure the study findings were linked to the data (Koch 1994).

This research was conducted at a unique residential setting which limits the generalization of the findings. It is not anticipated that anyone would attempt to generalize the findings to any other setting, however the findings should inform practices in other settings.

4.11 Summary

In this chapter ethnography, a qualitative research methodology, has been described. It has been explained why ethnography and specifically focused ethnography was chosen as the most appropriate method to explore the role of RNs within a large organisation. An interpretive approach to social reality, the current research focuses on the way human beings interpret and make sense of their subjective reality.

A succinct account of ethnography's traditional roots, in anthropology, provides background to ethnography as it is known today. Ethnography is described as a way of examining the culture of groups of people, deriving meaning and causing change. Examples of ethnographic research and focused ethnographies are given.

My position as participant observer, reflexively positioned within the study, is made explicit and research participants are introduced. In the latter part of the chapter the methods to collect and analyse data for this study are described. The actual research process is detailed beginning with the formulation of the research questions, through the fieldwork stage, to analysis. Finally, the issue of rigour or credibility is addressed. Subsequent chapters describe the themes which answer the research questions.

CHAPTER 5

Research Question, PART ONE

WHAT MAKES IT INTELLECTUAL DISABILITY NURSING?

5.1 Introduction

This chapter describes themes which answer the first part of the two part research question. Two questions are posed in the current research. These are:

- From the perspective of the nurse, client and other health care professionals, what constitutes intellectual disability nursing?
- What are the every day rituals, norms and patterns within the disability culture that shape and influence disability nursing for the Registered Nurse?

The second component of the research question, which examines cultural influences on the RN's role, is addressed in the next chapter. The current chapter explores the issue of what constitutes intellectual disability nursing and what makes intellectual disability RNs different from other nursing specialists? Themes emerged from data highlighting the role of the RN in the intellectual disability context stressing differences between
(a) the role in the disability sector and (b) nursing in other sectors

Themes, subthemes and important concepts related to the question "What is intellectual disability nursing?" extrapolated from the current research are summarised in Table 5-1 and discussed in the following section. The data reported are coded according to the convention explained in the previous chapter (page and line numbers and initials where participants full names are not used).

Table 5-1. Themes, subthemes and concepts related to the first part of the research question: “What is intellectual disability nursing?"

Theme	**Subthemes**	**Concepts**
Caring for the client who is institutionalised	*Having many varied skills*	Tasks specific to I.D. nursing Diverse range of skills
	Clients have complex care requirements	Planning required Time/space
	Registered Nurses as specialists	Having specialist knowledge Being an expert
The RN in the disability sector having certain qualities	*It takes special kinds of skills*	Job is not for everyone Not your “average patient”
	Providing a sense of family	Element of “family” to nursing care Work in client’s home
Working within a different paradigm	*The institutional model of care*	Still alive and well Observed in routines
	Rewards of the position	Status Doing a good job
	Downsides to the role	Communication Non-compliance
	The “hub of illness care” and future plans	“Dumping ground” “Little hospital”
Having to assume responsibility for a large number of unregulated workers	*Interaction with RNs*	Care workers know clients well Nurses support care workers
	The carer as a credentialed worker	RNs delegate care RN training required
	Training for the carer role	Inexperience No training in health care

Table 5-1 continued

Having to work alongside many professional groups	*Enrolled nurses*	Autonomy versus supervision A different role from most ENs
	Attitudes of general hospital nurses	Lack knowledge of intellectual disability Cannot cope
	Agency nurses	"Steer away" from intellectual disability Ill informed
	Allied health team	RNs had little input Team members unclear on RN role
Having different educational needs	*The need for education*	No formal training Learn on the job
	Management and training	Do not see the need No incentive

5.2 Caring for the Client who is Institutionalised

The current research setting was unique and the RN's role was affected by the process of deinstitutionalisation. Caring for the client who is institutionalised is different to nursing in acute settings where clients generally move from illness to recovery and subsequently discharge.

5.2.1 Having Many Varied Skills

As participant-observer, I was involved in the day-to-day practices of the RNs in the research setting and it became clear that the RN in disability practice was required to have many skills. Expectations of the role could alternate in a day from community nurse, to care giver in the Infirmary unit, to anaesthetic nurse, and this required good organisational skills. Fieldnote entries describe the RN delivering personal care at The Centre, between many call outs in the morning and visiting three hospitals "in different directions and calls for PRN authorisation along the way" in the afternoon (4. 03).

Larry, an RN and former shift supervisor, said that RNs *"do a lot of care"* (6. 41), and also enjoyed a specialist role within the system. He described the role as very flexible

"...calling upon everything from clinical to tutorial skills" (1. 47). He elaborated stating:

> *Also my role extends to direct care in some cases when I do work within the Infirmary, it certainly has to do with crisis intervention, assessment, clinical assessment and hospital visits... Work in the dental clinic as post anaesthesia, which goes straight back to the clinical* (2. 1)

Furthermore the intellectual disability RN was required to be flexible in order to accommodate clients' social programs. It was not unusual to have to return to a villa several times to perform routine care because clients were at swimming or art class, or indeed on a bus trip. The villa staff often did not anticipate the client's absence when they booked the RN. Clients were also seldom kept home from work or activities when they were ill. For example an RN was observed to be taking observations of vital signs from a sick client on a bus about to depart for the client’s day time activity (6.45).

The following were observations made by Verna, (a family member) about the personal care that RNs deliver:

> *...[the nurses] have to feed them and look after them generally, bath them, look after their personal hygiene because they [the clients] are unable to do it themselves, they massage their limbs, do everything possible for their patients...they work very very hard, they seem to always have a smile on their face, and enjoy their work, they give duty of care of course but they allow each of the clients to have their own privacy and dignity...* (5. 1).

Two RNs, employed by the organisation for many years, shared their insights into intellectual disability nursing. Larry stated that it was the skills he brought to the job, such as behaviour management and general nursing, that made him feel good about what he did (3. 32). Dean agreed with this, adding that although the majority of the clients do not need nursing support "*you* (RNs) *need training as you would for any specialist area"* (1. 5).

Those who had been employed by the organisation for a long time tended to "speak the same language", every culture having its own language. I understood the language that nurses used in general practice but there were differences in the intellectual disability nursing sector. For example, people with intellectual disability are more prone to epilepsy than the general population and it was the RN's responsibility to monitor the condition and provide intervention when needed. The RNs who were previously mental deficiency nurses were familiar with epilepsy and could easily describe a seizure. I, however, did not understand the meaning of "just a classic tonic clonic seizure" not having been taught about epilepsy in my training and having no experience of this in my previous work (1.02).

During the current study the RNs were required to constantly adapt to changes in their work load. Increasingly the role incorporated less first aid and more health management and health promotion. Larry (RN) explained this in terms of an ageing population. He was asked if he thought deinstitutionalisation was causing a decrease in the need for the nursing service:

> *The only downside to that is our ageing population. Nearly all our residents are in the baby boomer range..., and of course they fall victim to a great many syndromes and diseases brought on by many years of medication... we have no idea what major organs these things are going to [affect]. I've seen an absolute increase in our workload, this is not brought about by residential care, directly, this is brought about by pure and simple ageing [of the clients]*
> (5. 26)

Ron, a shift supervisor and former mental deficiency nurse, agreed that the job had changed for workers in all areas as a result of clients' ageing and he referred to the Centre’s original function, as a training centre:

> *There's a lot less training, a lot of the residents are in their 50s now, so it's just mainly maintenance with what you've got* (1. 27)

An Agency RN, Laura, was delighted that I had chosen to explore this field as nurses are usually inclined to research areas such as cardiac care. The participant agreed with my comment that intellectual disability nursing seems to incorporate many nursing specialties, because it covers such a diverse area. Laura stated that, in her opinion, the RN in disability service had an *"elite"*, or privileged position (1.10). Hospital nurses did not share this view, she stated, as they were scared of the clients. "*It's a confidence thing, they don't know how to approach them"* (1.10).

5.2.2 Clients have Complex Care Requirements

The complex care requirements of clients related either directly or indirectly to their intellectual and physical disabilities. These could have been due to syndrome specific conditions, long term medication usage or immobility for example. Care requirements included gastrostomy feedings, bowel management, and respiratory assessment due to the potential for aspiration related to swallowing difficulties. In addition other observations made are included in detail such as venipuncture and ear syringing.

Each nursing procedure, no matter how routine, required careful preparation of the setting. This was to ensure adequate space if care workers were required to support the client and hold onto equipment when needed. The RN needed to have perfected skills that RNs in other sectors did not, and tasks took a lot more time than if performed on the general population. Indeed the RNs appeared to be defined by the tasks they performed such as wound care and routine observations because other workers did not have that expertise.

Naturally, because of the unpredictable workload and the clients' frequent "non-compliance" the RNs admitted that it was difficult to perform tasks "by the book" (21. 9). An RN described how she often had to assist a care worker to dry a client in the bathroom after his morning shower in order to administer the client's morning dose of insulin. In order not to disrupt the client's or the care workersr's routines, nursing tasks were frequently conducted in unorthodox places such as the bathroom or at the meal table (25.5).

In fact there were many examples of tasks undertaken by the intellectual disability nurses that would not be considered a part of the role of RNs in other settings. Moreover, when the client has intellectual disability, routine tasks with which most nurses are familiar such as venipuncture could be challenging. Many clients with intellectual disability are on anticonvulsant medication which requires regular blood screening to ensure a therapeutic range. While most hospitals in South Australia use agencies to collect blood, at the Centre, venipuncture was the role of the RN and the RNs agreed that this could be a difficult task (L. 2.16).

Indeed most new RNs reported difficulty in obtaining blood. This was due in part to the clients’ poor circulation and veins that had been accessed for years. I was taught the skill of using a winged "butterfly" needle in the hand or foot for veins that are very small or particularly fragile (5. 02). However it was more likely that a client's resistive behaviour posed the greatest problem and the client who had a limited understanding of the procedure could shout and kick and attempt to run away. Optimally, two nurses should have worked together, but this was not practical and rarely occurred.

> *Two nurses should go on rounds together, from a safety and educative point of view. In the case of venipuncture for example, the carers aren't always helpful* (K. 1. 41)

A newly registered nurse reported that she had just made her third failed attempt at venipuncture and felt discouraged because she thought it was her technique. The RN who had been there a long time was able to assure her that the clients were difficult to take blood from and that all nurses experienced difficulties from time to time (3. 04). Another RN refused to take blood from a person who was known to present challenges and arranged for the client to be taken to the public pathology laboratory (6.13).

> I told an EN how difficult it had been to take blood from a client. The carer just stood there and when I put the needle in, the client jerked his arm, causing trauma, the carer could not understand how I wanted the arm supported. The EN described a scenario where they had to wrap the client in a blanket in order for the blood to be taken, she said "people out there wouldn't believe you if you told them that you had to do that" (Field note entry: 16.3.04).

Ear syringing was another skill to be learnt because people with intellectual disability are prone to ear blockage and infection possibly due to their being unable to clean their own ears appropriately. The medical officers examined the clients and delegated the task of ear syringing to the RN. Most clients did not like having their ears syringed and the following was the researcher's experience when faced with this task:

> I looked in the diary and saw "ear syringe", I grabbed the ear syringe tool and asked one of the ENs "Do I really have to do that?". The EN showed me what to do. Before and after syringing we are supposed to look in the ear with an auriscope. Well I'm still not sure what normal looks like. The syringing can be interesting as you try to juggle all the equipment with a sometimes struggling client. The role is multiskilled (Fieldnote entry: 17.9.02)

Most of the equipment in use was very old and the ear syringe equipment was not ideal because it had two main pieces that needed to be balanced. One of the pieces was a jug of water that had a weighted tube suspended in it and the other resembled a metal water pistol which was frightening to the person with intellectual disability. The RN had to juggle these tools and attempt to hold a kidney dish under the client's ear at the same time, often with no assistance.

Sometimes when a client was non-compliant, the RN had to abandon the kidney dish and drape a towel over the client's shoulder to collect excess water. At times, an examination with the auriscope was abandoned as the client became too distressed.

Ear syringing is just one of many skills the RN was expected to hold (or quickly acquire) and care workers and RNs alike agreed that many people would be incredulous at the sorts of skills required of the nurses at The Centre.

> Another RN complained she is supposed to listen to people's chests with a stethoscope but she was not taught the skill at university. When I first had to pass a nasogastric tube, it did not seem to bother anyone that I had never done that before. Fortunately, it was suggested I get someone from RDNS to show me how (Fieldnote entry: 17.9.02).

The RNs could seek advice from other agencies as one participant explained:

> *I can ring lots of allied services, RDNS, IMVS. People like that are usually open and happy to assist. I could even probably ring the casualty wards at the major hospitals, if I needed to* (A. 3. 26)

Indeed there are times when it was better to enlist the aid of an expert venipuncturist, for example, and the RN could then assist to hold and reassure the client. During the current study, assistance was sought from other agencies for such interventions as clients' bowel management, difficult venipunctures, stoma care and wound care. The RNs were observed to have individual special abilities (24.12). Generally, the nurses recognised their skills and sought education in areas in which they are unfamiliar. They supported each other and learnt from experts such as the Royal District Nursing Service (25. 4).

Notwithstanding these observations made during field work, there was a general assumption across the various levels of staff at The Centre that the RN had the necessary skills for the role but there is no "checking" to ensure they had. A senior manager stated "*You would think if they've already got through their nursing degree they've got all those things in place*" (G. 4.18). However it was widely known among the nurses that there were competencies required by the job that RNs were not taught in universities and this will be discussed later in this chapter.

5.2.3 Registered Nurses as Specialists

The concept of the RN as a specialist upholds the RN as an expert (Benner 1984) and this appeared to be the view of the clients and their care workers. Notwithstanding this the RNs admitted to not always being experts and sometimes finding the role challenging and yet other health professionals relied on the RNs' expertise. Medical officer, Mick, felt that RNs had multiple roles: ...*with responsibility for everything from hands on care to administering dangerous drugs and bowel management* (1. 2).

The "culture" respected the RN because clients and their care workers seemed to believe the RN had important knowledge. In the eyes of the client the RN could do no wrong and if they were told the RN could not fulfill a task, it was not unusual to hear the client say "yes you can, you're an RN" (Fieldnote entry 20.9.02).

One client stated "nurses fix you up when you are sick" (Fieldnote entry 20.9.02). Clients were observed to display their wounds and pull up their sleeves for blood pressure readings. There were times when knowledge of the client could save a visit to another health professional and clients were sent to the RN by the villa staff who liked to see that the nurse has "done something" (2.29). For example, performing some kind of treatment measure, such as hot or cold packs, and applying ointment or bandaids to "invisible wounds". A client complained of sore gums and her dental appointment was not for a week. The RN applied a placebo gel with good effect, albeit in much the same way as a mother might do for her child (19. 8).

Indeed as villa staff were not trained in health matters RNs were treated with the same respect as doctors. Bevan, a shift supervisor, felt it would be optimal for the RNs to be more involved in lifestyle planning for clients on the villas. He suggested that the nurses could also be involved in the annual medical review process and stated that he was happier, when wishing to discuss a client's medical condition, to seek out the nurses rather than the doctors.

Ron, a shift supervisor and former mental deficiency nurse, said he had completed mental deficiency nurse training many years ago and that he accessed the nursing service on a regular basis. He acknowledged the professional expertise of the RNs and, not having had recent nursing experience, he made the observation:

> *...well because it's been so long since I've been through my nursing, now the nurses we call on should have more expertise on more up to date things* (1. 34)

Of course the RNs are on duty 24 hours a day, 7 days a week, while most of the medical officers work part time. Consequently the RN was always the first to be called in the case of illness or accident and it was the RN's responsibility to determine whether or not the client needed to be seen by a doctor. The tradition of having "someone" on call seemed to be a legacy of the medical model, a part of the culture, in my opinion (6. 02).

> A student RN and I were discussing the role of the nurse practitioner and she described the role in general hospitals' accident and emergency departments as "fast streaming". I realised that triaging is what the RNs do here, often eliminating the need for clients to see doctors. She agreed with me that we would have to have a lot of doctors if they were called every time a client had a problem. Often the RN will recommend a simple treatment which is effective or just state that the problem does not require medical intervention. Examples are skin conditions and simple injuries which require no more than a bandaid, or illnesses that respond to paracetamol or bowel interventions (Fieldnote entry 14.12.02)

The care workers could administer first aid measures as one would in the home but it is the organisation's policy that all injuries are assessed by the RN. Indeed the RNs felt that they reduced the doctors' workloads and in most cases were able to prevent unnecessary waits in emergency rooms of general hospitals (2. 02). Ron, who only called the nursing service when absolutely necessary cited reasons for calls as *"almost anything from minor cuts to a person dying*" (1. 37). Because it is the policy, RNs are even called for minor abrasions and consequently the villas do not stock any first aid equipment.

Another shift supervisor, Bevan (former mental deficiency nurse), stated that he would take his concerns to the nurses, rather than the doctors *"...they've been with the clients more"* (2. 2). However nurses were not trained to diagnose, rather they could assess and refer to doctors, and a nursing opinion was not a medical diagnosis (8. 03). Non- nursing supervisors said that nurses *"patch people up"* and one suggested that having nurses saved having to call ambulances, especially at night (R.1. 30).
As they are not doctors, the nurses sometimes worried about the Centre's reliance on their assessments. There was certainly an element of first aid in the role of the RN. A first aid certificate was mandatory for all employees commencing work at the Centre, but this was not enforced when the qualification expired, leaving the RNs the only first aid certificate holders (9. 03). Presumably the reason the workers' first aid certificate status was not checked was because of the existence of a nursing service and ultimately the clients were deemed healthy.

At the same time, enrolled nurse (former care worker), Colleen raised the important issue of the necessity for staff who care for clients in the villas to possess at least basic assessment skills. She saw this as being imperative due to the clients' intellectual disability as most clients are unable to describe their own symptoms:

> *Carers don't see the signs and symptoms that I think they should know, like someone having a stroke or someone with a temperature, it might be related to something else, but they just don't see the signs. Like if someone's got diabetes, because these people are intellectually disabled, it's hard to tell because they can't tell you so, that's how you tell if someone's in pain or something. So if you don't see, you're not going to know* (1.17)

I am (at the time of writing) also a nurse specialist, specialising in psychiatric nursing. The following fieldnote entry depicts a scenario where that knowledge was very useful:

> I called a doctor to attend to an aggressive client who was yelling and destroying property. I wanted her to order some medication to calm him. "A tablet?", the doctor asked. "No, an injection" I replied, stating that he would not take a tablet. "What medication?", the doctor asked and I told her and then she asked "How much?", and I told her that too. Later the doctor, who is not used to dealing with people with aggression, phoned me and thanked me for my help (Fieldnote entry: 5.12.03)

Larry (RN/ former shift supervisor) described the trust afforded the RNs' judgement in this way:

> *When the chips are down and you're the only RN on and they really need your support, they're happy to see you and they know that when you have said that a situation in your assessment is so and there's no need for concern or there is a need to follow it up, they are happy to take the advice* (3. 24)

Such is the faith in, or expectation of the RN, a doctor asked if nurses could do suturing and the RN replied it was not usually a nursing task. No Centre nurse had been trained in suturing. The medical officer replied that it would be good if they were (9.12) The medical and other allied health team members acknowledge the support of the RNs and according to one medical officer *"...[they are] helpful to the doctors "*(M. 1. 2).

Larry (RN/ former shift supervisor) felt that to be acknowledged as a speciality the RNs needed to "*raise the level"*, so that intellectual disability nursing was seen as *"sustaining and interesting"* (6. 44) rather than something that other nurses did not want to do. Indeed from comments made by general hospital nurses and the poor response each time a position was advertised, it seemed intellectual disability nursing was not something that other nurses would want to do. It was reported that it takes a special kind of person to do intellectual disability nursing and this is discussed in the next theme.

5.3 Qualities of the RN in the Disability Sector

This theme encompasses the special qualities of RNs who care for people with intellectual disability. There were rewards such as providing the client with the "family" they may not have and yet negative aspects to the position were observed that, in some cases, caused staff to leave.

5.3.1 It Takes Special Kinds of skills

All of the participants in some way or other believed "it takes special kinds of skills" to work with people who have intellectual disability. The client with intellectual disability is "not your average patient", if there is such a thing, and some have severe physical disabilities as well, making observations and other nursing tasks difficult. As the researcher, I observed that it was the client who made intellectual disability nursing different because, in most acute settings where RNs worked, clients generally had some understanding of nursing interventions.

One of the participants, Laura (Agency RN), had personal experience with a child who has intellectual disability and she believed this gave her *"greater understanding"* even though she had also worked with others who have intellectual disability (1. 45). An observation made about nurses who work in general hospitals was "registered general nurses screw their noses up at the idea of what I do, they don't like our clients" (1.7). Laura stated *"it takes a special kind of person, it's not everyone's field"* (1. 44).

RNs in any setting see their primary role as care givers to their clients and the RNs in disability services are no exception (Alaszewski 2001). The difference in caring for the institutionalised client, unlike the typical therapeutic relationship, is in the personal relationship between nurse and client. The client perceives the nurse as a friend whom they can trust (Alaszewski 2001). Some clients approached the RN for counselling, "telling tales" about villa staff, issues the nurses had no knowledge of and often, depending on the situation, no power over. A client told the RN "I can tell you, you're a nurse" and "they (the villa staff who are not nurses) don't understand" (15. 3)

From observation in the field it became clear that RNs who care for people with intellectual disability had skills in health care that other workers in the field did not have, such as assessment skills. They reported they often used skills that were not required in other settings for example supporting and credentialing unregulated workers. Nevertheless it was their expertise in caring for people with intellectual disability that set them apart from nurses in other settings. Karen (enrolled nurse) agreed that the Centre's RNs had special knowledge of the clients that assisted them in their role. She described it in this way:

> *I do, I have an understanding of the client. Not everyone can feed someone and have them "chuck" down your leg. You're supposed to put up with being scratched and pinched, and just get on with your job. Hospital nurses can't cope, they're fearful* (1. 20)

Likewise I observed the friendly, happy manner in which the RNs carried out their work and the faith the villa staff have in them. This was reflected in the interviews. Sarah, a shift supervisor commented on the visiting nursing service:

> *I don't think I've come across a bad RN, they do their job, they come around and see the residents, stuff like that. All friendly, know the job* (1. 6).

Shift supervisor, Sarah agreed that the nurses had specialist knowledge the villa staff do not and a willingness to find out if they did not know something. She had this to say when asked if the RNs possessed the knowledge and skills required:

> *Definitely, and if they don't know, they get back to you. They say I'll get back to you on it and obviously they're going to check up on it and come back with the right answer, whether it be medication, you know the side effects of a medication. Somebody might be drowsy, is it they're unwell or is it because of a medication? Yes, they'll always come over and assess the situation* (1. 27)

RN (former supervisor), Larry put an interesting perspective on the qualities of the intellectual disability RN, describing their motivation. He suggested that the role of the RN in intellectual disability services was more "social" compared to that of the general nurse because they worked in the client's home. Furthermore nurses that worked in the Centre's Infirmary were responsible for providing entertainment for the clients such as music and games:

> *I think there's always a group of nurses who, sufficiently motivated not to be just runner of the bedpan and keeper of the orifices within the general setting, who would enjoy what we have got to offer here which is a more social environment and more time, we are very spoilt here.*
> (6. 21)

Moreover, unlike RNs in other settings, the registered intellectual disability nurse provided teaching and role modelling to the client in such things as good manners, anger management in dealing with peers, and health promotional issues. The concept of client training is not a new one and dates back to the Centre's opening and its original purpose of being a training centre for people with intellectual disability. The RN tended to teach by example and this was an important observation when dealing with a population of clients with intellectual disability and their care workers who will say "The RN did this" or "The RN said that", apparently believing the registered nurse could do no wrong (9. 02).

5.3.2 Providing a Sense of Family

Observations showed the registered intellectual disability nurse was skilled in handling difficult behaviour and could complete tasks with a minimal amount of disruption to the client's routine. This was thought to be due to the RN’s knowledge of the client and the clients’ acceptance of the nurse. The nurse was observed to become almost akin to an admired and respected family member to the client who may have limited family support, and the nurse subsequently appeared to form strong attachments to those in his or her care. These qualities were considered by the research participants to be the quintessential difference between registered intellectual disability nurses and nurses in the acute sector.

The participants agreed that RNs have always been care givers. Dorothy (care worker) made the observation *"nurses are carers too"* (2. 5). As the researcher, I observed this care giving contained an element of "family". Unlike RNs in other settings who have increasingly short term therapeutic relationships with their patients, registered intellectual disability nurses through long term contact were observed to become more emotionally attached to their clients. This was certainly evident from the number of clients using the Infirmary as a drop-in centre, to socialise with staff, have a cup of tea and have minor ailments attended to while they were there. I perceived that many health problems would go undiagnosed and wound dressings unattended, but for the comfortable relationships that clients had with nurses.

As previously stated it took time to gain acceptance in some quarters during the fieldwork, indeed to be recognised by the unregulated workers. It took less time to be appreciated by the clients, who accepted my gestures of friendship and care. Notwithstanding that, many of the clients could not contribute data in words and so many of their thoughts were reflected through the voices of their family or care workers.

There was a strongly held conviction among the nursing staff that knowing the client made a significant difference to the lives of this group of people, many of whom have no family involvement. I found that becoming a friend to the clients was an important part of gaining acceptance in the research field and this was not difficult to do. This scenario is an example: At 6am I was about to give a client a routine suppository when he announced, using my name "I have art class today". It meant a lot to be addressed by name and for the client to acknowledge my interest in what he was doing. At handover, the nurses talked about the rapport that develops between nurses and certain clients and it was agreed that all of the nurses have "their favourites" although they usually did not admit to this (17. 6).

Registered Nurse, Angela, found the work rewarding especially in terms of providing a sense of belonging for the client who may not have a family. She had this to say:

> *Some people don't have a lot of family, so you're dealing with them and you can sometimes be the most significant person in their lives, and that's a great reward, although you have to see that for yourself too. That you don't get thank yous from the clients here... So, yes, you have to see that for yourself. There are also a lot of families that are very grateful for the work we do* (2. 6)

RNs acknowledge the people that knew the client better than they did, for example, regular care workers and family members. When the grandparents of an Infirmary client visited and offered to feed him, the nurses were delighted. The client was known to be reluctant to eat, but his grandparents had no problem. The grandmother asked if the nurses minded if she assisted the client and the nurses replied it was appreciated (10. 8).

5.4 Working within a different paradigm

The Centre is in process of deinstitutionalisation (at the time of writing), having moved away from the "medical model". This theme incorporates data describing attempts to replace the medical model with the developmental model, and addresses the issue of the future role of the RN.

5.4.1 The Institutional Model of Care

While the developmental model may have replaced the medical model at The Centre, an institutional model of care was observed to be alive and well. This was evident in the routines and timetables that were strictly adhered to such as meal times, including staff meal breaks, and client bath times. There was a set time for rising and a time for retiring which in most villas was prior to the arrival of the night shift at 7pm. The rigid routines are related to an institutional model of care, but are also a response to perceived client need as people with intellectual disability can become distressed at different systems of care. New staff get caught up in this culture and as a result these rigid routines continue.

Former mental deficiency nurse and manager, George, who made the suggestion that the organisation had "thrown the baby out with the bath water" when it replaced the medical model with a developmental model highlighted the need for RNs who know the clients. He gave an example of illness that could be overlooked by someone who is not a trained nurse:

> *When we moved to the developmental model, it didn't happen overnight but people's health began to deteriorate because there were not nurses there on a daily basis and conditions weren't recognised. I always use the example of a person with Down Syndrome who has a cold. If a nurse was there, they would book him in for the doctor. Often that is not picked up by people whose basic training has been around mealtime management and the giving out of routine medication* (3. 8)

Of course there was a danger of duplicating the institutional model into the community houses and this culture fosters that because the same rituals and practices were being observed by staff. RN (former supervisor), Larry, discussed clients' difficulty adjusting to change but also acknowledged positive aspects of community living:

> *I think that we have to get out of the culture with the type of care offered in the Centre of learned dependence. I believe that a lot of the way the institutional thing operates is that people learn to behave in the way the system expects them to, and certainly community care...I used to think what is the point of taking people out who are operating at such a low level, they won't even know they are in a house, but I was wrong, in most cases there has been positive change for the better in the client's behaviour* (5.10)

Indeed during the current study there have been moves by clients to community houses as the process of deinstitutionalisation continues. Clients are reportedly less likely to be ill in community settings, according to Larry, who had observed a newfound wellness among his community clients:

> *If you've got people who are contented, then they appear to be less ill all the time or they don't have to do things to get attention of people* (5.18)

George (manager/ former mental deficiency nurse) described the effects of the introduction of the developmental model on RNs working in intellectual disability services in this way:

> *When mental deficiency nursing was phased out and we moved to a developmental model of care, there was a loss of skills of so many nurses by either transferring to that model or choosing to leave altogether and going off to other areas like mental health, management and general nursing, so it wasn't long before we realised that the health model needed to complement the developmental model* (2. 2)

The Centre has seen many changes but the management states that it welcomes ideas for improvement particularly in the nursing service. Changes in health care delivery, economics and the influence of deinstitutionalisation will mean significant change for RNs in intellectual disability services in the future. While a set plan for the future of nursing services was not apparent during the field work a meeting of the nursing staff was held to discuss possible changes and the manager stated he was open to suggestions (Meeting minutes, 14.11.02).

Indeed the RNs have been given the opportunity to design their own practice, but the role is steeped in tradition and the original RNs cling to the nursing service they have created. Many conversations on this subject indicated the nurses were unwilling to move away from that which is familiar and comfortable to them, although change is inevitable. They appear to be entrenched in the culture of the organisation, even though traditionally nurses have their own culture (Shui-Kang 1998). Moreover despite their criticism of the overall culture, their patterns of behaviour were observed by myself, as the researcher, to contain institutionalised ways (52. 20).

It is clear that a model for intellectual disability nursing needs to be developed. When asked about the model of care used by RNs at the Centre, a key nursing officer laughed and replied they do not use one. "We have our own", she stated, and with prompting, agreed that it comprised a mixture of case management, evidence based practice and a model of care that could be regarded as institutional (9. 03).

5.4.2 Rewards of the position

The status afforded RNs by the entire culture except by management, was obvious immediately; that is, if it is possible to have status with limited power (the theme of nurse's power is later discussed in chapter five). Larry, an RN who was formerly a shift supervisor described the kudos attached to his role:

> *The variety in the tasks and the associated rise in status, a recognition at last of the skills I bring to the job has made me feel so much better about the job* (4. 30)

On the other hand RN, Dean (former mental deficiency nurse), whose role was similar to Larry's except his clients were located within the Centre and Larry visited clients in the community, had a different perception. He described his role as *"fairly low key"* because the clients were not acutely ill such as those in a general hospital (1.18). He saw his position as providing general nursing care and support.

Rewards can come in different forms, a "Thank you" can be in the form of a smile, a little improvement or a complete turn around as illustrated by the following example: A young woman with social problems was admitted to the Infirmary one night for treatment of a medical condition related to her psychiatric problems. Treatment was hampered by her non compliance and much counselling ensued. I (a registered psychiatric nurse) had introduced primary nursing to the unit which was proving very effective. The client was assigned to one RN on each shift and encouraged to take all her concerns to that nurse. Prior to that she had been seeking out various staff members to get her needs met. The plan was hailed by all, including the treating psychiatrist, as a major breakthrough in this young woman's treatment.

When this client eventually left the Infirmary over one year later, the registered and enrolled nurses seemed to have become "surrogate aunts" to her. She stated that "nurses are smart, they fix people up". The client, being quite uninhibited would hug the nurses and tell them she loved them, and the nurses appeared to be the only social support the young woman had. When working with people with intellectual disability, the principle of maintaining one's own personal space is taught, yet it is rarely enforced, as the clients largely do not understand this concept. The registered intellectual disability nurse is not averse to client hugs and declarations of "you're the best nurse in the world" (6. 03). Colleen (enrolled nurse/ former care worker) stated:

> *We've had a lot of different clients come in- we had a psych. patient, she came a long way. Sometimes they've been in hospital for months...*(2. 2)

In fact primary nursing as a service delivery model appears to be a good avenue through which to role model for clients and this can be very rewarding for the RN as well as the client. The following is an example of the benefits for both:

> Spent time with the client for whom I am primary nurse. Have received comments from senior staff and her case worker about her progress and the "good nursing". That's rewarding. She's been to work today and she is tired and tearful. We chat and she tells me there is more to it, she has a problem with a fellow worker. I tell her what I would do and she seems happy with that... (Fieldnote entry: 17.10.02)

From the study it became clear that new nurses, enrolled and registered, do not remain with the organisation for long, often moving to new and seemingly more exciting areas of nursing. Eight nurses left the organisation during the current study. The ones that remain, although clearly suited to the role, cite the twelve hour shifts and the pay as being the reasons they stay (25.10). In fact one of the RNs commented on the changes to intellectual disability nursing and stated "it used to be a career, but now it is just a job" (3.01).

Indeed many unregulated staff cited the 12 hour roster as being one of the greatest attractions of the job. Despite the limitations of shift work on social opportunity, the staff enjoy working two 12 hour shifts, because they are followed by two days off. The staff are divided into "sections" one and two, on day shift and night shift. Workers are distinguished by which "section" they are on and there are times when this is useful in tracking information regarding incidents. Moreover the roster appears to benefit the clients, offering an optimal level of continuity of care, and a 12 hour roster has also been retained in the area of mental health in South Australia, where a primary nursing model is also used.

There is appeal in the rostering system, a tradition that has stood up to the test of time, and many industrial and political attempts to change it. Enrolled nurse, Colleen, stated *"the roster's good - the 12 hour roster"* (2.15). It is a part of the culture and it is different to general nursing. Nevertheless it became clear some of the participants believed that the roster or monetary rewards would not incite the "ordinary nurse" to work in the field of intellectual disability.

5.4.3 Downsides to the Role

The personality mix of a large number of regulated and unregulated workers, most of whom appeared to have the best interest of the client at heart meant there were bound to be days when things did not go well. For example the clients' inability to communicate or communicate effectively could be frustrating. RN, Larry, reflected on the problem of communicating with clients:

> *... you have no way of explaining to them that what you are doing is either ordered for their own good or will lead to a more comfortable outlook for them. That can wear you down* (4. 37)

Another downside to intellectual disability nursing was observed to be managing difficult client behaviours. At these times the RN draws on the care workers' knowledge of the client. In fact due to clients' intellectual disability, sabotage, such as removing dressings, and behavioural problems, even extreme aggression was commonplace. Aggression in the setting, however, was most often directed by the clients at themselves and "non compliant" behaviour was also entrenched. The following is an example of non-compliance the RNs had to contend with on an almost daily basis:

> The RN backs away from the 34 year old client stating "I can't do it, just put refused", he has been trying to convince the client to have her finger pricked for a routine test. Another RN decides to approach the client using another tactic. "I'll give you a lolly", she states and the client allows the test to proceed. The client reminds the RN about the lolly afterward. Later at handover, this story is repeated to the night nurse who exclaims "We just need to remember what age group you are dealing with". (Fieldnote entry: 1.12.03).

The RN's comment about the "age group" was, in my view, appropriate to the situation as was using the lolly as an incentive. Notwithstanding the organisation stresses that the clients are not to be treated as children, and there is an expectation that all interventions will be age appropriate. Intellectual disability nurses in this study, while seeming to appreciate the developmental limitations of clients, generally referred to them in an age appropriate way. In contrast, during the current study a general hospital RN referred to a Centre client stating that he had been a "good little boy", and yet the man was 57 years old (9. 4).

As previously observed, the occurrence of non-compliance in caring for people with intellectual disability makes it very different to other areas of nursing, and for these RNs it is well accepted and a part of the culture. However as RN, Larry (RN/ former supervisor) explained, it can become wearing:

> *There is a downside to working with the intellectually disabled. A lot of the motivation has to come from you and I think variety is necessary because if you get stuck in a purely caring role, you can start to get a bit inward and you get very tired of manipulating people, who still go about their business as though you haven't said anything, and you can take it personally, that they don't take any notice of you, or keep repeating the same mistakes or tearing at the same wound, or no matter what you do*

> *they are defying everything* (4. 38)

When asked about the support systems that he used, Larry cited his peer group and the villa managers stating that some of them are *"very good"* (1. 42) but admitted that he had known them for a long time and being in the job for a long time made it easier. In his earlier role of shift supervisor, some of the managers would have been his peers:

> *Mainly people I knew, that I had worked with over the years and who may have changed direction but were still in the system. And I knew I could go to them and voice any concerns, and confidentially pass [problems] on to them, and ask their advice* (2. 2)

Acknowledging that some incidents can be stressful for staff, the organisation offered staff counselling and debriefing sessions when required. Larry talked about not "taking it personally" and that it was very important to remain objective. He had these insights into what he called "the downside" of the job:

> *... any new recruit coming in here is going to be completely dismayed by the lack of cooperation of the clients. People could easily get very frustrated if all the work they are doing, hours spent doing dressings [for example] which are ripped off in an instant, and very little applauding, or word of thanks* (5. 38)

The following is an example from field notes: The RN who has been on duty was handing over to one commencing duty. He told of three calls to a villa to attend to a client's wound. The client had lacerated her finger and the first time the RN was called out he determined the need for the client to have a doctor suture the finger. The client's finger was sutured on site by the doctor on duty. The next call pertained to the client having removed the sutures. In consultation with the doctor, the RN applied a clean dressing. The final call came when the client would not keep the dressing on and the RN then suggested to the incoming nurse that the wound needed to be closely observed for signs of infection (12. 03).

Obviously as a result of frequent client behaviours, such as head banging, the RN is often called on to intervene with wound management and in extreme cases wounds are repaired with a "glue". This is a tissue adhesive that eliminates the need for suturing as many clients remove their sutures (1. 01).

What is more, RNs often felt helpless in certain situations, as in the following case. A young woman was banging her head on the concrete ground, splattering blood everywhere. The only sound to be heard was the "thud, thud, thud" as she cracked her head harder and harder. The RN stood helplessly by as staff attempted to cushion the blows with pillows. Staff did not have the strength to restrain her. "You can't do anything, you just stand there". After it was over, the client was still too agitated for an examination or a dressing. The care workers observed her and after two hours the RN was able to clean the wound and apply a dressing (17. 3).

While it is usual to conduct neurological observations on a client who has had such a severe blow to their head, and that is Centre policy, the RNs tended to use their discretion in that regard. Often when a client had a fall, the RN could not get near them to do neurological observations as the client is agitated and fearful of any intervention. In this case the nurse asked the villa staff to observe the client and report any concerns. The non-compliance was documented and the nurse left the villa, justifying her departure through thinking "if the client can resist that strongly, they must be alright" (20. 9).

Shift supervisor (former mental deficiency nurse), Ron, agreed that caring for people with intellectual disability is "different". He felt however that registered intellectual disability nurses would benefit from special training in the area of behaviour management:

> *Sure, in the general nursing service you can get difficult people, but I think we have a different kind of need, a different kind of service* (2.10)

Moreover many clients do not like having their personal space invaded, baulking at any invasive treatments and it is difficult to explain procedures to a client who cannot fully comprehend what is being said. The clients only see the nurse's uniform, the needle or the black bag filled with dressings. Consequently RNs in this study were faced with the daily challenge of not only being expected to use skills they may not be familiar with, but also having a non-compliant client with whom they cannot communicate. Laura (Agency RN) shared the following advice:

> *You need to understand them. You need to take a step back and go into their world, to think how you would feel if you were them* (4. 2)

Because of his background in mental deficiency nursing, Larry (RN/ former supervisor) was experienced at managing clients with challenging behaviours and he acknowledged that his expertise is called upon from time to time:

> *I also get called upon to assist when clients act in an abhorrent manner and need placating as they could be in a danger to themselves and others...* (2.1)

The following incident could have had a very different outcome had the RNs not had a special knowledge of nursing people with intellectual disability. A client with a full plaster cast on his leg was admitted to the Infirmary because he had been advised not to weight bear. He had become frustrated and angry and wheeled himself outside in his wheel chair where he stood up, just as it was starting to rain. The staff concerned about his plaster cast were begging him to come back inside (19. 20). The physiotherapist was called and all her begging and bargaining attempts were unsuccessful. Just then, the community nurse, previously a long time shift supervisor, arrived and got behind the client and with one swift pull he was back in the wheelchair. The RN pushed the wheelchair very quickly into the Infirmary, stating clearly to the client that this kind of behaviour was not acceptable and the client subsequently settled down. The RN apologised to onlookers, but not to the client, explaining that he had needed to be harsh (19. 24).

RN (former mental deficiency nurse), Dean, was concerned about issues outside of his control:

> *Issues are mainly outside of the nursing area like the quality of the staff they employ and the environment these people live in* (1. 11)

What is more, several ENs complained that equipment was not replaced and in short supply. Heather stated that *"nurses don't bother asking"* for things like more bedpans, hot and cold packs, and special aids for the Infirmary clients. They felt it was pointless to ask for such non-essential items as their requests would fall on deaf ears (1. 42).

Management of the client records known as Health Care Plans was considered, by RNs, to be a tedious ongoing task which remained the jurisdiction of the RN. Clients' Health Care Plans were kept on the villas and must accompany them to all appointments of a medical nature, including those that were out of the Centre. The client's Health Care Plan is a record of his/her health history including pathology results.

Accordingly the Care Plans should be kept in good order, however usually they were very untidy. The consensus of opinion was that this was because they are divided into sections for each discipline to write in and notes were entered in the wrong place making it very difficult to access information quickly.

During the current study, interest and responsibility for health care plan management fluctuated. There were spasmodic sparks of interest in plans designed to organise the nursing staff into teams to address the area, all short lived. The inconsistency in the maintenance of Health Care Plans was perceived by myself to be due to the busy schedules of the nursing staff and lack of clarity as to who was actually responsible for them. Management did not pursue the subject and the nurses' interest in fixing the system was short lived.

However in response to this issue, I conducted a series of information sessions for workers to assist them in understanding their role in Health Care Plan maintenance. These efforts were greeted with jokes and comments such as "why should I learn how to do that, that's not my job", "I'm only a carer", and "that's your job" (2. 02). The RNs found the job of Health Care Plan maintenance frustrating and time consuming and the problem was exacerbated by unregulated workers making entries in them incorrectly. All of the workers commented that it was not their job.

Laura (Agency RN) described the confusion about the Care Plans when Centre clients were seen in a general hospital emergency service:

> *The thing I'd find the hardest is the clients would come in with their big blue folders that have their entire history in it but if you want to look up something really quick you can't access it. We don't know how to read their folders, we don't know where to look when we need a quick overview. We need an overview when it comes to eating, drinking, continence management , ambulation...* (2.19)

Every client should have, in their Health Care Plan, a completed general hospital referral form ready to be given to hospital staff when the client presents for treatment. The following is an account by Laura of one instance when she was on duty in the emergency room of a general hospital when the referral form was not completed:

> *A lady came in with hypertension. Her BP was 270/180. The carer had never worked with her before and when I started asking questions, she couldn't tell me anything about the lady, she just handed me the care plan and all I wanted was a letter, I wanted something to give me a quick view of this lady, did she have a behavioural problem? Was she easy to handle? What is her past medical history?* (2.36)

I asked the participant "Did she have a general hospital referral form?", to which she replied:

> *I did suggest to someone that they could just have one piece of paper with client name, age and basic things like whether they can eat, drink themselves, whether they were independent or fully dependent, their continence regime, choking risk, behaviour, just grouped into low,*

> *medium, high - just so we know what to expect* (L. 2. 45)

This was an all too common occurrence where there was a form but it was not included in the client's transfer plan when attending a general hospital. It was unclear who was responsible for completing the forms. The general hospital referral form is an important document outlining the organisation's resuscitation policy stamped in red. It was policy that all end of life decisions could only be made by the director, and this included palliative care orders.

Another downside of the role was the organisation's attempt at keeping abreast of the times in a technological world. Notwithstanding the dated systems of communication and documentation, computer terminals were installed in the villa manager's offices during the current study. It is difficult to determine the purpose of the computer in the Infirmary nurses' office because only the RNs had access to it and that access was limited to the nursing data base, where information could be entered, but not retrieved. The RNs could also access the world wide web for information on intellectual disability but they were unable to obtain credentialing records for the staff they credentialed.

The introduction of computer technology meant that RNs were then required to estimate a time for every nursing action undertaken, and statistics were entered into the data base daily. This was not compiled in consultation with the RNs and it seemed to depersonalise care reducing it to service provider, location, intervention and duration. The statistics were kept to ensure adequate provision of nursing staff and reflect the use of nursing hours. Some treatments were costed back to the service recipient, so the statistics assisted in this process as well. Each nurse was listed on the computer as a service provider (11.1).

Obviously it was time consuming entering statistics into the computer. Until recently, the monthly statistics were compiled by RNs manually from the diary, and that often took a day depending on interruptions and callouts. Nevertheless RN, Larry, compares the Centre's practices to those of general hospitals:

> *We are given time to do things here, and we are not forced into clinical movements by a computer, by Excelcare, which says this job should take 5 minutes and you'll need these three bandages, and it will cost this much* (6. 27)

In fact (at the time of writing) the computers at the Centre were not used to design nursing care plans and the RNs were afforded licence to record the actual times that interventions took. It could be the organisation's intention to use the computers to replace some of the paperwork although this seemed unlikely as much of it required the signature of a manager because villa managers were required to consent to treatments. Consequently there were forms for referrals to health professionals, treatment orders, medication approval, annual medical review forms, to name a few of the commonly used forms.

5.4.4 "The hub of illness care" and future plans

The commencement of the Centre's nursing service in the late 1990s was largely due to the efforts of two RNs who have remained in the positions they helped to create. A key figure in the reconstruction, George (manager/ former mental deficiency nurse), described the evolution of the 24 hour nursing service which initially was a day shift only position for RNs, with care workers working in the Infirmary.

> *Down the track it became clear that we needed people with a health focus so we could be freed up on more of an outreach basis. We proposed that the positions in the Infirmary, the disability officers be transferred to residential and we took on ENs....it's important to note that the criteria for employment wasn't to have a disability background because health was the main thing. Disability awareness could be improved and built on down the track* (G. 1. 21)

A short time later, RNs were assigned to the night shift, creating the 24 hour nursing service:

> *...looking after the seven bed Infirmary and supporting all of the people that are here (the Centre), long stay clients and then that gradually increased to nominated community houses as the community numbers grew* (G. 1. 30)

As a result of the introduction of the developmental model, the Infirmary became the hub of illness care within the Centre and out- patient services were provided by the Health Centre. The non-life threatening milieu of the Infirmary was the perfect place for rest and recuperation and it was often referred to as a *"little hospital"* (A. 2.16). The Infirmary was also a base for the RNs.

However, in recent times the Infirmary became a place of respite for clients who have nowhere else to go. Colleen (former care worker/ enrolled nurse) spoke of how some clients entered the Infirmary for treatment *"and then remain awaiting placement often for a year"* (1. 5). For example when clients are awaiting placement, the villa managers could select clients they considered to be compatible with the environment and clients currently living in their villa. Similarly, the family of clients awaiting placement had a choice of whether they considered the villa to be a suitable home for their loved one. The decision making process about suitable residential placement often resulted in clients waiting in the Infirmary for long periods of time. During the current research, one mother visited her son in the Infirmary because he had special care requirements and was difficult to place. While his mother wanted a good villa or house for him she was pleased with the care he was receiving in the Infirmary and did not seem to want to rush the decision making process about placement (3.12).

RN (former mental deficiency nurse), Dean, agreed that the Infirmary setting was not acute *"we don't have very sick people"*(1. 14). Karen (enrolled nurse) was concerned about the Infirmary being used as a *"dumping ground"* and made the following comments:

> *The downside is the way they fill the place up with people who are crisis or respite cases. Oh, and the noisy ones get me down. We don't get enough support. They have the wrong priorities. We're expected to know everything about these clients and everyone has different skills. I learnt off my partner (enrolled nurse). We are a very vulnerable group. We can't administer medication for example to violent ones. You have to think of other client's safety as well* (1. 24)

However during the current study the Infirmary was often the solution when villas were reluctant to keep clients for one reason or another, such as when there could be a danger of further injury from fellow clients. Sometimes, the villa manager just felt happier for clients to be looked after by nurses, and sometimes people with behavioural problems or nowhere else to go found themselves in the Infirmary. The nursing staff did not always agree with admissions and some clients stayed for a long time and ultimately were put on waiting lists for alternate accommodation (10. 02). However George (manager/ former mental deficiency nurse) stated that the situation had to change:

> *...because the Generational Health Review [state government] wants the health care of all South Australians to be provided by the health sector [hospitals]* (2. 43)

Indeed having an Infirmary was not a part of the organisation's long term plan and during the current study there was a trial period when it was closed however it was found there were sick clients who needed to be in the Infirmary and it was reopened.

During the closure many care workers expressed their concerns about who would care for sick clients because they did not want the responsibility of clients who were unwell on the villas. In addition the RNs were concerned that plans to close the Infirmary would have an adverse effect on clients.

Manager, George (former mental deficiency nurse), described plans to close the Infirmary once a *"specialist disability support service"* is established (2. 20). He elaborated stating the service (at a local hospital) would provide:

> *...a referral or multi-disciplinary, multi-professional approach for general practitioners and disability support agencies...we'll look at the best way of meeting a person's health needs in terms of clinical pharmacology, psychiatric support, behavioural intervention, general practice from our experienced GPs, neurological support, nursing assessment and nursing support, physiotherapy unit ...we're also looking at the role of the nurse in general practice* (2. 27)

Notwithstanding these plans, there is no provision for acutely ill clients in the Specialist Disability Support Service which opened in 2005 although George conceded:

> *There might be a need for a day clinic, for example to conduct Midazolam trials, or whether we can arrange to do this in rooms with a nurse present, or in a hospital setting. I don't know* (2. 47)

At the same time no participant could think of any suggestions for changes to the nursing service. RN Dean stated *"No, none that I can think of"* (1. 23) and most reported a high level of satisfaction with the service. This was consistent with Verna's (a parent - see Table 4-2) comments:

> *No, I'd just say they're doing a wonderful job and I can't think of anything else they could do to better the service* (2. 4)

Likewise Sarah, a supervisor, stated that *"there is always room for improvement"* but she could not think of anything that could be done to improve the nursing service (2. 2). Moreover clients appeared to be happy with the service and it seemed that both clients and workers, would have liked the nursing service to remain as it was, because they do not feel comfortable with change. A culture that does not like change was clinging to that which was familiar (34. 8).

Naturally the changes to the nursing service, the down sizing of the complex, and the move toward community living had affected the staff. Some now (at the time of writing) worked in different areas and with different work partners and client groups. Many expressed some degree of uncertainty and fear over the security of their jobs, but most of this concern was for the future care of the clients.

Indeed the workload in the Infirmary and the RNs’ community commitments were not taken into account when determining nursing staff numbers. However the number of nurses was always maintained at one RN and two enrolled nurses during the day. At night, one RN was based in the Infirmary where they delivered hands on nursing care to any number of clients, up to seven. There were times when there were people in beds in the lounge room, but mostly during the current study, the average number of clients was four (7.12). As stated previously absent staff were usually replaced by an Agency nurse.

On the other hand the nurse manager was seldom replaced during periods of absence despite it being a part of the RN's job description that they may be required to replace the manager. During such times extra pressure was placed on the RN:

> It's very busy and the health services manager is away, the nurse manager is acting in his place but no one is appointed to the nurse manager position. I have more work to do. (Fieldnote entry: 15.12.02)

Replacing the nurse manager with a RN would have required a replacement for the RN. The nursing service which has a casual pool of one RN and an Agency nurse would be a costly solution to the problem so, at those times, the registered nurses were observed to take on some of the nurse manager's work such as purchasing medical supplies and liaising with villa managers (3.02).

The uncertainty about the future of the Infirmary has most concerned the Enrolled Nurses; they are entrenched in the current culture of the organisation. The RNs have been assured by management that their jobs are safe and they are being encouraged to make suggestions for positive change.

5.5 Having to Assume Responsibility for a Large Number of Unregulated Workers

It was observed that the RN had day-to day contact with many staff and a large number were unregulated workers or carers. During the current study there was no requirement that care workers have any qualifications and some of them had no previous experience in the health care sector (Personal Communication: F. Walsh 2.2.06). Others had been employed by the Organisation for many years and had a good understanding of the client. Indeed it was often the case that RNs became acquainted with the clients needs through their care workers.

5.5.1 Interaction with Registered Nurses

Most of the clients had known each other since they were children, having grown up together. There were many close friendships, some bickering, laughter and genuine camaraderie. Many care workers knew the clients well and could tell stories for example about outings they used to have when the clients were younger. A carer related a story about a client, who used a wheelchair at the time of field work, who used to walk when they went shopping together and always carried a handbag. (17. 3).

Shift supervisor, Sarah, expressed the belief that the group of nurses currently employed (during the study) had good skills that everyone felt comfortable with and "*when you know someone, you can ask them anything"* (2. 34). Colleen, an enrolled nurse who was formerly a care worker, spoke of the special knowledge that care workers also had of clients, stating that nurses had the knowledge to look after the clients' needs but *"with the help of the [villa] staff that look after the clients as well"* (1. 31).

Indeed villa staff agreed on the benefits of mutual trust that developed between the registered nurse and the villa staff (21. 9) because often the villa staff could get clients to comply with treatments, when the nurses could not. Thus the registered nurses found it useful to get on well with the care workers. Care workers often knew "little tricks" to get clients to comply and if the nurses had problems, they often called on villa staff, even when clients were in the Infirmary. Nevertheless it took time to build a rapport with care workers as they needed to learn to trust the registered nurse in order to share information about the client. Similarly, the care worker could call the nursing staff when clients were sick as the care worker was with them frequently and knew what was usual (25.11). Colleen, an EN, formerly employed by the Organisation for many years as a care worker, stressed how important it was for the nursing staff to *"have a good relationship with the (villa) staff*" (2. 2).

Because care workers knew the clients well, Colleen believed it was possible to enlist the aid of staff who look after the clients and that they did have the potential to be taught basic health care skills. For example she suggested training for care workers in *"...general nursing and hygiene*" (2. 23). Describing it as a "*team effort",* Colleen expressed the view that the clients needed input from the care workers as well as the nurses, and said *"if you get a lot of input, you'll get a good result"* (1. 32).

Care workers had knowledge of the client and while they were unable to explain nursing procedures they could provide support, Sarah (shift supervisor) explained:

> *It's a bit hard, but they get to learn some of the behaviours to look out for and to get a better understanding of them by working directly with people* (3. 10)

George (manager/ former mental deficiency nurse) highlighted a major difference between general hospital nurses and Centre RNs in this way:

> *Our nurses' role differs from that of the hospital nurse because it contains a support component for the carers- they rely heavily on the nursing staff. Whereas in hospital it's usually short term and your job is to support the client* (3. 45)

Indeed the perceived dependence of care workers on the RNs was observed to be a part of the culture. The exclamation "But I'm only a carer!" was often heard, and this is discussed in chapter six, in terms of lack of knowledge, and the theme "attitudes of workers" (60. 22). Being *"only a carer"* (and that was the worker's opinion, not necessarily the RN's), provided an opportunity for the nurses to share their knowledge on health care issues (DF. 2. 15). In exchange, the workers shared insights about the clients, for example:

> I was called to see this client who "is not his usual self", not eating. By the time I arrived he was doubled over and had a temperature of 38.4. I sent him off in an ambulance and he was admitted to hospital with IV fluids for investigation for a possible bowel obstruction. Good call? I don't know, I just listened to the carers who know him well (Fieldnote entry: 16.9.02)

Nevertheless the RN needed to exercise good judgement and discretion in deciding on actions that could be perceived as "interfering" and the following observation is an example of the interplay between the RNs and the villa staff. A client visited and complained about issues on her villa. The RN suggested that these issues should be taken up with the villa staff but the client persisted, stating that the RN should help her because "You are a nurse". Such is the unquestionable faith clients had in nurses and the expectation that they could fix any problem. The client complained that the villa staff did not listen and did not care.

At the same time the RN knew something of the client's history and that she had a potential for self destructive behaviour when confronted with such feelings of helplessness. The RN telephoned the villa and spoke with the person in charge who was able to paint a clearer picture of the problem. Given this new information, the RN was able to help the client solve the issue (15. 3).

However, not all of the RNs interactions with care workers were positive, and some care workers could be rude and dismissive, for example:

> There is a message that a client has a "sore eye". I take an eye pack and go to the villa, the shift supervisor is nowhere to be seen, so I go to the client's unit. No one acknowledges me, they are busy giving out breakfast and I speak to a carer, but she doesn't look up from what she is doing. I examine the client and perform an eye toilet. I tell the carer to observe it and let me know if it gets any worse, but I may as well be talking to myself, there is no reply. I write in the client's health care plan and in the report. I leave knowing that I have done the best I can (Fieldnote entry: 1.12.02)

In addition RNs conducted a good deal of informal staff counselling and the following is an example. A visit from Centre care workers had caused a problem at the local general hospital. The Centre RN was making a routine visit to the hospital to be told that a hospital employed nurse was in the tea room in tears after being confronted by two villa care workers who complained about a client's care. The intellectual disability RN adopted the role of counsellor, listening and trying to explain that "some of the carers treat the clients as if they were their own family" (8. 11).

This situation was then reported to senior management who agreed with the RN's actions, later stating at interview:

> *Everyone in the team is ambassador, you shouldn't wait for your manager to build the bridge, everyone should be doing that* (G. 4. 20)

The care workers’ attachment to their clients was observed in such actions as visiting sick clients in hospital, in their own time. Patterns of care worker behaviour indicated a strong concern for the client and most conversations with the RN revolved around the client as a person and sometimes the client as a patient.

Moreover RNs provided role modelling, not only to the enrolled nurses they supervised, but to other workers. This applied to their nursing practice as well as adhering to the rules of the organisation, for example:

> Frantic call from a shift supervisor to ask for help to find a medication because the other section has gone off for the weekend without ensuring

> an ample supply. She wants to "borrow" from another client if possible. I point out that this contravenes policy and organise for a locum doctor to prescribe the medication (Fieldnote entry: 28.4.03)

Incidents such as in the previous scenario describe the manner in which the role of the RN was constructed because of the responsibility of overseeing the actions of a large number of unregulated workers. The RN was accountable for ensuring workers are competent to perform delegated care tasks and, as a "senior" member of staff, were responsible for upholding the Organisation's policies.

5.5.2 The Carer as a Credentialed Worker

The RN's workload was eased through delegation of care, in as much as certain health procedures could be taught to care workers and the most common example of this was medication administration. The RN conducted the training for this skill which was called "credentialing". Although there were seldom any reported incidents with medication management a concerned family member (Verna) made this observation:

> *I believe that only nurses should give out medication, because I believe that the carers in the centre and out in the community are not experienced to handle drugs and personally there has been an error made with my own daughter, where medication has been forgotten through inexperienced people handling drugs* (1. 33)

Intranasal Midazolam was (at the time of writing) a good example of a drug which should only ever be administered under the strict guidelines of RNs, as the ampoules were designed for intramuscular administration, but it has been discovered that intranasal Midazolam is therapeutic in the treatment of prolonged seizures. The Centre RNs credentialed care workers to administer the drug by the intranasal route. Generally, however, the RNs and non nursing staff believed that invasive treatments should be carried out by registered nurses.

In the future it will become mandatory for RNs to complete a Certificate 1V in workplace training prior to undertaking any credentialing. This is a nationally recognised training package in Australia and, in 2005, the RNs at the Centre were given the opportunity to complete the course at no expense to themselves. Three of the RNs, realising they would need the qualification to do their jobs, accepted the offer. Those that did not undertake Certificate 1V training believed their skills would be better utilised in other areas besides credentialing.

Prior to the introduction of Certificate 1V, RNs were "thrown in at the deep end" as far as credentialing was concerned. (5. 01) A basic training in credentialing was available, but this was not enforced. This has meant that for RNs the only preparation for the task has been his/her RN training and the individual's experience. This issue will in future be resolved, because by 2007 no care worker will be employed in any health care setting without having received medication credentialing (a Certificate III qualification).

In fact RN (former shift supervisor), Larry, described credentialing as the organisation's way of replacing the trained mental deficiency nurses that used to work in the service. He felt comfortable with his teaching role and with his level of knowledge:

> *It's mainly community based and the core of my work is to credential carers in the procedures that used to be the role of trained nurses in our service, when we had trained nurses* (1. 8)

Care worker, Dorothy agreed, stating that RNs *"have all the professionalism behind them so you trust them"* to conduct credentialing (2. 4). In contrast, on a cautionary note, EN Colleen was asked to comment on the RNs' skills in credentialing and whether she felt they were qualified:

> *I think it depends what area they're credentialing in and the knowledge they have and the study [they have completed] and their background* (1. 36)

The RNs are aware that credentialing does not end with the initial skill taught as evidenced by the following example where a care worker should have been checking medication administration records against administration:

> A care worker is observed administering medication from the packets, when I ask him where the medication folder is, he points to it on another bench, stating "I put it there for you, because I heard the car pull up". I accept this reason, but do not really believe it (Fieldnote entry: 15.11.02)

Credentialing for medication administration is the most common skill that RNs taught, but officially there were a number of health procedures that care workers could be credentialed against. These included routine observations of blood pressure, temperature and pulse. Care workers could also be credentialed to test blood glucose levels (BGL) which involves a finger prick and the use of a small machine to measure the level but not many care workers chose to do this, and it was generally the role of either the registered or enrolled nurse who were also the only ones who can give insulin:

> The client's BGL has not been done and the carer claims that he thought the RN did it. I asked if he was credentialed for BGLs, which he is and I explained that the RN will only do the BGL if there is no credentialed carer. I do the BGL. The carer enquires "Who normally does the insulin?", as if he has never seen me before. He has. I tell him myself or another RN and he asks "What about that blonde girl?", he is referring to one of the enrolled nurses. I tell him that sometimes the enrolled nurses do it to help out, but that it is not really their job (Fieldnote entry: 23.12.03)

At the same time, unofficially, RNs taught such skills as catheter bag emptying. A client's catheter kept "falling out" and the RN was required to give some basic anatomy lessons to the care workers to ensure this did not happen (6. 03). The RNs have also conducted some training in diabetes management and the treatment of constipation. In delegating care it was essential to ascertain the skill level of non-nursing staff, as mistakes could easily be made.

5.5.3 Training for the Carer Role

The quality of untrained staff employed at the Centre was of concern to all of the RNs and to some of the long employed workers who had to work with inexperienced people. A carer cited the two things wrong with the Centre as being the training of care workers and the management. He believed there was no proper training and gave a comical example of a new employee who put a client's shoes on the wrong feet.

He advised it was generally the case that long employed workers did not like working with new recruits who "do not know what they are doing" (21. 3). Another care worker was of the opinion that "you can't do anything right" because he believed the organisation does not acknowledge people's skills. He was referring to poor skills mix on the villas such as two casual care workers working together who did not know the clients (28.12). There was a general feeling that care workers needed more educational preparation for their role. The care workers had basic training in interpersonal skills as part of their orientation, but many of them were young and did not know how to manage difficult client behaviours.

Enrolled nurse, Heather, made the following suggestion:

> *Carers need more intense training. Quite often they come in off the dole queue or are just desperate for a job and think OK, I can do that, it's not so hard, you just get these people into the showers. They don't see that these people have special needs. They need a disability training course* (1. 27)

Colleen, an EN who had been a carer, also stated that care workers should receive some health care training and suggested this could be in the area of "*communication, behaviour, and general hygiene"* (2. 22). She also said that the care workers have *"special skills"* which could be better utilised if they were to receive some basic training in health issues (1. 27). She elaborated stating:

> *For carers, basic nursing care, like ENs do and basic observations temperature, blood pressure etc. and communication - they don't talk but there are other ways you can tell if someone's in pain* (C. 2. 27)

5.6 Having to Work Alongside Many Professional Groups

The nursing service at the Centre was separate from other service provider groups. The registered nurse was overseer of health care and leader of the nursing team, second only to the nurse manager who did not play a clinical role. Clients and their care workers appeared to have a good grasp of the RN’s position in the nursing team. On the other hand some members of the allied health team and other nursing agencies did not seem to understand the RN’s role.

5.6.1 Enrolled nurses

In most nursing settings registered and enrolled nurses work as a team, however the intellectual disability EN’s role appeared different because it was largely autonomous. The RN placed a great deal of trust in the enrolled nurse and vice versa because the EN needed to know that the RN was available when needed to give support and supervision.

ENs were an integral part of the nursing team, and care for the clients in the Infirmary, usually with minimal supervision. South Australian Nurses Board legislation requires that an enrolled nurse must be supervised either directly or indirectly by a RN. Enrolled nurse supervision in this setting was usually provided by telephone as the RN was not always present in the Infirmary.

EN, Heather, confirmed my observation about the level of supervision of the ENs at the Centre:

> *I feel the enrolled nurses here have a lot of autonomy actually more so than I ever did in general (nursing), but the registered nurses are here if you need them as well. A lot of things we do here are in support of the clients, so not everything is vital that you need someone standing by all the time, but if you need the support, it's there* (1. 36)

Another enrolled nurse, Karen, described her confidence in the level of supervision and support provided by the registered nurse in this manner:

> *Totally! One, because we have the phone all the time and if anything happens we can call and there's always back up from someone, otherwise we just call an ambulance. Even though the registered nurse is not here most of the time, because they're out and about, we know where they are, and if we can't contact that particular registered nurse, we can always call the Health Centre or something. There's always support here for us, most of the time by phone* (2. 45)

RNs were observed to have more day-to-day contact with the ENs than with each other and Laura, an Agency RN had this to say about the nurses currently employed by the Centre's nursing service, who supported her in her role:

> *All the RNs here have got heaps and heaps of experience and I find that I can ask each of them anything and they fill me in which is helping me. The more I come here, the more I learn. In general there's not much they don't know, the experience they have within the Centre and the community and the Infirmary, it's amazing* (4. 32)

Registered nurse Larry was asked about his supervisory role of enrolled nurses:

> *Fairly loose. I don't work fulltime in the Infirmary so basically because I find their level of competence is so high I'm only too glad, unless they come to me with a problem, when I'm in charge, they work unsupervised, and have to. The system is set up like that, to allow the registered nurses to be on call to 300 clients, living in the Centre, and to meeting the needs of "come here quickly, so and so's fallen and split their head open". So there are times during the day when you can all get in the office and certainly, it isn't idle gossip, most of the chat is around clients and it is fairly normal for them to ask our advice, and it is a loose relationship* (4. 13*)*

Sometimes however it was evident that some additional support would have been welcome and enrolled nurse, Heather, shared the following concerns with me:

> *The negative aspects or areas where I sometimes feel I'd like more direction would be the judgemental things, all the iffy things, things where it's really hard to put a finger on something because they're not really yes or no answers. When someone needs PRN, a judgement call, when someone is unsafe, when someone is unable to be in that environment....* (2. 16)

The RNs acknowledged the benefits of the EN's ideas and the assistance they gave based on their special knowledge of the client. Obviously clients were influenced by the nursing staff and RN, Angela, suggested the service could be expanded to include:

> *Promotion of better health, like telling people of the community the stuff that we do, visiting them, and doing stuff like 'slip, slop, slap' and giving up smoking, that sort of positive stuff, relaxation, encouraging people to destress, that sort of thing - we could do that* (3.5)

Although they knew the RN is "the boss", clients related to the EN in much the same way as they did the RN. Moreover the managers and care workers always requested to speak to the RN rather than the EN, consequently when the RN returned from community visits, there were always a number of messages. The messages often pertained to issues the enrolled nurses could deal with, but the villa staff persisted in speaking to the RN.

5.6.2 Attitudes of general hospital nurses

Some participants felt that intellectual disability training should be offered to general hospital nurses. Larry (RN/ former mental deficiency nurse) spoke of the historic downside to intellectual disability nursing, and suggested that a solution could be to conduct lectures for general hospital nurses:

> *...for years the mentally deficient as they were called, which is bad enough, were the Cinderella of the service. [Mental deficiency nursing] was the last stop that nurses went into. Instead of being seen as a specialty, it was seen as something those who wouldn't make it as nurses went to do. Unfortunately it seems to be somehow we need to promote the specialist role. We don't need many people, but if we could just capture a few nurses that suddenly think 'this doesn't look too bad'. At least when we present at a general hospital, [they would think] 'Oh yes, I remember those lectures this person is straight out of the text book, as far as their behaviour is concerned'. I can see it as a win - win situation* (7. 2)

Sarah, a shift supervisor, suggested that knowledge of intellectual disability nursing needed to be more widespread, due to the high number of clients now living in the community. In fact with an increase in community style living, many staff felt that programs are needed to heighten the community's awareness and acceptance of people with intellectual disability.

Moreover there was a perception that general hospital nurses did not know how to deal with people with intellectual disability as illustrated in the following excerpt. The visiting RN from the Centre approached a room in a general hospital, just as a nurse emerged. On sighting the visiting RN, the hospital nurse said "he just broke a window". The visiting RN entered the room, but by this time the ward staff were organising restraints. Apparently the client was upset because the nurse offered him medication which he was unable to swallow whole. He had then flung it out of her hand, picked up a chair and broken the window (13. 9).

Dorothy, a care worker, described the approach of the general hospital nurses that she had encountered, stating that they did not know how to deal with people with intellectual disability, so *"they just stand back and don't know what to do*". She expressed the view *"they may be good nurses, but they have no idea"* (2. 17). She stated that general hospital nurses were *"lost as to what to do"* when faced with the person who has intellectual disability (DF. 2. 30). One of the night shift supervisors suggested that *"working with the disabled for a period of time would be of benefit"* to general hospital nurses, to aid understanding of care issues (R. 2. 10).

There is a feeling that general hospital nurses are frightened of people with intellectual disability and I, as the researcher, and others can relate to this because sometimes clients could be frightening, until you got to know them. Enrolled nurse, Heather, described the fear of the unknown by stating *"it is frightening at times to be left alone with people with behavioural problems*" (1. 34)

In contrast Laura, an Agency RN, said she found it more daunting in the accident and emergency section of the general hospital to be confronted by a mental health client who was seemingly out of control than a person with intellectual disability. She described a different approach by general hospital nurses to the mental health client:

> *...[hospital staff] seem to be able to run to them and sit on them and control them. They seem to view the two differently* (3. 8)

Furthermore she stated that there was a false perception in the general hospital that all people with intellectual disability have behavioural problems:

> *In fact there's really only perhaps a minor percentage that have a behavioural problem linked to the intellectual disability. I observed that the staff in A & E (Accident and Emergency; now called ED Emergency Department) didn't spend much time with them either. Whether it was their lack of understanding or fear* (3. 2)

It was a part of the disability RN's role to make daily visits to clients who are hospitalised and such observations were not unusual. I made this observation:

> It is unfortunate that the general hospital nurses have no idea of what our role is. I have been refused information and told that "his other friends came in this morning, ask them". That is the main problem, they confuse us with the carers and have to be told that we are RNs repeatedly before they will give us any information or respect. There is no RN on the general hospital liaison committee although we are the ones who visit the hospitals (Fieldnote entry: 15.10.02)

Notwithstanding Larry (RN) had this to say about the manner in which the Centre's nursing service was accepted by the general hospital staff:

> *I really find that in general hospitals it's good to remember to say who you are and the fact that you are a RN, because they are used to everyone from domestics to carers to managers ringing them up and asking all sorts of details of a person's status or why wasn't such and such done or when was it getting done or has a decision been made on a prognosis, and they're firm on protecting a person's privacy....I find very little resistance to us, in fact some people are so pleased you're a registered nurse because they can identify with that role in you and then they perceive that you have a more specialised information* (4.1)

Similarly, Angela (RN) felt that the general hospital nurses who care for clients during periods of acute illness were grateful for input from the RNs from the Centre:

> *They treat us well, they're sometimes unsure of our role but once you introduce yourself they're most helpful and grateful for your assistance. Sometimes I think they want reassuring that they're doing the right thing for our clients. Because we speak for our clients in areas where they can't speak for themselves* (3. 22)

Laura (now an Agency RN) had been a student nurse on placement in the accident and emergency department of a general hospital. She described the experience of going to hospital as frightening for a client with intellectual disability, however she suggested it would be for anyone:

> *If you look at it from the client's point of view, they're going into a strange environment, it's busy, lots of people, they are going to be frightened but no more than the general public person. I don't think that enough reassurance is given and I feel that if nursing staff just took the time to reassure them, they'd be a lot easier to handle, they wouldn't need specialling* (3. 33)

Laura referred to "specialling" a situation when the Centre or indeed the hospital provided a care worker to support the client during all or part of their admission to hospital. It was common practice to "special" people who have behavioural problems or those at risk of interfering with such things as intravenous lines and catheters. In fact Laura stated:

> *A couple of inpatients recently had carers because the staff just couldn't look after them or they didn't have time or they viewed them as too hard to look after but once they got back to the Infirmary, they weren't specialled. I know that we had five clients here a couple of times and sometimes only one staff member, so it just goes to show that you do have to know what you are doing and understand the clients you are looking after. I don't understand how one person can look after five people here and yet in a general hospital five people can't look after one* (3. 26)

I asked the participant (Laura) "How does it compare with the way they (general hospitals) treat psychiatric patients?". She replied:

> *It depends on the situation the psych patient is in. The more violent, they are treated aggressively, ID clients are much more ignored. One day, a man came in [to Accident and Emergency] from here [The Centre] to have sutures removed from his head, he came in with 4 carers and we had to gown up because he was a spitter. There were 8 of us. We had on big plastic masks and gloves. We would have looked like aliens to him, which made him more frightened. Intranasal midazolam didn't work, he sneezed it out, he was held on the floor. A procedure that should have taken 10 minutes took 4 hours because the staff didn't know how to treat him. In the end, a doctor who works at the Centre was rostered on the afternoon shift and we waited for him. I went in with him and 2 carers and we got the sutures out in 5 minutes* (3. 39)

The previous scenario demonstrates the difference that knowing how to treat the client made. I commented: "So you really need experience?!" and again Laura stated that all that was required was to put one's self in the place of the client:

> *If you look at it through their eyes, they are frightened, we must have looked like we were from Mars* (4. 3)

5.6.3 Agency nurses

Of concern was another group of nurses who appeared ill informed on the subject of intellectual disability nursing. This group involved enrolled and RNs employed by nursing agencies who were utilised to fill shifts in the Infirmary during times of staff absenteeism. Laura's (RN) first contact with The Centre was through working for a nursing agency whose staff did not tell her the business of the Centre when booking her for the job. She stated this was because nurses tended to "*steer away from"* intellectual disability (1. 24). Laura, reported having to acquire skills at the Centre she had never before used (6. 3).

Accordingly, the care workers generally viewed Agency nurses as strangers who did not know or understand the clients. A long time care worker had this to say about

Agency RNs:

> *...I feel sorry for them in a way, you do your best because they have not worked with intellectually disabled clients... you're doing your best to initiate them to the clients' needs* (D. 2. 20)

And nursing viewpoints:

> *I've worked with a couple of Agency people who just can't work here. They come here 'cos it's money and that's it. They don't put in the care like the people who are long term here* (L. 1. 35)

Karen, an enrolled nurse, was of the opinion that Agency nurses felt frightened and out of their depth:

> *There's just the need for orientation. Agency nurses are frightened. They get no preparation...* (2. 4)

Shift supervisor, Bevan, had only positive comments to make about the Agency nurses who are employed by the Centre:

> *...the Agency nurses we have had have never stuffed up badly, I mean they've never done anything that we've had to call them back and say this is unprofessional and I guess the [regular] nurses that are here at the moment, I have a lot of faith in them, I think they're doing a good job* (2. 10)

In contrast, highlighting the need for good general nursing skills, enrolled nurse Karen described a scenario where *"even a registered psychiatric nurse [Agency] was out of her depth with no physical assessment skills"* (2.3). Moreover a care worker was adamant that the Centre was no place for Agency nurses. She said she did not envy them the daunting task of working in unfamiliar territory and that more funding should be available for more regular RNs:

> *It's not fair on the agency nurses having to put up with all that stress, the client and the agency person, it's not fair. They should do something. The government should have a better understanding all round* (DF. 3. 32)

5.6.4 The allied health team

In addition to being clinical leader of the nursing team, the RNs played a major role in the Centre and the wider organisation. However the RNs tended to work alone or with other nurses, having little to do with the other members of the allied health team located in the Health Centre. The RNs were based in the Infirmary, but much of their work was carried out within the Centre and the wider community. There were two RNs based in the Health Centre which was in a separate building to the Infirmary.

Because those RNs' roles were different to the Infirmary based RN, one was the occupational health nurse and the other a community nurse, any nursing issues were always referred to the RNs based in the Infirmary.

However, because they cared for them and could report on their progress, doctors and physiotherapists tended to consult with the ENs about the Infirmary clients. Doctor Mick, who was unable to define the role of the RN in disability service, observed that registered nurses are *"good team members"* (1. 5). Similarly, one physiotherapist had trouble knowing the difference between an enrolled and a registered nurse and despite repeated correction, insisted on delegating work to enrolled nurses for which they were unqualified (5. 42).

During the current study, a psychologist enlisted the aid of the two RNs who are trained psychiatric nurses to conduct client counselling. The result was a pleasing team effort which benefited the client and is ongoing at the time of writing (11.02). Overall, the relationship was one of mutual respect, a team of professionals working for the good of the client. I developed an easy rapport with the medical officers and one in particular was observed to take an interest in the current study.

Members of the allied health team were observed to utilise the RNs' special knowledge of intellectual disability. It was clear some of the RNs had developed a good rapport due to longer contact with the clients than other members of the team. Larry (RN/ former supervisor) described the vast wealth of knowledge the RNs brought to the team:

> *Most of them bring if not a direct knowledge of intellectual handicap, certainly years of experience in psychiatry and other community care of all sorts of people. So what a wonderful mix of both clinical and psychological and psychiatric assessment tools these people come with* (2. 22)

5.7 Having Different Educational Needs

The cessation of mental deficiency nurse training in the early 1980s had left South Australian nurses without educational preparation for careers in intellectual disability nursing. The current study revealed that the role of the intellectual disability nurse was limited by lack of opportunity for education. Furthermore systems should be in place to educate nurses in other settings about intellectual disability, since much of the knowledge and skills associated with intellectual disability nursing will be lost when the current population retires.

5.7.1 The need for education

Some syndromes are common to people with intellectual disability and there was a range of these that could be observed in the clients at the Centre. A well known example is Down syndrome, a condition resulting from a chromosomal abnormality. RNs at the Centre also encountered a number of quite rare syndromes in clients such as Phenylketonuria, Williams Syndrome, Prader-Willi Syndrome and Angelman's Syndrome. Syndromes such as these may dictate not only client behaviour but also health maintenance needs. Mental deficiency nurses were taught about the known syndromes and expected outcomes and appeared to have been comfortable in managing the relevant health related issues associated with these syndromes.

The following is the view of Verna, a parent, who said that RNs should be taught about the different disorders they encounter in their work. She stressed that training in the management of epilepsy would benefit the RN:

> *...dealing with epilepsy because there's different types of epilepsy and mainly that's one area that the nurses could be trained in what to look out for in the various seizures* (V. 2. 13)

Colleen (enrolled nurse/ former carer) had this to say about where training should take place:

> *In the Centre, because you've got the support of other people that you're training with and you've got the hands on as well. If you just go and sit in a classroom somewhere, you're not going to get the hands on. If you combine the two together, you're going to have a better result* (2. 37)

Heather (enrolled nurse) made this comment about registered intellectual disability nurses:

> *They need specific training too, preferably on the job with a supervisor who can give assignments and back up with theory* (1. 33)

Karen, an EN, was concerned that some of the nurses had not worked as RNs before and that their orientation program left much to be desired.

> *Not all have good skills. Not everyone is proficient. They need more education, at tertiary level, they need to learn more about the different syndromes. It would be good to see more training at an independent level, not just staff development, RDNS* (Royal District Nursing Service) *for example. They also need to know what is expected of them, otherwise it is too much of a shock.* (1. 10)

Sarah, a shift supervisor, argued that the RNs needed *"a mix of general and mental deficiency nursing in their training*" (2. 34). Colleen said that the RNs should receive special training and explained:

> *It's a totally different area of nursing altogether, working with people with intellectual disability* (2. 34)

On the subject of training for the role, Larry (RN/ former supervisor) suggested an orientation and short courses on intellectual disability, including knowledge about syndromes, should be offered. He stated:

> *At least you get some feedback from clients in the general hospital, but if someone was coming straight from general with no experience of aged care or psychiatry, I think they should certainly be offering some sort of orientation and some short course on intellectual disability, and a quick run down on some of the syndromes and why certain behaviours are occurring and that it's not the clients [they are] unable to control these things. It changes your view on what you might see as disruptive behaviour* (5. 38)

Bevan (supervisor/ former mental deficiency nurse) said that training for intellectual disability nursing could be conducted partly at tertiary level and partly on the job:

> *I don't know what general nurses study at the moment, and I don't know if they study stuff like Piaget and sensory motor breakdown in cognitive development. I think if that was overt in their training then coming to a place like this, that would help them to identify where people are stuck in different developmental stages. I guess, to put on training here would put an artificial view on intellectual disability [it would defy the principle of normalisation]* (2. 30*)*

Larry (registered nurse/ former mental deficiency nurse) stated that such training could be conducted at the Centre, however he had observed that the universities have added a disability component to their curricula and felt this was also effective:

> *Why should we do anything different from what is being done successfully already? If you could get people interested or if it was seen as a meaningful adjunct to nurse training to either ask them to give the time or make it compulsory to have a small amount of time on intellectual disability and you could have an accompanying visit to a site. Really you can actually put people off by flooding them with intellectual disability. This isn't just nurses, this is visitors and relatives. Seeing intellectually disabled people en masse can be quite disturbing when you've only seen individuals in shopping centres and not that many, so I think a classroom approach followed by a small placement would be in everyone's best interests* (6. 7)

Ron (shift supervisor/ former mental deficiency nurse) said that training for this nursing speciality should take place initially in universities, but that hands on experience was needed as well. He explained:

> *I think it's a bit difficult, going through your training and then suddenly you're trained, and you have to put it into practice. With the disabled, I think that's a bit difficult to do. So if there was some on the job training as well, along with lectures etc* (2. 19)

Laura, who recently completed a bachelor of nursing degree gave the following insight into the training for nursing specialties. She stated that at that time, in the hospitals, there was an emphasis on nursing specialties. Nurses were encouraged to undertake post graduate studies and even assisted with the cost. She stated that she would feel comfortable working in the area of intellectual disability, even though there is no post graduate training (26.6). In fact, depending on the university, there are limited opportunities for nursing undergraduates to gain knowledge in the area of intellectual disability, and according to Laura:

> *It should be incorporated into their studies. At uni our options are mental health and paediatrics, there's no disability option, it's just not talked about* (2. 2)

5.7.2 Management and training

Bevan (supervisor/ former mental deficiency nurse) described a culture that appeared to view itself as "different" by describing the role of the RN as "more than general nursing stuff". He was referring to the leadership training which was commenced in 2002 and was then ceased without explanation. His comment was about the speaker's remarks on the history of intellectual disability:

> *...given that there's a whole history of how people with intellectual disability have been treated over the years, and there is a division between intellectual disability and mental illness, there has to be some knowledge base which is more than general nursing stuff* (2. 20)

I had in fact been invited to attend the leadership training that began in 2002 and remembered there was no mention of the health needs of people with intellectual disability in the speaker's introduction. There was however a lecture given introducing the idea of the new medical practice where people with intellectual disability would have all of their health needs met (3. 02).

Notwithstanding these comments and those of many others, a senior manager said he was happy with the level of training the RNs of the day received. The following was his reply when asked if he could see a day when general nurses who were not equal to the task were applying for the positions:

> *The nurses we have at the moment, yes most do have MD background*

> *but only a couple of years ago we had people who only had general. I don't think that creates a huge problem, because we'll always have within the team someone that has built up experience working with people with intellectual disability and so as a part of the introduction to new nurses into the team they'll have the opportunity to develop skills and there will be a transfer of knowledge* (G. 2. 7)

George (former mental deficiency nurse/ manager) agreed that the nursing and medical curricula in the universities was under review:

> *We are working with the universities to review their curriculum. We're working on the nursing curriculum and the medical curriculum to make it a more comprehensive model of learning so that people don't just go out of nursing with a whole bag of general skills, but that they understand mental health issues, disability issues* (2. 14)

In a tea room conversation a medical officer shared with me, as the researcher, his concerns that there was no educational preparation for doctors who chose careers in intellectual disability (7.02). However during the current study only five medical students and the same number of student nurses were observed to undertake placements at the setting.

Nursing care was delivered on an "as needed" basis. George described the provision of care:

> *I guess it evolves on a daily basis as we become aware of gaps and unmet needs* (1.45)

Even though the current study indicates a need for education in intellectual disability nursing, there are varying opinions on how this should be approached. What is more there are senior figures within the organisation who told the researcher they do not consider that RNs need specific training in intellectual disability.

Colleen (enrolled nurse/ former care worker) expressed her opinion on the updating of clinical skills for both enrolled and RNs. She stated:

> *The only reason my clinical skills are kept up to date is because I do them. (The Organisation) doesn't encourage us to do anything like that, it's up to the nurses themselves. It's the same with the RNs. They put advertisements out for courses, RDNS (Royal District Nursing Service) etc, but when it comes down to it, it's oh no there's only this number allowed. The person who goes is supposed to come back and educate the others, but it never happens, people are too busy or are on a different roster. They will pay for half a course or give you time off to go, but mostly it's left up to you* (3. 8)

However, there was no in service training for the clinical skills required and in extreme cases, other nursing agencies were used to complete tasks, but this practice was frowned upon by management who had to pay for such expertise. There was an expectation that nurses employed by The Centre would acquire these skills, often in their own time and sometimes at their own expense.

Considering the diversity of tasks that make up the role of the RN in disability service, a procedures manual would seem to be essential, but there was not one. Two of the registered nurses were going to compile one but the idea was not greeted with enthusiasm by management and this initiative subsequently waned (10. 02)).

5.8 Summary

In this chapter themes were presented which will contribute to answering the first part of the research question, “from the perspective of the nurse, client and other health care professionals, what constitutes intellectual disability nursing?” While the clients' perspective was often voiced through care givers, some clients were also able to express their views. Indeed it is the client that sets up intellectual disability nursing as a “totally different” area of nursing.

Clients with intellectual disability often lack insight into their health needs and there was an increased burden of responsibility on the RN to provide a good assessment. Consequently "RNs as specialists" and "complex care requirements of the client" are among the subthemes of "Caring for the client who is institutionalised" (see Table 5-1). The RN's essential role in the health and well being of an ageing population and the diversity of the RN's work are presented in this theme.

The theme "the registered nurse in the disability sector having certain qualities" describes a different kind of nurse and a different approach to nursing that not every nurse would enjoy. The registered intellectual disability nurse is described as "having special kinds of skills", requiring patience and the ability to be a mother or father figure to the clients. Furthermore it was evident that a lack of knowledge of the client with intellectual disability affected the care given by agency and general hospital nurses.

Notwithstanding efforts to deinstitutionalise or "normalise" people with intellectual disability they are different and they have different nursing needs to others in the health system. While most people in the general population are able to communicate their needs and wishes, the client with intellectual disability often cannot. The RN relied on unregulated workers to deliver delegated care and to communicate for the client, and indeed RNs were often called upon to advocate for clients they knew well.

The theme "Having to assume responsibility for a large number of unregulated workers" acknowledges the significant impact of care workers on the RN’s role. The care worker’s knowledge of the client is invaluable, as is the role they play as credentialed workers. The registered intellectual disability nurse was responsible for training and delegating health care to unregulated workers and had ongoing accountability for such care.

“Having to work alongside many professional groups” describes the interaction RNs have with enrolled nurses, agency nurses and members of the allied health team. While roles were clearly defined within the nursing team, there was confusion among members of the allied health team as to the roles of registered and enrolled nurses sometimes resulting in inappropriate delegation of tasks. The registered intellectual disability nurse was the overseer of health care and was respected by clients and unregulated workers.

"Working within a different paradigm" is a theme that highlights the significance of deinstitutionalisation for the role of the registered nurse. RNs work within a different context of care, a "home" as opposed to the medical model used in hospitals. A subtheme is "the hub of illness care" which refers to the Infirmary, and indeed its inevitable closure was of concern to most workers. The registered intellectual disability nurse dealt with uncertainty and unpredictability on a daily basis and downsides to the role were revealed such as managing non-compliance and other difficult behaviours.

The art of intellectual disability nursing was observed in a small group of RNs who have been employed at the Centre for many years and who are relied upon to "hand" their knowledge over to upcoming nurses. The theme "Education for the role" highlights the need for educational preparation for intellectual disability registered nurses.

The role was described as "more than general nursing" and a "totally different area". Registered intellectual disability nurses had to deal with a range of people with differing levels of ability. They had day-to-day contact with clients, care workers, allied health team members, other nurses, management and often nurses in general hospitals. The next chapter explores the culture that exists within the organisation, and its subcultures, and how that ultimately impacts on the role of the intellectual disability nurse and sets up his/her ability to function effectively. The themes within which this perspective are immersed will be discussed in detail in chapter seven.

CHAPTER 6

Research Question, PART TWO

CULTURAL INFLUENCES

6.1 Introduction

In the previous chapter themes were presented which relate to the study's initial question “what makes it intellectual disability nursing?”. Themes extrapolated from the data were: "Caring for the client who is institutionalised", "Registered nurse in the disability sector having certain qualities", "Working within a different paradigm", "Having to assume responsibility for large numbers of unregulated workers", "Having to work alongside many professional groups", and "Having different educational needs" (see Table 5-1).

The purpose of this chapter is to present the themes that address the second part of the research question, "what are the every day rituals, norms and patterns within the disability culture that shape and influence disability nursing for the registered nurse?". The material presented here interrelates with that of the previous chapter as it examines the culture that dictates the role and function of the RN. The culture was observed to impact significantly on what comprises intellectual disability nursing because, as will be revealed, unaffected by the dynamics of modern day nursing, the service is influenced by traditional values and norms dictated by an organisation in which there has been little attention to recent developments in nursing practice. Themes explored in this chapter are presented in Table 6-1.

6.2 Hierarchical structure

The Centre had an explicit hierarchical structure that began with the Director and worked its way down to the care worker. There appeared to be many powerful people at the top of the hierarchical structure. The Nursing Service sat under the auspices of Accommodation Services within Health Services. Table 6-2 outlines the branch of the organisational tree applicable to the Centre. The separateness of Health Services from Residential Services is demonstrated. Moreover the RN's low ranking on the hierarchical scale is shown and the clear division between the Health Centre and the Infirmary is illustrated.

Table 6-1. Themes, Subthemes and Concepts related to the research question "What are the every day rituals, norms and patterns within the disability culture that shape and influence disability nursing for the registered nurse?".

Theme	Subthemes	Concepts
Hierarchical structure	*"Ad hoc" system*	Disorganisation Clinging to tradition
	Management's role in constructing the nurse's reality	Acknowledging client's health needs Management's power
The RN's position	*Like a family*	Client centred focus RN is "useful"
	Outsider status	Being a visitor Being excluded
	Nurses' "power"	Autonomy versus policy Clinical role
	The Infirmary as the nurse's domain	"Oasis" amid chaos Having control
Role confusion	*Back covering*	Delegating responsibility Following rules
	Attitudes of workers	Rigidity Cooperation
	Running around in circles	Effects of change Shift supervisors

As will be revealed, the cultural values of the organisation were reflected in its style of leadership and these values played a large part in shaping intellectual disability nursing at the Centre (see Table 6-1). The theme of "hierarchical structure" highlights that the RN occupied a difficult position in terms of working as a health professional in a non-nursing setting and with no clear nursing structure. The culture is summarised in the final subtheme as being "like a family" (see Table 6-1). However the RN, although needed and respected for having valuable knowledge, was not included as a part of the "family".

Table 6-2. An organisational chart showing the structure within the areas being considered in the current research

Board of Directors
Chief Executive Officer
Director Accommodation Services
Assistant Director
The Centre
Accommodation Services

Residential Services	*Health Services*
Area Managers	Health Centre
Villa managers	- Manager Health Services
Shift supervisors	- Nurse Manager
Care workers	- OHS nurse
	- Community nurse
	- Allied health team
	Infirmary
	- RNs
	- Enrolled nurses

6.2.1 "Ad hoc" system

Health care appeared to be delivered "ad hoc", or on an as needed basis, not unlike the system prior to the 1990s. In fact a shift supervisor, on day shift, a former mental deficiency nurse, Bevan, described the old system of care prior to the demise of the mental deficiency nurse as "ad hoc":

> *Health care used to be delivered primarily on the basis of an ad hoc basis from the villas. We did the training for the mental deficiency certificate, we came in at a time when the medical model had been scrapped in favour of one that talked about a developmental model and normalisation goals, so we didn't have any extensive medical training and we didn't study any anatomy or physiology or pharmacology. That translated into health services on the villas being picked up by the charge nurse, and the staff nurse just picked up information along the way* (B.1. 23)

Bevan described a system of nursing care that did not require a 24 hour a day nursing presence. He offered a vague description of the role of the RN at that time:

> *I only used to know of two RNs and one used to manage the health centre or the treatment centre as it was known then, and they assisted with the dentals and the procedures that were done over there, and then there was usually a RN on nights and that meant basically assisting [with routine care]* (3. 13)

The Centre does not appear to have progressed in terms of distinguishing between the roles of the RN, shift supervisor and villa manager in health care management. The scenario that follows is an example of common occurrences:

> The care is so disorganised, no one seems to know who is responsible for what. Today a client approached me because she was constipated and she thought (correctly) that this was a nursing issue. I cannot give any medication without a prescription and we didn't have any prune juice. I rang her villa to see if she was prescribed anything only to be told that this was "attention seeking behaviour". I was made to feel silly for caring (Field note entry: 2.1.02)

An example of the "ad hoc" nature of the system was also the use of the Centre's Infirmary as a "dumping ground for too hard cases". The following scenario illustrates this:

> I arrived at the Infirmary to find the place in darkness, no TV, all the doors locked and the living area cleared of every moveable object. I sat through handover glancing at the bare room beyond and then the day RN said "and the bad news is....". It seemed I was to expect a new admission, a client from the community who was unmanageable in that environment. She had been sedated at a local hospital and apparently all afternoon the hospital had rung to delay the admission here by half an hour. A carer was sent to "special" the client, and we waited. We waited for a long time. Eventually we spotted the ambulance's reversing lights through the glass back door. I opened the door and greeted the carer who had accompanied the client, "she won't be staying" he exclaimed "the sedation has worn off" (the client had become restless and would not be easily managed in the Infirmary). The ambulance officers agreed and since this was the agreement that had been made with the hospital, the client was returned there. I had been instructed to ring the (Centre's) director. I knew nothing about this client or her situation (Field note entry: 12.4.02)

The current study revealed a fragmented health care service. For example:

> ....bloods taken in the Health Centre and the Infirmary RN didn't know anything about it. The results were 'phoned through at night and none of the RNs could find out who ordered the tests - you feel embarrassed for trying to follow things through (Fieldnote entry: 5.1.02)

There was no nursing model and because clients are not considered to be sick, nursing care was delivered on an "as needed" basis. George (manager/ former mental deficiency nurse) described the provision of care:

> *I guess it evolves on a daily basis as we become aware of gaps and unmet needs* (1.45)

6.2.2 Management's Role in Constructing the Nurse's Reality

Despite the organisation's original grounding in the medical model, the introduction of the developmental model meant nurses were an "add on", retained for their professional expertise. A senior manager revealed the Organisation still had to be convinced a nursing service was necessary. He summarised his understanding of the RN's role in the following way:

> *We have been successful in convincing the organisation that there is a need for a nursing service and one of the things I say is that the role of the nurse is to complement all those other areas of care. Without health, how can you be involved in life? We hear people in the developmental area talk about activities of daily living, but if you're not well, your level of involvement is not optimal. So that is the role of the nurse, to promote healthy lifestyle. It's not about being reactive, that's not the way I want the team to work. I want them to be proactive. I want them to be out there, have a knowledge of the client* (G. 3. 36)

Acknowledging the health needs of people with intellectual disability, he spoke about plans to create a *"one stop health shop"*, incorporating the disciplines of nursing, medicine, clinical pharmacology, and providing behavioural and psychiatric support (G. 2. 25). His vision was for the health service to have a *"much more obvious presence in the disability sector"* (G. 2. 50).

Naturally the nurses were interested in how changes to the Centre would affect them:

> Some interesting developments around the Centre, more clients being moved out into the community and talk of the nurses becoming consultants eventually. The Director apparently wants the Infirmary to stay. Everything is heard second hand. Our manager is attempting to set things up so that he can still justify our employment when the Centre is only a few villas. He talks of us being proactive, rather than reactive, seeking out opportunities to educate and promote health. We have had ideas thrown at us and it is up to us to set up actions, all that and our heavy work load. There are many challenges, but not time to set the wheels in motion. The nurses are saying that this hasn't been explained to them properly (Fieldnote entry: 19.8.03)

However the nurses did understand that management proposed to replace the RN on night shift with an enrolled nurse. Obviously this idea was opposed by all parties; the unregulated workers because of their dependence on the RN, the enrolled nurses because they did not want the responsibility, and the RNs because it devalued their role.

The following observation demonstrates the different behavioural management strategies of senior managers, medical officers and nurses and the manner in which RNs' skills were not fully utilised :

> A carer was assigned to care for a client who refused to go to a doctor's appointment until she was told that the doctor would have a gift for her. On hearing this, the client quickly got ready for the appointment. Once there, the doctor produced the present which was a special pen. The client's eyes lit up. After showing the client all that she could do with the pen, the doctor said "but you are not getting it, because you broke a window last week". The client was outraged and began screaming and breaking things. A RN was summoned to attend to a scratch the client had sustained during her aggressive outburst. A manager was called and he gave the client money in exchange for a promise that she would behave (Fieldnote entry: 3.3.02).

A clear indicator of the division between nursing culture and the overall organisational culture are beliefs about managing difficult behaviours. In the previous scenario, the doctor's poor attempt at discipline (promising then withholding a gift) triggered a negative response in the client who was then "rewarded" by the manager. A nurse was then called to apply a dressing to the client's arm as she had lacerated it breaking the window. The RN's counselling skills and knowledge of the client were not called into play and she was "dismissed" as being there only to administer first aid. The RN, who was not included in the client’s behaviour management plan, thought that the doctor should not have offered a gift that he did not intend to give and that the exercise was counter productive because the manager then gave the client money (3. 02).

Similarly villa managers dictated the role of the RN and there were "good and bad villas" depending on how the manager interacted with nursing staff. The villa managers had fixed ideas and were not readily swayed by nursing or indeed medical staff. The RN’s attempts at being assertive appeared to be ignored and as a result nurses complied with the manager's wishes. Villa managers were required to give consent to all procedures and treatments and they could over-rule the medical and nursing staff. For example, a doctor wanted to order Clonazepam for a client who was agitated and aggressive but the manager would not approve it. The organisation does not like benzodiazepines (the group of medications to which Clonazepam belongs) being ordered because staff might steal them as they are addictive and such drugs have to be locked away (19.3). As a result another drug was ordered which was not the drug of choice for the client's problem.

This was RN, Angela's, understanding of the Centre's beliefs regarding the use of psychotropic medication:

> *Because the clients here have an intellectual disability, a lot of the staff know them. I think here they would be less likely to use sedation, things that we would use in the acute sector if someone was behaving in a way that was aggressive, or something, and we didn't really know them. If we didn't know what they were capable of, didn't know their history...* (2. 26)

In fact I witnessed an incident where a client was acting in a violent manner and one of the Centre's medical officers ordered an injection. The prescription was printed, but could not be taken to pharmacy because the manager needed to sign the approval, and the manager was off the villa. It was unclear whether the RN could act as a consenting officer under the circumstances, however the nurse manager eventually signed the form. The entire process took over an hour, during which the client suffered extreme anxiety. By the time the medication was available, the client had settled, and it was no longer required (19.24).

In another scenario, a villa manager was annoyed because a client had a tooth extracted during a routine dental examination to which the villa manager had consented. However consent had been given for a routine examination and not for any further dental work:

> The villa manager was angry when a client had a tooth extracted under general anaesthetic. As a result of this incident, the health services manager has circulated a memo stating villa managers should accompany the client and remain until the examination has been completed. This makes good sense as we don't want to keep putting people under GA (general anaesthetic). The health services manager has handled this in a good way that puts the responsibility back on the villa manager - nice to feel supported in that way (Fieldnote entry: 4.9.02)

Colleen (enrolled nurse/ former care worker) stated *"sometimes the management won't support you when you think they should" (*2. 13) Enrolled nurse, Karen, also complained about lack of support, for everything from clients yelling to *"serious life threatening situations"* (1. 28). Indeed, disenchanted with management she issued an invitation for them to *"come through and see what it's like"* (1. 36). The nurses appeared to be "controlled" by management and yet unwilling to take a stand.

The RNs felt that nothing was ever followed through, which dampened their enthusiasm. In addition their ideas were dismissed as too costly or impractical. The manager initiated several projects, such as asking the RNs to nominate special areas of interest and designing a card record system for the clients' health issues. A procedure manual was another project that was not continued. The RNs started enthusiastically but received such lack of support and encouragement that they did not continue (25. 9). On the other hand Angela (RN) perceived that support was available when required and in her experience the villa managers were *"always supporting services"* (1. 23).

One of the Agency RNs at handover, where a lot of nursing insights were shared, commented on how it was different at the Centre to anywhere else she had worked. "Here they let anyone, even casuals feed these people". That would not be allowed in other places, where a clinical nurse or even the clinical nurse consultant would feed a client who is at high risk of choking, if an RN was not available. Most agreed that traditionally the Centre's villa managers did not tend to leave their offices and enter the clinical area (6.03). However, Larry (RN/ former shift supervisor) described management as providing good input. He stated *"there's some very good managers"* (1.41).

The level of support amongst the nurses is illustrated in the following fieldnote:

> We don't see other RNs very often, but we all get on very well together. We recognise each other's skills and accept each other's weaknesses. The nurse manager does "a bit of everything", she has had many years experience. She is very fair and easy to work for. She and the health services manager support each other, always present at [performance] appraisal interviews and whenever you make an appointment to see the health services manager, you can expect to see both of them they know the [villa] managers and the culture of the place (15.1.02)

At times the RN was invited to assist the villa manager by explaining the client's health needs to the workers. For example when a client who is particularly prone to constipation was allowed to go for 21 days without a bowel motion, the villa manager was annoyed and frustrated and called a meeting of the villa staff to try and solve the problem. The RN on duty was asked to attend and she suggested that bowel massage might help and this idea was embraced as something the RNs could do. The policy of completing bowel care charts was reiterated by the villa manager and the RN (3. 04).

The following example is of another occasion where the RN felt "included" by a villa manager:

> ....spoke with the manager of the villa where the client lives who had an operation yesterday at (General hospital). He shared his experience of having visited her last night. It is good when the managers talk and discuss client issues (Fieldnote entry: 20.2.02)

During the current study the entire Centre appeared to be well staffed in my opinion. However some concerns were voiced that because management had been out of the work area for some time, they had an unrealistic picture of the work load. Some workers felt management had not kept abreast of the times regarding rostering. A common grievance was that the ratio of clients to staff is archaic and was designed for a time when the clients were much younger and fitter. Currently the clients are older and more dependent but the ratio of staff has remained the same, which is consistent with McPhail's (2005) findings with regard to another South Australian service.

Thus far the client staff ratio has been maintained as staff move with clients out into the community. Larry (RN/ former supervisor) believed there were considerable improvements for staff working in community living:

> *The custodial care is not of the intensity that it is within the institution with its endless shifts and endless staff replacements and inconsistent handlings* (5.13)

Management's power and influence on service delivery was reflected in the client-staff ratio of the organisation which impacted on the RN's role. Among the unregulated workers, there was a high number of casual staff, some of whom did not remain with the organisation for long because it was not an attractive, well paid job. Consequently “a lot of different staff coming through tend to lead to inconsistent care, all manner of incidents and is not conducive to the homelike environment the clients deserved"(Fieldnote entry 3.3.02).

Inconsistencies in staff could be of concern when clients were unwell and Laura (Agency RN) cited the hospital Emergency Department as an example because:

> *...if the carer comes in [with the client] and they're not with the client all the time then they can't tell us [about the client] either"* (2.17)

6.3 The Registered Nurse's Position

Unlike most health care settings with their focus on health, the culture in the current research setting could be described as rather "like a family". While in the previous chapter the RN has been described as "providing a sense of family" to clients, this theme emphasised the separateness of the RN who was relied on but also excluded by other workers. The attitudes of the culture and the nurse's professional status prevented the RN from being a part of the "nuclear family". However clients were observed to welcome the nurse's visits and treated the nurse as a "favourite aunt/ uncle".

6.3.1 Like a Family

The Centre's original purpose was to provide a home and training for clients with intellectual disability and, according to many accounts, they, along with their care givers became "like a family". Those were clearly the "good days" for staff who have remained at the Centre. Ron, a night shift supervisor described the Centre's early years when the clients were younger and the setting was a training Centre:

> *I have seen a lot of changes over the years. Yes, particularly a lot of changes in the age groups of the clients. In the beginning, they were quite young, 30% - 40% would have been school age, but there are no school age people here now. We tend to have elderly people, so when the people come into the Centre, they are already trained to a reasonable degree, whereas when they were younger, there was very little training done prior to them entering in, so most of the staffs' work was in training in everyday living abilities* (1. 12)

Registered nurse (former shift supervisor), Larry's memories also date back to times when The Centre was best known for being a training centre for people with intellectual disability. He and others like him often shared their memories of clients "*from 20, or more years ago"* with more recently recruited nurses (4. 22).

Most staff at all levels were observed to have a client-centred focus which was reflected in the organisation's Code of Ethics (Department of Human Services 1999). A genuine concern for clients by most workers and by clients for each other was observed and, in fact, "family" seemed an apt metaphor to describe the culture. The unregulated workers who cared for the clients knew them better than the RNs and the following is a typical tea room scenario:

> The carers were on their tea break and I decided to join them for a chat. They were talking about a client who was ill in hospital. You would think they were talking about family. They asked me if I had been to visit the client and what I "thought". I told them the client was very unwell and tried to tell them in simple terms what the problem was. Two of the carers decided they would visit her on their next days off (Fieldnote entry: 28.3.02)

Care workers were also frequently observed to visit clients who were ill in the Infirmary, in much the same way one would visit a family member in hospital, and occasionally visits were made on the care worker’s day off. Similarly, fellow clients would visit their sick friends and bring them gifts and handmade "get well" cards (9. 3). The RN was also asked to relay information from the general hospitals and translate it into terms that the villa managers could understand.

When a client was unwell, the news soon travelled and it was not unusual for the RN to receive enquiries from other villas as to the state of health of the client. Clearly the Centre was unlike a hospital where confidentiality would prohibit the exchange of such information and the registered intellectual disability nurse discreetly complied with requests for information about sick "friends". The Centre was slowly being moved to the community but clients and staff knew each other well and the sense of being part of a large family appeared to have continued.

In keeping with the homelike environment, during the current study there were many rituals such as birthday parties where clients were "thoroughly spoilt on their special day" (9.12). In fact clients living at the Centre, and those who had moved to new homes in the community, seemed happy and well cared for. However the RN was seldom offered a cup of tea or invited to clients’ birthday parties.

6.3.2 Outsider Status

A decade after the initial introduction of the Nursing Service, the organisation has clung to traditions embedded within its culture. These include the exclusion of nurses from health care planning for clients and the requirement for nurses to respond to even the most minor of health issues. These mandates were observed to hamper the delivery of a professional nursing service despite Health Services management's claim to be aiming for a "proactive" service. In fact RNs were observed to deliver care, but were not involved in service delivery planning.

The culture appeared as a tight circle with the RN at the margins, only entering when required and only when invited. This was notwithstanding an often close bond between client and nurse and the client's efforts to draw the RN into the "circle". Indeed the rituals, norms and patterns of everyday life seemed to exclude nurses and made them appear rather more like "outsiders" than a member of the "family". The RN was, appropriately, treated as a visitor in the client's home, albeit a visiting health professional:

> Maybe we are treated that way because that's how you treat a visiting health professional, like the locum doctor, or something. It's hard because I don't want to just be the one who calls in when they need a signature or a bandaid - I want to be a part of a team. (Fieldnote entry: 12.7.02)

Due to the nature of this relationship communication was often a problem as the RN was not always kept informed of important changes and events. The following is an example of a commonly overheard telephone conversation:

> Shift supervisor: "Hello, it's.... (often just the name of the villa, not the caller's name) here. You're coming to do an enema at 8 o'clock.", RN: "I don't have it in my diary", S.S.: "Well it's been booked, it's in our diary" (20.9.02)

On the other hand, the following example illustrates another communication problem, that of confusion over who was responsible for what. The villas where people with diabetes live kept their insulin giving and glucose monitoring equipment in the clients' units. A supervisor was dismissive, when asked for more test strips declaring she never touched the RN’s equipment. The supervisor said "I don't know anything about it" yet the individual villas needed to order these requirements (10. 8).

There was considerable ignorance about diabetes and the registered nurse was frequently being questioned about its management. One client had a very high blood glucose level before breakfast and the registered nurse wrote "fasting" in the comments section on the recording sheet, indicating the client had not eaten. The villa manager rang because her staff had inquired if that meant the client was not to eat (8.03). Nurses have their own language which is not always understood by those who are not nurses. This example called for better communication on the part of the nurse. A further scenario describes a problem with the language nurses may use:

> The registered nurse was called to assess a client who was "unwell" and before leaving the villa made an entry in the day/night report stating that the client had "no SOB". Thinking no more about it the RN went about her work, until she received a call from her manager. In a serious voice the manager asked "what does SOB stand for?". The RN replied that it meant shortness of breath. The manager explained he had received a call from the villa manager because no one could decipher the term (Fieldnote entry: 17.4.02)

In the above scenario, the villa manager had chosen to approach the health services manager rather than the RN concerned. This is an example of "going straight to the top", and of how easily nurses can be misunderstood. As a result, the nurses began to compile a list of commonly used medical abbreviations. Indeed Larry (RN/ former shift supervisor) described a part of the registered nurse's role as *"... decoding specialists' diagnoses so that carers can understand what is happening"* (2. 1).

The client referred to previously who spent a year in the Infirmary paid frequent visits back there, unhappy with her accommodation, feigning illness to be cared for by the nurses in the Infirmary. She was not alone; another client telephoned the registered nurse on night duty wanting "someone to talk to", stating that "they" (the villa staff) do not listen. Because nursing was so separate from accommodation, nurses often felt powerless and ill informed. The RN did not know how to advise the client, and she could only listen and make a note in the report (24. 10).

Heather (EN), stated that the nursing staff were often not given crucial information about clients being admitted to the Infirmary:

> *Often there is no background information. I would ring up the villa and ask what this person likes, dislikes, idiosyncrasies, toys, names, signs, etc. No one tells you, you have to work it out the hard way* (1:37)

In fact it was not unusual to find that clients had moved and the nursing staff were not told. This was a waste of time when nurses were booked for procedures in clients' homes and visited for no purpose (24. 8). An example follows:

> A client is sent to hospital and I ring to find out how they are, only to be told that they have been discharged back to their villa. The nurse is always the last to know. They (villa staff) run to us with their problems, but often do not give feedback. When you ring the managers to complain, you are told it is none of your business. The nurses find this upsetting, when they invest so much time in helping people. (Fieldnote entry: 2.10.02)

People could be very sick and even go to hospital but the nurses were only ever told if their services were required. On one occasion a young woman was changing villas which caused her extreme anxiety and she informed the RN about it. The nurse knew nothing of the situation and was powerless to give advice as she did not know the "full story", as was often the case. The registered nurse could only reassure the client and attempt to attain some clarity, which was very difficult when information seemed to be kept as a closely guarded secret (24.8). The situation was further complicated by the client's intellectual disability, anxiety and inability to give a clear account of events.

Even though there have been very ill clients in the Infirmary and the nurses cared for them, the clients remained very much a part of their villas. The villa managers remained their guardians. At another point in time a very ill man from a non English speaking background was in the Infirmary and his family were very concerned about him, asking all kinds of questions of the nursing staff. The RN initiated a family meeting with the doctor, to discuss his care. While this occurred the nursing staff were excluded as the villa manager said "the nursing care was adequate" (11.1). Another example of the separateness of the nursing staff from business at the villas occurred when someone made a casual enquiry of a villa manager, "Which RN is on?". The manager replied "I don't know, we are nothing to do with the nurses" (26. 6). Indeed the RNs felt excluded and made comments such as "they never tell us anything" (21.3) and "it would have been good if we had been told" (43.7). The RNs felt they could not provide an optimal service if they were not included in the client's overall care.

There was a general attitude that nurses "had to be there for a reason" (on a villa), usually because a client was sick and RNs were not "invited for coffee" (3.41). As a result the RN felt excluded from being a part of the team and only ever knew the villa staff on a superficial basis. There was, however, socialising observed between villa staff particularly those who had known each other for a long time

The nurse's uniform further distinguished the registered nurse from clients and other workers. The unregulated workers were not required to wear a uniform although some of the "older" female workers were observed to wear culottes which were a part of the uniform in the 1990s. The nursing staff and physiotherapy aides were provided with a blue "polo" top and navy trousers which most wore. The RN was easily recognised by his or her uniform and identification badge. Unregulated workers were issued with identification badges which they were not required to wear.

6.3.3 Nurses' "Power"

The RN was described as a person everyone respected and whose actions went unquestioned and the clinical role of the RN in disability service was considered to be largely "autonomous"; RNs made crucial decisions on a daily basis. RNs could have a very powerful role in the organisation but the culture disempowered them by giving authority to senior managers and villa managers. Nurses’ "power" was confined to their nursing knowledge and experience because legislation dictated they were the ones qualified to make such decisions. RNs were low on the hierarchical ladder (see Table 6-2) and played a purely clinical task oriented role; their decisions could be overruled by the organisation's policies.

One example to illustrate the nurse's lack of authority occurred when a client appeared overmedicated, and the RN was asked to explain her nursing actions by a manager who did not work in the clinical area. The registered psychiatric nurse had administered medication as ordered by the doctor and dispensed by the Centre's pharmacy which labelled medication very precisely as it was mostly administered by unregulated workers. In this case, the RN had made a clinical decision based on the client's presentation and yet her actions were challenged by a Manager who did not have the required training to do so (2. 4).

RNs in disability service were authorised consenting officers for medication that clients were given only as required (PRN, Latin for *pro re nate,* whenever necessary). Villa managers, although not registered nurses also had the power to authorise the administration of PRN medication. In the general nursing setting, only an RN has this power and the client would be physically assessed to ascertain the need for the medication, and the effect of the medication would be carefully observed and documented. This did not occur at the Centre because the RN often gave permission for PRN medication over the telephone and signed for the medication later that shift.

However I, as the researcher, was not aware of any reported adverse incidents regarding the administration of PRN medication (6.1).

Medication was also sometimes given without the RN’s permission, and one particular shift supervisor asked the registered nurse to "countersign" an order. There was a consensus of opinion among the RNs that this was not the correct way to gain approval to give PRN medication. An RN pointed out to a shift supervisor that consenting after the event was not countersigning. The shift supervisor who had, prior to the career changes, been able to authorise PRN administration did not, or did not want to, understand the need to seek prior permission from the RN (3. 03). The next excerpt describes a typical scenario.

> There is the voice of a shift supervisor on the other end of the telephone. It's 9am: "John Smith is doing his usual head banging, Can I give him PRN?", RN: "What does he have ordered?", SS: "Well, there's only his Diazepam", RN: "OK, Diazepam's good, that is what he should have, what dose is he prescribed?", SS: "Says he can have one or two", RN: "What strength, what milligrams are the tablets?", SS: does not know: "They are yellow", RN: "Look, you say this is usual for John, what does he normally have?", SS: "One tablet", RN: "Alright, that is what I'd like him to have, one tablet", SS: "So, it's alright then, I can give it to him, when will you sign the form?", RN: "Before the end of my shift", SS: "Thanks" (Fieldnote entry:12.9.02)

On occasions however, the RN did have a certain amount of "power" to direct the work of non-nurses. For example an RN telephoned a villa manager and issued an instruction based on the client's health needs and the words "this is the RN" worked like magic. The enrolled nurses did not have the same authority (2. 4). RN, Larry, agreed with this observation:

> *... sometimes a magic door opens when you say you're a RN* (4.11)

However this was not always the case. For instance, RNs were responsible for diabetes management and yet there was no diabetic diet on the menu. The kitchen sent a regular meal for all of the clients and it was the untrained care workers' duty to apportion food for the clients with diabetes. Often the carer was uncertain about the meal and sought the assistance of the RN on duty. Subsequent fluctuations in blood glucose levels were often attributed to the food selection. Concerns like these were frustrating to the RN who was powerless when it came to overseeing such things as the catering at the Centre.

There were two people with diabetes at the Centre and part of the RN’s role was to administer their insulin and check their blood glucose levels. The RNs complained among themselves that there was unnecessary paperwork involved when conducting blood glucose levels and giving insulin. The RN was required to write the same information on two charts, one for the insulin and one for the blood glucose test. The procedures were simplified by the provision of a body chart for the insulin administration and a finger chart for the blood glucose test. Even though they should not require such explicit guides, the RNs were treated in much the same manner as the unregulated worker

Similarly RNs have no authority concerning major decisions regarding the clients, in fact Bevan (supervisor/ former mental deficiency nurse) described his perception of the limitations of the role:

> *There's occasionally first aid treatment and rarely advice given about medical conditions and treatment options* (1.44)

On the other hand it was often stated by care workers and supervisors that "RNs have the power" (17.11), "they are accountable" (9.02), even "RNs are the big shots" (2. 4). However, the notion of an RN becoming a nurse practitioner was not well supported by management. During the current study an influential manager suggested that the RNs could qualify as nurse practitioners. I decided to follow this up and after obtaining nurse practitioner criteria from the state Nurses Board started to compile a profile. A meeting with the manager was arranged and I presented my case. Nursing management stated "you would have to get past the [villa] managers" (1. 9). It was a fruitless effort and I did not pursue it any further due to a perceived lack of support for the concept (25. 9).

The villa managers were very influential and their power was seen as a major obstacle to nurses who wanted to become more involved in service delivery. Long standing issues appeared to exist between villa managers and nurses dating back to a time when the medical model was in full swing and subsequent changes have created role confusion and a "power struggle". It appeared that instead of persisting, RNs had given up the fight and succumbed to the managers' collective power.

The following are examples of the style of leadership which left nurses feeling powerless and having to explain their clinical decisions. A client was allowed to leave the Infirmary when she had been admitted for overnight observation pending a general anaesthetic. The reason the client was allowed to leave was that she had become agitated and threatening. The RN was subsequently asked to explain in writing by the Director why the client was allowed to leave the unit (14.11). Similarly, on one occasion protocol was not strictly adhered to regarding the after hours medication cupboard. Unfamiliar with the process and keen to obtain the required medication for a client, the paperwork was not completed correctly. The nurse responsible for accessing the cupboard was asked to explain and made an example of by the subsequent issue of an internal memorandum (from Health Services management) reinforcing the manner in which doses of medication were to be documented (9. 2).

The RN’s autonomy at the Centre appeared confined to technical skills and clinical practice, areas in which the organisation's management had no knowledge. In fact the Director issued orders and directives, yet there was no consultation with nursing staff:

> The general hierarchy of the place causes a "them and us" culture between nurses and carers and the nursing staff and management. The health services manager does things because he is "the boss". There is never any consultative process, just a memo that says "you will". There are times when you really need to keep your cool, especially when you find out decisions have been made without consulting you. Sometimes you have been very involved in a client's care and management just undermine you without even a word (Fieldnote entry: 6.11.02

The cultural organisation appeared to be such that the workers reflected the values of an extremely powerful management and an example of this appeared to be in beliefs about health issues. In an organisation that denied its clients are sick, workers panicked when a client had the slightest symptom of ill health. A line appeared to have been drawn between care workers' work and nurses' work, which I, as the researcher, understood as part of the culture.

6.3.4 The Infirmary as the nurses' domain

Another "invisible line" separated RNs who worked in the Health Centre and those who worked in the Infirmary (see Table 5-2). Neither group seemed to cross the line to show an interest in what the other was doing. The RN and the ENs who worked in the Infirmary worked as a separate cohesive team.

The Infirmary as a base for the RNs (at the time of writing) could be described as an oasis in the middle of what appeared to be overly managed chaos. RNs had jurisdiction over the Infirmary and it was there that they felt comfortable and in control. Their Infirmary represented special "space" owned by the nurses, and the RNs appeared to be able to contribute to the "family" by welcoming clients, some of whom would visit on a daily basis. Clients that visited would share their joys and concerns with the RN and health issues were often raised, making visits therapeutic in a "social" setting.

The RNs had no control over admissions and discharges to the Infirmary and their opinions were seldom taken into account. The Director was ultimately responsible for such decisions. The practice of hospitals discharging people after short admissions impacted on the level of care required and villa managers were happy to leave it to the nurses for the duration of the client's stay in the Infirmary. In fact villa managers appeared anxious that sick clients should be admitted to the Infirmary as they needed "nursing care" (11.12).

Yet having an Infirmary was not a part of the organisation's long term plan and during the current study there was a trial period when it was closed. It was discovered, however, that sick clients needed to be in the Infirmary and it was reopened. During the closure many care workers expressed their concerns about who would care for sick clients because they did not want the responsibility of clients who were unwell on the villas. Similarly the RNs were concerned that plans to close the Infirmary would have an adverse effect on clients.

6.4 Role Confusion

Confusion over the role of the RN in the disability sector became clear through the varying perceptions of staff at all levels. This theme explains confusion over the RN's role as observed in patterns of behaviour within the culture that impacted on disability nursing. Subthemes are "back covering", "attitudes of workers" and "running around in circles", a subtheme describing the impact of former mental deficiency nurses. Confusion about the role of the nurse, and indeed about the role of the care worker, influenced the scope of intellectual disability nursing at the Centre.

6.4.1 "Back covering"

"Back covering" was an expression the RNs used to describe what they called "time wasting" and it was a pattern of behaviour observed throughout the culture. The term "back covering" was used by the RNs to describe the unnecessary calls they received because unregulated workers appeared to need to pass their concerns about clients' health on to the RN in order to "cover their own backs". This appeared to be because policy stated the need to alert nursing staff to *any* changes in the clients' health status**.** Hence the expression that all of the nurses understood, "covering one's back". As the researcher, I observed the phenomenon and surmised it belonged to a culture of "passing the buck" (1.02).

It became clear during the research that the villa managers and shift supervisors made no secret of the fact they called the RN to assess a client, to cover their backs. These staff tended to "panic" and, it appeared, perceived that they would not be seen to be doing their jobs properly if they did not report even the most trivial health concerns to the RN. Often these staff would wait all day and make the call at handover time in the evening, because they could not go home without imparting the information (4. 03). RN, Larry, described it well:

> *The registered nurse has the last word. As far as the system has been set up, a hierarchy has been created. A lot of the work we do are nuisance calls about meaningless incidents that occur on the villas. A scratch, things that really require very little urgent medical intervention. Sometimes they are presented to you and you go there and have a look and you actually say "For God's sake, you called me out of what I was doing for this?" "Oh, we just want you to write it up for us because we want to cover our backs" So "back covering" is something we are seen as doing very well. Getting people out of trouble* (3. 33).

Often the "back covering" was prompted by the pending arrival of a family member, particularly if the client had some obvious injury. The villa staff were happier to be able to tell the client's visitor that the RN had attended to the ailment. This is demonstrated in the following scenario:

> I stood there looking at this scratch that did not even justify a bandaid, I had been called and told the matter was urgent. I had rushed to the villa with dressings and "glue". I stated the obvious, that it was a scratch. Then the supervisor asked me to "write something because his mother is

> coming in today". The villa staff are the ones that family members complain to. It's as simple as making an assessment so the staff can say "The RN has seen it". They believe it is being treated and feel better (Fieldnote entry: 20.10.02).

Of course it could be problematic for an untrained carer to assess the client as they did not have the required skills and could have overlooked a serious illness. However, one competent shift supervisor, when confronted with a sick client, called the RN stating it wasn't urgent "but I just need to cover myself". The supervisor had taken observations and formulated a diagnosis and effective treatment by the time the RN arrived. The RN asked "What do you need me for?". "It's the rule, we have to call the RN" (12.03). No matter how competent the unregulated worker the shift supervisor was following the organisation's policy that the RN has to attend sick clients.

In the same way, one evening during handover, the day RN received a call to administer medication to a client in an adjoining villa. While there, she was asked to examine another client's "rash" but it could not be seen. The care worker responded "The other carer saw it, so I have a witness". The care workers were assured they were believed and instructed to call the RN should the rash reappear (6.03). Equally the RN was often called to "put a dressing on a vulnerable pressure area whereas anyone could do that" (Fieldnote entry: 4.12.02).

"Back covering" as a cultural phenomenon is shown in the following scenario:

> ....a carer rang me as the shift supervisor had told her to "ring a nurse, nurses know about beds". The problem was a very old hospital bed that was literally falling apart. At first, I suggested putting the mattress on the floor but the carer protested because the client had an order for cot sides. That is what she kept telling me as I tried to explain that you can't fall very far off a mattress. For safety's sake I pushed the bed up against the wall and wedged it to stop it from tipping. But in order to "cover them" I had to write in the report explaining what I had done. It is of concern that these carers are credentialed to give medication (Fieldnote entry: 2.2.02).

There was evidence of "back covering" at all levels. For example, notwithstanding the organisation's denial that clients were sick and in need of routine nursing and medical attention, there was a focus on preventative health measures. The annual medical review (AMR), which every client had, was preceded by a RN conducting a full set of observations. The RN’s involvement did not end there as they conducted treatments prescribed by the doctors. Some common treatments resulting from AMRs are described in the following field note:

> The registered nurses have noticed this week that they have a lot of blood to take and there seem to be more than the usual amount of ear syringes to do. When they checked the client Health Care Plans, these tasks are a result of AMRs (Annual Medical Reviews) last week (Fieldnote entry: 1.5.02)

In spite of modern communication technologies a relic of days gone by was the day/ night report which was completed at the end of each 12 hour shift. The nurses wrote in their day/ night report issues concerning Infirmary clients and matters of importance around the Centre. The RNs also made entries in the day/ night reports of villas that they might have visited:

> The report is such a tradition, it's a wonder we don't get RSI from all of the writing, you write in the notes, in the report, and depending on what it is we may need to write it in our report. As long as you write in their report they are happy (Fieldnote entry 3.4.03).

The nurses were also observed to have to cover their own backs. For example diary listings of the many tasks required of the role were apparent to any new RN. Diaries were kept as documented evidence of how nursing hours were spent. The enrolled and registered nurses also used a communication book to relay information between shifts. This was considered to be useful. Apart from ensuring information was passed on, it also provided written documentation of what had been done, or needed to be done.

Communication also took place at handover when the day and night shifts overlapped by fifteen minutes in the morning and twenty minutes at night. Apart from giving the RN the opportunity to hand over issues that the incoming nurse needed to know, handover was often an opportunity for exchange of knowledge. New skills were taught during the handover period, such as the operation of a new enteral feeding pump (7. 02) and the management of a subcutaneous infusion (10.01).

6.4.2 Attitudes of Workers

The attitudes of workers were embedded in the culture which in turn shaped the role of the RN. Concepts such as task orientation, rigidity and cooperation or lack of it form this subtheme. Worker's attitudes toward the RN varied and often were determined by the worker's length of service with the organisation. "Older" staff

members appeared more stubborn and set in their ways, while those more recently employed were more flexible and open to suggestion. This was observed in the manner that long time staff described as "the way it is done here" (9.4).
The concept of task orientation and workers adhering strictly to procedures in the face of obvious indications to the contrary was new to me. It was not that one would want staff to break the rules, but many workers appeared totally inflexible in their approach to work. If they had been taught to perform duties in a particular way, that was the way it had to be done. A classic example was a care worker handing a client a bowl of breakfast cereal after his hand wound had been cleansed in preparation for a dressing because "this is what should happen at this time". The care worker lacked the perception that a wound dressing requires an aseptic technique and that a variation in standard routine would be required (69.8). It was these aspects of the culture that the RN had to contend with daily. Often there was no room for any kind of decision or procedure that contravened policy. Another example follows:

> The registered nurse received an urgent call to go to a villa where a client was choking on a peach. On arrival it appeared the client had attempted to swallow a whole peach and the leaves of the peach tree could be seen protruding from his mouth. He was rapidly going blue in the face. All attempts to dislodge the peach were to no avail. The registered nurse called out "call an ambulance" and when no one responded headed to the office to do so herself. On her return, she observed a carer attempting to change the gasping man's T-shirt. "What are you doing?", she asked, only to be told "I'm changing his shirt, it has peach juice on it" (Fieldnote entry: 24.2.02).

It was just such a lack of common sense and poor care worker judgement that had the potential for devastating effects as illustrated in the following observation. An RN received a call stating that a client had "choked on his medication". The client could be heard yelling in the background, displaying a good set of healthy lungs. The care worker mentioned he was alright after they "sat him up". The RN advised the care workers against feeding the client lying down (6. 03). The Centre has experienced so many problems with clients who are difficult to feed and who aspirate food into their lungs that they have now enlisted the services of a speech pathologist to conduct swallowing assessments.

An RN spoke about an incident in which a client had appeared on the Infirmary doorstep at 10.30 pm on a cold night. The client claimed to be sick and when asked how she got out of the villa she replied "they don't care". The RN was unable to leave so she examined the client, did not find her to be seriously ill and sent her back on foot. The RN made a telephone call to the villa and suggested that the client should not be walking around at night, especially when she was claiming to be unwell. The carer replied there was a policy stating they were not allowed to keep her in the villa and that she had to be let out on demand (4. 3). Again care workers were observed to be merely resorting to policy rather than weighing up the benefits and results of their actions. It seemed clear that more effort needed to be put into encouraging the client to stay rather than just reverting to policy.

The villas did not stock any medical or nursing equipment except such items as diabetic monitoring equipment and nebulisers and these items were owned by individual clients. When on call the nurses were required to take their own supplies of every item that might be needed, however basic supplies such as "sharps" containers were provided. In the following scenario, an RN was called to a villa to give an injection on two consecutive nights. The first night she was told the villa used to have sharps containers at all the sinks, but now the sharps container was on top of a cupboard in a locked bathroom, out of the RN’s easy reach. Client safety was the obvious reason, but the office door was locked as well, and that was where the injection was being prepared. The second night the carer had the "sharps" container on the desk "I know you like it handy" she gestured obligingly (6. 03).

By way of contrast some care workers could be most uncooperative. For example the RN arrived at a villa to conduct a procedure that was booked into the nurses' diary. It seemed unusual the villa had made the booking for the evening meal time, but the nurse managed to fit the appointment into an already tight schedule. The care workers were outraged because the client was about to have his evening meal and they refused to allow the nursing intervention. The RN suggested the client could have a late meal, but the care workers insisted the nurse return later (24. 8).

Among care workers, a level of comfort with familiar things was observed. Staff appeared suspicious of newcomers, which led them to seek out the long term RNs. "When is (other nurse) on again?" (6. 01), they would ask. Indeed bookings were postponed because staff wanted a certain nurse and there were comments such as "(Other nurse) doesn't do it like that" (10. 01).

On the other hand, early in her employment Angela (RN) found the non-nursing staff to be very solicitous and had this to say:

> *Yes, all the staff I've met have been full of advice and telling me all information that might help me, or asking me if I want to know where something is, or if I need help. Everybody's been really good* (2. 37).

The attitudes of the non-nursing workers were taken into account by those who understand the culture. The following observation demonstrates this:

> The health services manager has said the proposed changes to the nurses' rosters (RNs working a 5 day week and less support for the villas) will have to allow a period of adjustment for the villa staff to get used to them. The villa staff rely on the nurses and you can't suddenly take away or reduce that support. They will need to be informed every step of the way so they feel comfortable with what is happening (Fieldnote entry: 8.5.02).

The culture of the organisation was distinguished by the attitudes of its workers and it was difficult to determine where nurses sit within that culture. The nurses were repeatedly reminded "you are being paid more than I am" (25.8) and "I don't get paid to do these things" (10.2). The RNs were able to treat comments such as these with humour as they were often posed as a joke even though an underlying resentment could be felt. Indeed exclamations of "Why should I? That is not my job" (15.10) were often heard, as well as "I could do it, but I'm not allowed" (45.9) and "The RN has to do it" (30.6). There appeared to be a dogged belief that health interventions were nurses' work.

In the main the non-nursing staff were friendly and attempted to assist the RNs but, as previously depicted, they often lacked even the most basic understanding of health procedures. This lack of knowledge made it frustrating when attempting to explain health procedures to the care workers.

> Like carers, most of the shift supervisors have no medical or nursing knowledge - they cannot do obs, they don't know the terminology, some of them can't stand the sight of blood. They, too are credentialed for medication administration. Some do suppositories or blood pressures, but there seems to be no requirement they are able to do these things. (Field note entry: 20.9.03).

A health issue that was frequently found among the clients at the Centre was constipation. Among people with an intellectual disability constipation is prevalent and is due to lack of exercise, the medication taken, inadequate fluid intake, and a lack of understanding about regular bowel evacuation. For this reason, part of the RN’s daily role was to administer suppositories and enemas. It became obvious that staff considered it a "bit of a joke" that RNs gave enemas (1.10). While the unregulated workers could be credentialed to administer suppositories, most refused; traditionally this was regarded as the role of the nurse and they did not care to do it.

As the researcher, I perceived that workers at all levels had clear views about what was "RN work". This was made clear in the following example:

> I received a call from a villa manager "my client needs Betadine (an antiseptic) painting on her knee, can you come and do it?". Such a simple thing. I replied "Can't you do it?". The villa manager (a former mental deficiency nurse) replied "yes. I could, but it's not my job. That's your job". I complied and needless to say I never asked that villa manager to save me time again (Fieldnote entry: 8.3.02).

As previously stated care workers could be credentialed to test blood glucose levels, but not many took the opportunity. Even those who were credentialed for blood glucose testing seemed to leave the task to the RN. When asked to describe the role of the RN in disability service, clients, care workers, nurses, other health professionals and relatives all listed a set of tasks. RNs were clearly defined by the tasks they performed. The following was a care worker’s perception of what the RN stood for:

> *[Someone who does]... things like suppositories and taking blood, with different things they have to test for. The dressings and sometimes PRN stuff if they need to do injections that way say if a person has epilepsy and if he needs anything to do with seizures, like if they need intramuscular or rectal diazepam. (*D. 1. 1).

Indeed unregulated workers were reluctant to take the initiative in treating minor ailments such as scratches. In an emergency they were not "allowed to" call an ambulance until the RN had assessed the need. The lower levels of worker would not accept any accountability or responsibility and this aspect of the culture was set by the system. Local influences on the culture were observed to be the workers who complied with the organisation’s rules and had fixed ideas about RNs being responsible for health issues. Similarly the care workers were reluctant to accept assistance from nursing staff with what they perceived to be "their work". For example attending to client's hygiene or toileting as demonstrated by the following example:

> I was passing through a villa where a carer had been left on her own to care for 7 clients. They all seemed to be noisy, demanding the carer's attention and she was attending to a client who was on the toilet. She apologised for keeping me waiting. I had gone there to collect medication for an Infirmary client. Rather than "cool my heels" and wait, I rolled up my sleeves, put on a pair of gloves and assisted the carer. "You don't have to do that", she said, apologising all the while for inconveniencing me. Rather than just keep accepting her apologies and grateful thanks, it seemed easier to make small talk about how I used to be a carer..... (Fieldnote entry: 2.8.02)

Rituals and procedures were very important to this culture. An example was given in the previous chapter of clients being sent on bus trips and other routine activities when they were sick. The unregulated workers clearly feared the repercussions of not complying with the organisation's rules. A "reporting" culture was observed. All breaches of the rules were reported to the managers in charge of the villas. Reports about nursing staff were dealt with by the health services manager, a senior disability services officer. Severe infringements of policy went "upstairs" and were personally dealt with by the Director and staff knew what it meant when a colleague was called "upstairs".

Examples have been given throughout this and the preceding chapter of care workers' rigid adherence to routines and their inflexibility around clients’ meal times. An example of the effect this has on the registered nurse is described in the following scenario:

> I arrived 10 minutes late to credential a carer for giving out the lunch time medication. "you're too late" the carer stated with a broad grin on his face. "What do you mean, I'm only 10 minutes late?". "They had to eat", the carer replied. Of course the medication is supposed to be given with food (according to the label) and I don't suppose the carer would know which tablet was alright to give on an empty stomach. I guess postponing the meal would have been out of the question. He would have had to get permission from someone to do that (Fieldnote entry:15.8.02).

Staff meal breaks were of equal importance and "all work grinds to a halt" while this ritual is adhered to (3. 8). It was not unusual to have care workers literally stop what they were doing to "go to tea" and the RN was often refused attention because "I'm on my meal break" (3. 9). Nurse's meal breaks did not hold such importance and they were sometimes observed to answer the telephone and attend to clients during their breaks.

Client's bed times appeared to be dictated by the number of clients care workers had to assist to bed and "7pm lights out" a legacy of the 12 hour shift because the clients "need to be settled before the night shift commences" (1. 02). Admittedly clients arose early for showers and breakfast which enabled the RN to administer treatments prior to clients departing for activities.

6.4.3 "Running Around in Circles"

The changes that occurred in the late 1990s, referred to by Sarah (shift supervisor) as *"the career structure"* (2. 26) continued to cause concern and bitterness among staff who liked the system as it was. Indeed such was the culture of the Organisation that changes to their comfortable institutionalised existence appear to have had profound and lasting effects.

As a result of the changes, the nursing service did not appear to sit comfortably within the overall hierarchical structure of the organisation. Intellectual disability nursing appeared to have been marginalised and yet, as can be seen, the registered nurse was essential to client care.

There was evidence in some of the comments made by shift supervisors that they felt de-skilled and devalued through the introduction of the nursing service. A shift supervisor said to the RN as she arrived to give an injection "I could have given it". "Why didn't you?", the RN quipped back at him. "Well, you're the nurse" the supervisor quickly replied (9. 03). Comments like this suggest that it had been a difficult period of adjustment for the long time mental deficiency nurses who became shift supervisors. No longer "nurses", they were instrumental in creating the existing culture of the organisation.

In the community houses, there were some shift supervisors, former mental deficiency nurses who gave insulin to a small number of clients with diabetes (11.01). Shift supervisors were the overseers of the care workers' work and had a certain amount of responsibility in the villa manager's absence (for example on weekends). They however were observed to be "a law unto themselves" only doing those tasks which they chose to and claiming it was not their job when they did not want the responsibility (40.15). Some were former mental deficiency nurses, and a few of them proved quite helpful to the RN. However most of them were confused about their own role and that of the RN.

Prior to calling the RN, some of the more confident shift supervisors administered basic first aid to clients, such as the application of an ice pack and if they had the equipment and the skills they would do a full set of observations (6. 03).

> Some of the old MD nurses will assess people, offer simple treatments and call for a "second opinion" or an "expert opinion". They will tell you what they have done. Sometimes they do obs. One even gives routine injections. They are helpful. They save us time. (Fieldnote entry: 25.9.02)

Ron was every RN’s idea of a "good shift supervisor", because he possessed common sense and a background in mental deficiency nursing. His role was to investigate calls from care workers who had concerns about their clients. When the call pertained to a client's health, he assessed the situation to determine the need to call the RN. He claimed the calls he received were for *"..anything from minor cuts, to a person dying"* (1. 37). Notwithstanding the nurses' *"expertise*", Ron insisted on being the first point of call, stating simply "*that's the way I like it"* (1. 41*)* and adding that he did not like to waste the nurses' valuable time:

> *...because otherwise the nursing service would be running around in circles half the night for things that are not necessary* (2. 3).

Shift supervisor, Bevan claimed to utilise the nursing service more on weekends when he had more villas under his charge (1.43). Not all shift supervisors were well regarded by RNs. In this scenario the day RN reported at handover that she was sick of the "stupidity" of some shift supervisors. She said they would ask a question, knowing the answer, as if they just need the RN to answer it. She cited the example of an incident involving medication where the supervisor knew the right thing to do, but would not make a decision and expected the RN to reinforce what was already known (16. 6).

Indeed a similar situation unfolded as the RN, in the absence of the occupational health nurse was required to attend to staff casualties. An RN was called to an incident where a staff member had cut her finger. The RN suggested a bandaid, but the shift supervisor arrived and announced that the injured staff member needed to go home. The RN protested "It's only a cut finger, she doesn't need to go home". The care worker stated she did not want to go home and that she was angry her immediate supervisor had called the more senior supervisor. The care worker remained on duty (11.1).

Larry (RN/ former supervisor) was fortunate to have entered the realm of nursing with many years of shift supervision already behind him. He felt he had a deeper appreciation of the culture because he had been "one of them" (a mental deficiency nurse) and he described the shift supervisors as people who "*know my foibles and I know theirs"* (3. 14). He described an adjustment period during which he struggled to prove his worth as an RN, because he was previously a shift supervisor. He was quick to point out that the other shift supervisors had been given the same opportunities as he had. He knew that he was qualified to do the job he was doing, but had other people's misgivings to contend with.

> *I definitely had more status and then not everyone loves everyone, so there were cases of in the beginning people thinking that I had risen above myself, and what gave me the right to think or for management to think that I had anything to offer that they didn't, despite the fact they didn't go for the job* (3. 22).

Admittedly there were shift supervisors who appeared to resent RNs, and the following was an example of this. The RN returned to the Infirmary to hear an EN saying to an acting shift supervisor "The RN is my boss, you are not my boss". It seemed the supervisor was suggesting something the EN did not agree with and the RN, when asked, did not agree with either. When the RN said "this is what I want you to do", the supervisor claimed "I am more qualified than the lot of you". The RN tried to explain to him that although he had kept up his Nurses Board registration and occasionally worked for a nursing agency he was not employed as an RN (26. 11).

The enrolled nurse reported that this particular supervisor signed "RN" after his name on official documentation. I observed that other shift supervisors, who were formerly mental deficiency nurses, did this as well. It was this group that appeared least likely to comply with the organisation's policy on obtaining consent for PRN medication. A key figure in the nursing team stated that shift supervisors were required to be credentialed, as were enrolled nurses employed by the organisation (3. 05). One shift supervisor pointed out that even though he was in charge he does not earn as much as the RNs. He appeared resentful of the RNs and obviously bitter about the changes that have occurred and the loss to his status in the organisation (14.12).

Informants stated that the organisation had recognised the distress of some staff since the changes (deinstitutionalisation) and commenced leadership training that included such shift supervisors. However the training had been abandoned without explanation. The general consensus of opinion was that it was "typical of management- 'they' set up something and then after a while abandon it " (20. 6).

6.5 Summary

In this chapter themes have been presented that answer the second part of the research question, “what are the every day rituals, norms and patterns within the disability culture that shape and influence disability nursing for the registered nurse?” (see Table 6-1). The system dictated the culture in this organisation which in turn had an enormous impact on the role of the RN. Historical influences, such as the introduction of deinstitutionalisation and the cessation of mental deficiency nurse training, were also observed to affect the culture and subsequently the role of the RN.

In the first theme "Hierarchical structure" the organisational structure of the research setting was described (see Table 6-2) and subthemes are "'ad hoc' system" and "management's role in constructing the nurse's reality". The organisation's style of leadership was highlighted in this theme with concepts of the limitations to the RN’s role and the power of management that shaped and influenced intellectual disability nursing. In particular, the villa manager was seen to be an obstacle to strong nursing leadership.

The theme "The registered nurse's position" described the culture as a metaphor for family yet the RN appeared to be "circling around the perimeter". A strong sense of the RN being excluded was evident in the subtheme "outsider status" which described the RN as being relied on yet nonetheless an outsider with "no power". The Infirmary was described in a subtheme which shows the "space" where RNs had jurisdiction and where the client felt comfortable to visit. Indeed the RN's close relationship with the client was felt to enhance care.

The theme, "Role confusion" with subthemes of "back covering", or time wasting, "attitudes of workers" and "running around in circles" demonstrated the attitudes embedded in the culture that contributed to role confusion. Concepts included the attitudes, resentment and fixed ideas of care workers and shift supervisors that had a profound effect on the RN’s role and, subsequently, client care.

The culture struggled with old fashioned rituals while attempting to be viewed as keeping abreast of the times. They were observed to be a group of people all working in their own prescribed roles but there was little evidence of team work. In an inflexible rule-bound system, created by its leaders, workers were not encouraged to make decisions. Indeed they were required to conform to the norms of the organisation and there was no room for individuality or creativity. RNs did not appear to sit comfortably within the system as senior management did not understand their role.

The culture was different to the settings where most nurses work and has impacted enormously on the role of the registered nurse. The impact of its long held traditions on intellectual disability nursing will be shown in the next chapter as the themes are discussed in detail.

CHAPTER 7
DISCUSSION

7.1 Introduction

The study adopted an ethnographic approach to examine the role of the RN in the intellectual disability sector. This involved examining the culture of a large organisation and the interplay of its leaders and other workers considered significant in shaping the RN's role. In the previous two chapters, in seeking to answer the research questions, analysed data were presented in themes (see Tables 5-1 and 6-1). Themes relevant to the first question ("What constitutes intellectual disability nursing?") related to descriptions of the RN’s role and comparisons of intellectual disability nursing to nursing in other sectors. Themes relevant to the second question ("What are the every day rituals, norms and patterns within the disability culture that shape and influence disability nursing for the RN?") related to descriptions of the long held beliefs and traditions within the culture that impacted on RNs and separated them from other workers.

In this chapter I discuss the themes and their significance to the research questions. Relevant literature is also presented to support my conclusion that intellectual disability nursing is quite different to nursing in other settings. As participant observer in the study, I observed the special qualities that registered intellectual disability nurses appeared to possess. The role was found to have rewards but also downsides which required coping strategies and skills that could be considered distinctive of intellectual disability nursing. Concepts about caring for a client who is institutionalised and may not fully understand procedures are discussed.

The Centre's move toward deinstitutionalisation has impacted on the nursing service as RNs move their practice into the community. Moreover, the trend toward delegating care to unregulated workers was considered to influence the role of the RN who was responsible for their training and assessment. Notwithstanding the most powerful influence on nursing practice appeared to be the managerial structure of the organisation with its non-nursing leadership and different set of values. The research found the role of the RN to be juxtaposed with the influence of the culture of the organisation. The role of the RN in caring for people with intellectual disability, discussed throughout the chapter, is described as different to that of RNs in other settings.

7.2 Intellectual Disability Nursing is Different

The research setting is one of the few in South Australia providing a nursing service specifically for people with intellectual disability and the role of the RN was found to be different from other health settings. In other parts of the state, people with intellectual disability have their nursing needs met by specialist agencies and the Royal District Nursing Service who provide a different kind of service. The RNs in the study believed their specialist knowledge of the client enhanced their ability to deliver optimal care. The theme “Caring for the client who is institutionalised” (see Table 5-1) encompasses subthemes of *Having many varied skills, Clients have complex care requirements* and *Registered nurses as specialists.*

7.2.1 The Client

Unfortunately, the term "intellectual disability" conjures up an image in many people's minds of "someone who is somewhat deformed, with little or no speech" and a high level of dependence (Gallagher 2002, p. 205). In fact, the intellectual disability label is considered to be one of the most powerful and most stigmatising (Wolfensberger 1975). Nevertheless Gray (1970), a former registered Mental Deficiency Nurse, described the client as no different to "normal", needing those things that every human being needs:

> ... affection, love, security, acceptance and discipline. They can feel hurt, discouraged, lonely, or frightened; they respond to kindliness and encouragement and can be taught to make the most of their limited capacities (Gray 1970, p. 9).

Clients who may not be able to express their needs, pain and wishes were central to the purpose and function of the organisation, its workers and indeed the RNs. The success of some of the more difficult health care interventions was attributed to the RN's relationship with the client (as shown in Table 5-1).

The intellectual disability RNs' need to fit in with client schedules clearly had an impact on their role. Routines, rituals and repetitive practices were observed to be a part of the client's every day life. For example, meal times were strictly adhered to as most clients would become very agitated if they were kept waiting. Bus trips and other activities held high importance for the client whose needs were well accommodated in terms of entertainment. Importantly, those most affected by any change to routine were the clients and their behaviour often reflected this. People with intellectual disability often rely on "structure, routine and order" in their environment "to cope with their day-to-day lives" (O'Connor & Davis 1999, p. 77). Consequently staff appeared to adhere to strict routines because the clients and their care workers needed them or had become accustomed to them.

Clients believed the RNs were health experts and some would approach the nurses for treatment without the knowledge of the Villa staff, or when Villa staff had "dealt with" the problem. This was particularly difficult because the clients seemed to have such faith in the nurses and could "play staff off against each other" by returning to their Villas claiming "the RN said …" (15. 3).

7.2.2 Meeting Client Care Requirements

Because of their knowledge of the client, registered intellectual disability nurses are able to promote good health and assist general practitioners in making diagnoses. Indeed The National Review of Nursing Education (2001) reported an opinion poll which portrayed nursing as "the face of healthcare in the community" (p. 11). Clients with intellectual disability have complex care requirements and, according to research conducted in the UK, registered intellectual disability nurses:

> ...were acknowledged to have unique knowledge and skills in providing care and support (Alaszewski et al 2001, p. 2).

This study revealed that much of the RN's time was spent assessing and treating health problems. It was found that the role incorporated less first aid and more health management and health promotion as the client population ages. Syndrome-specific conditions accounted for many of the health problems experienced by people with intellectual disability and increased longevity can lead to "older-age associated problems" (Evenhuis, Henderson, Beange, Lennox & Chicoine 2001, p. 177).

Periodic comprehensive health assessment has been shown to be effective in the over 75 age group and current research suggests this simple measure also results in improved health in people with an intellectual disability (Lennox 2002). Accordingly, each client at The Centre has an annual medical review conducted by one of The Centre's doctors and prior to this, the RN takes routine observations to assist the doctor.

Beange (1996), a New South Wales Visiting Medical Officer, believed that if the health of people with intellectual disability was valued "their lives would be longer and happier" (p. 160). Preventative health services and health promotion "would save enough money to make other special services available", such as dental and eye clinics, psychiatric and neurological services–which were available in The Centre's Health Service in this study (Beange 1996, p. 160). Beange agreed RNs can play a significant role in providing "comprehensive and continuous health care" to people with intellectual disability (Beange 1996, p. 160). Furthermore, she suggested primary care should be shared between general practitioners and clinical nurse specialists. Clinical nurse specialists should be "attached to" local group homes that are replacing institutional care (Beange 1996, p. 160).

Even routine health care procedures require careful preparation in terms of allowing space for care workers to support the client and "more time and resources than the average patient" (Beange 1996, p. 160). Moreover, the registered intellectual disability nurse needs to have perfected skills that are not required in other sectors. For example, in my research, skills such as taking blood from people who were shouting and kicking because they did not understand the procedure. A similar scenario was witnessed many times as RNs syringed clients' ears.

Ear syringing is a common procedure performed by doctors in general practice and a task for which the registered intellectual disability nurse is skilled, but it has potential complications such as perforation of the ear drum and infection (Bird 2003). Staff performing ear syringing should be appropriately trained and the equipment should be checked. Bird (2003) stated that ear syringing is contraindicated in "young children who are uncooperative" (p. 3) and although not children, many of The Centre's clients are uncooperative with health interventions.

It is in managing the frightened client, who does not understand the necessity for treatment, that registered intellectual disability nurses' expertise becomes visible as they accomplish tasks with a minimum of fuss. Indeed, even a less invasive procedure such as blood pressure monitoring could be an arduous task for a nurse inexperienced in intellectual disability nursing. Moreover, RNs were observed to use their initiative in adapting equipment to suit the situation and delivering care in unorthodox places such as bathrooms and even at the meal table because clients did not like to have their routines disrupted. Imagination (problem solving in an imaginative way or creative thinking) is essential for the intellectual disability RN to adapt, make changes and respond to "the demands being placed upon us in an orderly way" (Griffiths 1999, p. 3).

Registered general nurses are not confronted by such scenes as these in their daily work; one research participant described hospital nurses as "fearful" of people with intellectual disability (K. 1. 20). On the other hand, most people with intellectual disability appeared to accept RNs as people who care and also, in some ways, appeared to believe that RNs could do no wrong.

7.3 The RN Requires Special Qualities

The study revealed that intellectual disability nursing is not an attractive career option for every RN and special qualities are required. Indeed the second theme describes “The RN in the disability sector having certain qualities” (see Table 5-1). Subthemes are *It takes special kinds of skills* and *Providing a sense of family*. Participants described these qualities using words such as "understanding" (L.E. 1. 45), "friendly" (S. 1. 6) and "motivated" (L. 6. 21). Notwithstanding that ideally all nurses should have these qualities, Piteo (2001) explained that many nurses in other sectors do not have an understanding of intellectual disability. Many general hospital nurses report feeling inadequate when faced with caring for the person with intellectual disability and this can affect clients both physically and emotionally because of a sense of fear that their needs are not understood (Piteo 2001).

As a result, nurses in other settings often provide inadequate or inappropriate care to people with intellectual disability (Piteo 2001). Piteo (2001) suggested acute care nurses should consider people with intellectual disability as people first and not approach care based on their intellectual disability diagnosis. The intellectual disability RNs in the study appeared to acknowledge that many people with intellectual disability are able to make decisions about their own health and a person's right to have control over their life is "central to ethical thinking" within nursing practice (Holloway 2004, p. 283).

The organisation believes every person with intellectual disability is "an individual with unique abilities and personality, problems and needs" (IDSC 2005, p. 1). In keeping with that philosophy, the RN was observed to recognise clients' individual needs. People with intellectual disability have similar healthcare needs to those of the general population but the impact of a particular disability on the individual and their family may vary significantly as each client is unique (Smith 2002).

There is a great deal of public interest in general nurses and very little in intellectual disability nurses (Borbasi 1995). Borbasi (1995) described this as indicative of the value placed by society on people and things where medical advances such as transplantation surgery care is given high priority for example, whereas the needs of the mentally ill and their carers are not. Consequently there is a perceived hierarchy among nurses carrying out differing caring roles leading to "the group closest to the dominant force being afforded the most power and control" (Borbasi 1995, p. 10). In fact the social stigma attached to intellectual disability appears to have been retained by a range of people working in caring professions including the RNs who one participant described as "the Cinderellas of the service" (L. 7. 2).

The registered intellectual disability nurse wears a casual style of uniform that is dissimilar to that worn by general RNs, and also works in a variety of settings. One participant suggested the role of the intellectual disability nurse was more "social", because registered intellectual disability nurses often worked in the client's home (L. 6. 21). Because of this, registered intellectual disability nurses were often perceived as trusted friends and confidantes by their clients. They provided a sense of family that many clients would not otherwise have. Often "counselling" took place over a cup of tea and health assessments were discreetly conducted under the guise of sharing concerns with a caring friend. The concept of the registered intellectual disability nurse as friend is supported by research into the role (Alaszewski et al 2001).

Other features distinguishing the registered intellectual disability nurse from other nurses were found to be "activities, appearance and location" (Alaszewski et al 2001, p. 3). Indeed, the RNs in the study were observed to engage in less "technical treatments" than general nurses in the acute setting (Alaszewski et al 2001, p. 3). During fieldwork it was necessary on occasions for the organisation to employ agency enrolled and registered nurses who agreed the work is different to other sectors. Some agency nurses were observed to be out of their depth with the different concept of caring for people with intellectual disability and the volume of the work required.

7.3.1 Diversity of the Role

The study revealed registered intellectual disability nurses to have highly developed organisational skills. An example was given of providing personal care at The Centre in the morning and visiting three different hospitals in the afternoon, as well as attending to "call outs" (4. 03). This scenario would not apply to most nurses in other sectors; however, Seal (1998) described skills required by intellectual disability nurses as follows:

> Learning disabilities nurses have a wide range of skills which enable them to care for clients of all ages and with widely differing levels of disability, carrying out simple and complex nursing tasks in both social and health care settings. Qualified carers in learning disabilities need to be highly flexible so that they can respond to changing needs and opportunities (p. 46).

Intellectual disability RNs have a different kind of role to nurses in other settings largely because they care for the client who is institutionalised. They are considered by other nurses to be specialists in intellectual disability and because other nursing services are rarely used, they are required to have a diverse range of skills. Indeed, the intellectual disability RN "wears different hats" and needs to be flexible and adaptable (4. 03). A research project conducted in England to examine the current roles of intellectual disability nurses found a greater diversity of roles performed by intellectual disability nurses in recent years than was the case in the past (Alaszewski et al 2001).

McIntosh (2000), who examined the skills required by community nurses, stated that it is a very common perception, particularly among non-nurses and managers, that "certain nursing tasks require specific levels of skill" (p. 105). However, that perception is not useful for explaining the "complexity and range of nursing skills" required in community nursing (p. 105). Often during the course of a visit, McIntosh (2000) explained, a community nurse is required to undertake a number of different nursing interventions and it is important for the nurse to have sufficient skill for all of the care that has to be given.

RNs who work in hospitals or nursing homes care for their clients in one area and community nursing teams mostly have set schedules, but the registered intellectual disability nurse's workload was less predictable. They had schedules as well, but the intellectual disability RN also responded to emergencies and requests to "look at this client" and "while you're here..." (9. 5). In fact many requests from Villa staff were a waste of the RN's time, often because unregulated workers refused to take a reasonable level of responsibility for their actions in health care.

Nurses care rather than cure and it is for care that patients enter healthcare settings (The National Review of Nursing Education 2001). However, during the study the RN was observed to have assessment skills that may not develop in nurses in other settings where there are more medical staff members. In fact, it was often the RN's knowledge of the client that contributed to diagnoses and treatments. For example, a case of life threatening pneumonia that Villa staff had dismissed as a common cold (9.17) and bowel obstructions were "diagnosed" by the RN (1. 32).

Participants in the study referred to the ageing of the organisation's client population and this presents a further requirement that registered intellectual disability nurses are skilled in assessing and communicating with older clients. There are a substantial number of what Bigby (2002) described as "the current cohort of older people with disability", the first to have survived into later life (p. 231) The aged care system is in itself a specialist one and the ageing population of people with intellectual disability is considered due to their increased life expectancy and the "demographic bulge of the baby boom generation" (Bigby 2002, p. 231).

The registered intellectual disability nurse will often be required to care for older clients; however, the organisation's nursing home, which is run separately to The Centre, was not included in the study due to its geographical distance from The Centre. Moreover, the RNs in the current study had no role in the Nursing Home after initial staff training (in which they played a minor role) had been completed.

In addition, skills in another nursing specialty, mental health, were observed to be beneficial as there is increasing acknowledgement of the prevalence of psychiatric disorder in people with an intellectual disability (Davis 1999, p. 101). Two of the registered and enrolled nurses were trained in mental health nursing and provided informal counselling to clients when required.

7.4 A Very Different Nursing Practice

The RN's practice in the study has been described as different from other types of nursing (“Working within a different paradigm” – see Table 5-1). Subthemes *The institutional model of care, Rewards of the position, Downsides to the role* and *The “hub of illness care” and future plans* are subthemes. Nurses worked in the client's home with whatever resources were available**,** often adapting the environment and the equipment to suit the task. They were relied on to provide nursing care often at a moment's notice within The Centre and the wider community.

It was essential to keep an account of how nursing hours were spent to ensure adequate staffing. Nevertheless, while this was time consuming, the introduction of computer technology during the study improved the way that RNs recorded their statistics. Similarly, a study conducted by Alaszewski et al (2001) found much of the registered intellectual disability nurse's time was spent in record keeping. The statistics were useful, though, in providing guidelines for nursing service changes which occurred after the completion of field work. One participant stated that, unlike in other health settings, Centre RNs were given time to do their work and resources are not limited (L. 6. 27). This fact should be attractive to generalist nurses who struggle to provide an adequate service in their sectors.

7.4.1 Adapting to Change

It was not that long ago that "persons requiring care not cure" were marginalised from mainstream medicine and viewed as inferior together with their care givers (Borbasi 1995, p. 9). However, the process of deinstitutionalisation is attempting to remove the stigma from intellectual and other disabilities and during the study an increasing number of people with intellectual disability were observed to be living in the community and using the same services as the general population. However, the research demonstrated that institutional approaches are evident in the sample studied as shown by the strict time tabling of meals and a "bed time" of 7pm for Centre clients (3.9).

The principle of normalisation has been loosely applied in the research setting: specialised health services have been retained and it appears that these are necessary in order to provide clients with intellectual disability with the health care they require. It was Wolfensberger's (1972) belief that people with intellectual disability could utilise the same services as the general population. Nevertheless one of the participants, a senior manager, expressed the view that people with intellectual disability would be in danger of having their health needs neglected without the provision of specialised services (G. 1. 34). The current research demonstrates the value of registered (and enrolled) nurses who specialise in intellectual disability.

The work environment of intellectual disability RNs is constantly changing and differs from other sectors partly due to the effects of the introduction of deinstitutionalisation. Deinstitutionalisation has increased the intellectual disability RN’s work load, rather than reducing this. Maintaining Health Care Plans, credentialing care workers and travelling time to different geographical areas to visit clients are issues that have impacted on this increased work load.

Moreover, the typical general practitioner is likely to be "extremely inexperienced in this area of health care" (van Loon, Knibbe & Van Hove 2005, p. 176). Even so, some clients in the community did consult general practitioners and RNs commented on the reduced volume of calls to community houses. One participant said he felt community clients were more contented and "less ill" (L. 5. 20). This is consistent with research showing that, in comparison to institutional settings, community-based homes "generally result in better outcomes for residents" in terms of adaptive behaviour, community and social networks and self-determination (Heller 2002, p. 1).

Furthermore, deinstitutionalisation has meant the clients are not all under the one roof and RNs are often called to visit clients in community houses some distance away from The Centre. A wide range of skills are required by any nurses who care for clients in the community as well as the ability to work alone and unsupervised for considerable periods of time (Bramadat, Chalmers & Andrusyszyn 1996). This practice is now common throughout the world and was considered to impact significantly on the RN (Alaszewski et al 2001, p. 2). There are plans for a further 150 clients to move from The Centre over the next three years (IDSC 2005) and this will reduce the number of clients at The Centre to 90, again impacting on the future role of the intellectual disability RN in the setting explored through this research.

During fieldwork, RNs provided a 24 hour service, working a 12 hour roster; however, in 2005 the roster was changed by health services management in order to provide a more proactive service. The new rostering system divided RNs into two teams, three working in the Infirmary (on 12 hour rosters) and three providing an outreach service to The Centre and the community. The outreach nurses work five days a week and each is in charge of an area where they have been able to build rapport with managers and this is seen as a positive move by the RNs.

The roster changes are not perceived to alter the findings of the study as the nature of intellectual disability nursing has not changed as a result. Nevertheless, changes to the system of health care provided by the nursing service came under criticism by the care workers who did not appear to like change although the twelve hour shift was retained for most workers (5. 02).

7.4.2 Challenges and Rewards

Because the clients were not regarded as acutely ill, one participant described his role as "fairly low key" (D. 1. 18). Nevertheless, while clients are not acutely ill, the role presents challenges not usually faced by RNs in other sectors. These arise in part from working with such a large group of regulated and unregulated workers, all of whom have their own perception of what is in the best interest of the client. Another downside to the role is communicating with clients who may not be able to speak or understand what is being said to them. For example, the assessment of pain in people with intellectual disability who present to the emergency department of a general hospital has been the subject of research (Foley & McCutcheon 2004). In attempting to develop a tool to measure pain in people with intellectual disability in an emergency department, these researchers concluded that a carer who knows the client should accompany the client.

Moreover, because the client is often unable to describe symptoms, the registered intellectual disability nurse needs to be more sensitive than most nurses to client needs and to changes in their presentation. Indeed, communicating with the client can be particularly difficult for RNs when they are unable to explain procedures effectively. Some clients have challenging behaviours and can be resistive to the point of aggression.

Providing information in simple language assists clients to understand what is required (Piteo 2001). The RNs in the study were skilled in communicating with clients; this quality was often observed in the intellectual disability registered (and enrolled) nurse who has developed communication skills not commonly required by other nurses. Intellectual disability RNs were observed to act as advocates for people with poor communication skills (Jones 1999).

Patience was required when seeking consent for a procedure from a client who uses a "communication board" (a selection of pictures the client points to) for example. However, unlimited patience is not a prerequisite for the intellectual disability RN; rather what is needed is a good sense of humour and a "desire to help an underprivileged group of people" (Jones 1999, p. 61). Consequently, the registered intellectual disability nurses in the study found their role rewarding and they were afforded recognition by clients and other workers for their skills. Rewards were observed to come in different forms such as a smile or a "thank you" and, for the RN, a sense of "doing a good job" despite obstacles and resistance.

As another downside, because some of the buildings were in a state of disrepair, some nurses raised the issue of the environment the clients lived in, which was not optimal**;** however the organisation was undergoing major changes, including upgrading or replacing residences. Other participants complained that some equipment was in short supply; however, their main concern was the management of the clients' files called Health Care Plans. Management of Health Care Plans is the jurisdiction of the RNs. Confusion about Health Care Plans and other documentation was observed to contribute to inconsistent communication.

7.5 Delegating Tasks to Untrained Staff

The RN was observed to delegate aspects of care and to have skills in competency based assessment which was a requirement to credential unregulated workers to conduct health care procedures. The theme “Having to assume responsibility for a large number of unregulated workers (see Table 5-1) has subthemes of *Interaction with RNs, The carer as a credentialed worker* and *Training for the carer role.* RNs were accountable for the care delegated to unregulated workers and ENs. Enrolled Nurse supervision was also an element of the RN's role as in any health setting although, as will be shown, the EN role in the research setting was also found to be different from many other health care settings.

The RNs were observed to work independently of the allied health team but enjoyed a close working relationship with the ENs. The RN appeared to be the leader of the nursing team while their Villa manager fulfilled the role of their manager. Villa managers were the clients' guardians and had jurisdiction over the Villas and the staff who delivered personal care to clients.

7.5.2 Influence of Care workers

Philosophically, within the field of disability, people with intellectual disability are not considered to be "sick"; however, as a group, they have the potential to suffer from more health conditions at a higher rate than the general population (Table 2-1). For most people with intellectual disability, health care means the promotion and maintenance of good health but for some, it can mean daily nursing intervention. Time constraints and geographical distance mean some health care is delivered by care workers rather than trained health professionals.

Consequently, the most workers at The Centre were found to be minimally trained care providers, many of whom had been employed there for many years. The increased use of unregulated workers is common in health care settings and was also observed in the general hospitals that use care workers from agencies to "special" patients requiring close observation (3. 5):

> Many healthcare institutions have been downsizing, increasing the proportion of casual workers, reducing management positions and introducing larger numbers of unskilled or semi-skilled workers (The National Review of Nursing Education 2001, p. 19).

The Nurses Board of South Australia (2005) is a statutory authority established to regulate nursing in the public interest, and has recognised changes to the health workforce and outlined standards for delegation by a RN (or midwife) to an unlicensed healthcare worker. The RNs remain accountable for aspects of their professional work delegated to unlicensed healthcare workers and are required to ensure "adequate knowledge, competency and supervision arrangements" (NBSA 2005, p. 1). Furthermore, according to the Nurses Board of South Australia (2005) all delegated tasks should be in the best interests of the client.

During field work, most care workers were "credentialed" to administer medication and some chose to be trained in other basic health procedures such as blood glucose monitoring and taking routine observations. It was the RN's job to ensure that care workers were trained and deemed competent in basic health care procedures. Since the introduction of Certificate 1V in Workplace Training and Assessment as a mandatory requirement for RNs who conduct training, the term credentialing has been replaced by *competency based assessment.*

The primary function the care workers were observed to perform was assisting clients with their activities of daily living. These included hygiene, feeding clients who were unable to feed themselves and organising recreational pursuits. In some of the Villas, care extended to behaviour management and, in the case of clients living in the community, shopping and cooking. Apart from medication management and certain health care procedures for which care workers had been deemed competent, all nursing tasks were performed by the RN.

However, the RN relied on the care worker not only to report client health concerns, but to provide support to clients during health care procedures. The carer's knowledge of clients was invaluable to RNs, particularly those RNs who were new to The Centre:

> Persons with intellectual disabilities may have difficulty cooperating with examinations and procedures. Healthcare providers need to be educated regarding the confusion, fear, and frustration that many people with intellectual disabilities may experience when they access healthcare services ... more time may be necessary to reassure someone with an intellectual disability (Evenhuis et al 2001, p. 183).

A care worker from The Centre accompanied the client when attending general hospitals and remained until the client was admitted. This proved helpful to staff in the hospital Emergency Department, particularly in acquiring a history of the presenting complaint from a client who could not communicate. While people with intellectual disability are more likely than the general population to require hospital treatment, most hospital staff "show scant understanding" of intellectual disability, therefore known care workers provide "reassurance and familiarity" (McMillan 1998 p. 22). McMillan (1998) stressed that care workers are not there to cover the health care needs of the client as that is the role of the hospital nurse.

During field work I observed a rapport between the intellectual disability RN and most care workers that has been described as "mutual trust" (21. 9). Piteo (2001) stated that good communication with people with intellectual disability is essential and stressed the importance of developing a therapeutic relationship with both the person with intellectual disability and family members or caregivers.

With the exception of the aged care sector, where a large proportion of staff are unregulated workers, the daily interaction with care workers observed in this study appears to be unique to the role of the registered intellectual disability nurse. General hospital nurses do not usually have an ongoing working relationship with unregulated workers; their job is to support the client. This was highlighted by a senior manager who described the role of the intellectual disability RN as including a "support component for carers" (G. 3. 45). The care workers appeared to depend on the RN and the cry of "but I'm only a carer" was often heard when a care worker did not want to take on extra responsibility. On the other hand, care workers were observed to have fixed ideas about client care and were rigid in their approach to tasks for which they did not want to be held responsible (60. 22).

In the main, care workers were observed to have what appeared to be a genuine concern for the client; indeed, some were seen to visit sick clients in hospital in their own time. However, not all care workers were friendly and welcoming to me as the researcher and it took time to establish a rapport. The care workers’ lack of knowledge and indeed disinterest in health care was obvious; for example, as mentioned, failing to fast people for blood tests and general anaesthetics. The care workers who displayed the most health knowledge were nursing students and those with some life experience, such as those who had children of their own.

7.6 Other Professionals and Teamwork

Subthemes *Enrolled nurses, Attitudes of general hospital nurses, Agency nurses* and *Allied health team* form the theme “Having to work alongside many professional groups (see Table 5-1) and address concepts of teamwork and communication. The RNs complained that their knowledge of the client was seldom called on by the multi disciplinary team, notwithstanding evidence of the benefit of team work. In fact the success of a large UK community team comprising a health team for people with intellectual disability was attributed to “balance, competence and imagination” (Griffiths 1999, p. 2). Griffiths (1999) described the balance required in this way:

> In order to manage such a varied target population it is essential that our group includes a range of health care workers whose work is complementary to each

> other (p. 2).

The multi disciplinary team at The Centre included general practitioners, psychologists, a psychiatrist, neurologist, dietician, speech pathologist and a physiotherapist who was assisted by a team of physiotherapy aides. The RN's place in the multi disciplinary team appeared different to most other settings as there was less consultation and RNs accepted much of the responsibility for assessing client health needs and determining whether medical intervention was required. There appeared to be confusion over the role of the RN because traditionally the intellectual disability RN's role was restricted to the delivery of hands on care (L. 6. 35). Furthermore, nurses appeared to lack the leadership and motivation to have their voices heard adequately.

Very little interaction was observed between the RN and other team members, although doctors occasionally consulted with the RN. In Australia there are few doctors trained in the specialty of intellectual disability and Beange (1996) suggested doctors, although "a decent lot", as a group can be impatient and have difficulty communicating with the client who has intellectual disability (p. 159). Indeed, during field work a number of doctors were observed to take up postings with the organisation for only short periods of time.

As a result of the doctor's lack of knowledge of the client, RNs were most likely to be asked to assist due to their expertise in managing clients, when the doctor might be perceived to lack confidence. Indeed it was often the case the RN knew the client better than the doctor. Interestingly, two doctors who had a long association with the organisation, and had developed excellent rapport with clients, were rarely observed to consult with RNs.

The Centre's ENs were observed to fulfil the role of liaising with other members of the multi disciplinary team because of their more continuous contact with sick clients in the Infirmary. It was often the EN who kept the RN informed of client progress and their needs. Moreover, the ENs were a valuable resource to the RN and a positive team spirit was observed. Good communication was found within the nursing team who were able to consult with each other; they acknowledged each other's strengths and weaknesses and were supportive of one another.

In overseas intellectual disability health settings, the role of the registered intellectual disability nurse within the team is described as the liaison person between the client and other members of the allied health team, ensuring that the team is aware of the client's needs (Piteo 2001). Generally, nurses work within a team and, being available 24 hours a day, are in a good position to facilitate networking as they know "who to call for what" (National Review of Nursing Education 2001, p. 30). However, RNs in this study appeared frustrated in their efforts to "have a handle on things"; care was fragmented and good multidisciplinary teamwork was not evident, as other health professionals delivered their own specialised care (9. 42).

The exclusion of RNs from team decisions did not appear intentional as they were often included as members of committees focussing on client issues. Their absence was usually due to their heavy work load and subsequent difficulties attending meetings. Poor communication within the multi disciplinary team appeared to affect the RN's role and, as a result, client care appeared fragmented. The problem was exacerbated by Villa managers' expectations and poor communication with unregulated workers. This is contrary to the notion of teamwork as described by Griffiths (1999):

> We operate a relaxed but highly professional approach based on mutual respect and support, knowing that should any one of us not know the answer to a question we will be able to ask our colleagues ... underpinning the system is the recognition that good communication is essential (p. 3).

7.6.1 Enrolled Nurse Supervision

Research indicates a shift in practice over the last two decades for all levels of nursing, amplifying the work of enrolled and registered nurses, and what was once considered expanded practice is now the expected norm. Indeed, ENs "perform an increased number of technical competencies" (National Review of Nursing Education 2001, p. 25). Nevertheless, it is a Nurses Board requirement that an EN is supervised by an RN and, despite the expanded practice of ENs, there is a clear need for the RN at The Centre.

During the current study some RNs felt that ENs "think differently" to RNs (8. 05). RNs use planning and judgement skills that ENs may not possess and the ENs were observed to seek advice frequently from RNs. There were tasks that ENs could not perform because of their limited training. For example, ear syringing, venipuncture, catheterisation, naso gastric tube insertion and rectal examination. Moreover, the ENs did not conduct competency based assessments (credentialing).

The RNs who provided supervision to ENs needed to ensure they were competent and safe practitioners as the supervision was often from some distance away, usually by telephone. Changes to the rosters in mid 2005 saw an EN on night duty, alone, in charge of The Centre and the Infirmary with telephone support provided by the nurse manager or health services manager. Staff felt very insecure about not having an RN on duty 24 hours a day and there were many complaints. The unregulated workers knew the difference between an RN and an EN and expressed the view that there should "always be an RN available" (6. 10).

7.6.2 Divisions Within the Nursing Team

Foucault's (1977) writings influenced the analysis of the processes involving the use of geographical space. The use of space involves partitioning certain groups of workers from others and can be seen in the separateness of various ranks of nurses (Foucault 1977).

Divisions were observed within the nursing team pertaining to rank and the various ranks of RN were geographically partitioned from each other. The more senior ranks had offices in the Health Centre while the level one RNs were based in the Infirmary. Neither group appeared to have knowledge of what the other was doing, with the exception of the nurse manager who was well informed about the entire Centre.
The Centre did not always adhere to a schedule of regular RN meetings and Infirmary meetings in which the ENs could participate. When held, RN meetings were beneficial as the RNs did not work together and they welcomed an opportunity to exchange ideas. Meetings also assisted in presenting ideas to management about health care issues.

7.7 These RNs Have Different Educational Needs

Intellectual disability registered nurses were found (to be) “Having different educational needs” (see Table 5-1). This theme has subthemes of *The need for education* and *Management and training.* Up until the late 1990s, care of people with intellectual disability was traditionally the domain of mental deficiency nurses in

South Australia but that qualification is no longer acknowledged in this state of Australia. This was seen as a progressive move as RNs are now trained through tertiary institutions and currently general trained nurses are eligible to undertake post graduate studies in disability (Bottroff et al., 2000). Coursework in Down syndrome, Autism, and other areas of interest including health related matters is offered but there is no specific educational preparation for intellectual disability nursing.

Consequently, in the research setting, there was a need for more "on the job training" than required by RNs in other sectors and knowledge was handed on from one generation of nurses to the next. It seems nursing's specialist knowledge in disability care is in danger of becoming extinct. In fact, even experienced ENs were found to teach novice RNs the art of intellectual disability nursing including tasks not commonly performed by nurses in other health care settings. Similarly, a study conducted in the UK found deficiencies in educational preparation for intellectual disability RNs in terms of "clinical skills, health care, communication, management and leadership skills" (Alaszewski et al 2001, p. 1).

Notwithstanding that registered intellectual disability nurses in the study appeared to be multi-skilled, they were also observed to have their specialties. For example, lack of knowledge in venepuncture might be compensated for in wound management expertise. There was an expectation that the RNs in the study acquire the necessary skills for the role and most appear to have done this without complaint. However, a lack of learning opportunities exist for undergraduate, and indeed postgraduate nurses, interested in the field of intellectual disability. There is also no training in place for the many technical skills required by intellectual disability nurses such as ear syringing which is learnt on the job without a hint of an evidence base.

Furthermore, it was evident that opportunities were lacking in training specific to their role in caring for people with intellectual disability for the enrolled nurses involved in the study. Smith (2002), the director of a UK Centre for people with intellectual disability, believed it is important for nurses to be knowledgeable about disabilities to provide the best level of healthcare. In addition, in Smith's study, observation of care workers' practices suggested that the orientation in client care they currently receive was not sufficient to provide them with the knowledge required to provide adequate health care for such a vulnerable group.

My study identified wide ranging deficits in knowledge about intellectual disability which one participant described as unfortunate because people with intellectual disability "live everywhere now" (S. 2.18). Another suggested a community education program would assist in developing knowledge and breaking down barriers (A. 3. 2). While the community's attitude to the person with intellectual disability is of ongoing concern, the study considered the knowledge of general hospital nurses was of particular importance for the health care of this group. A poor understanding of intellectual disability was considered to contribute to the attitudes of the general community and other health professionals.

Indeed, general hospital nurses appeared to display a very poor perception of people with intellectual disability and education efforts at management level did not seem to filter down to ward staff. Clients in hospital settings were observed, on occasions, to be shackled to their beds in order to preserve intravenous lines and catheters and this was not considered to be good nursing practice. Confusion about the role of the intellectual disability RN often meant they were excluded from discharge planning leading to inappropriate admissions to the Infirmary. The intellectual disability nurse was often treated as a carer when visiting general hospitals, and consequently their knowledge was not utilised, which also affected client care.

Nevertheless, advancement was made in the area of education during the study in the opening by the organisation of a specialist medical practice and as a result, the Adelaide University awarded 1.5 fully funded PhD scholarships over the next three or four years to research in this sector (IDSC 2005). In addition, support has been sought to fund three important areas of research and the health services manager is currently negotiating with all South Australian universities to support the inclusion of intellectual disability in their curricula. Indeed, the main finding of the research was the lack of opportunity for the field of intellectual disability to gain recognition as a nursing specialty. This is despite many English speaking countries providing specific education in intellectual disability nursing.

Recognising its leaders were nearing retirement, the organisation commenced leadership training in 2002 in an attempt to pass on knowledge about intellectual disability to the next generation of leaders. These included managers and supervisors and as the researcher, I was invited to attend. Leadership training was informative and explained the historical development of the organisation as well as some causes of intellectual disability. However the training was abandoned after five sessions, without explanation. Such a course would be beneficial to the RN interested in intellectual disability (See recommendations for education in chapter 8).

7.8 The Future of Intellectual Disability Nursing

Throughout history, nurses, particularly nurse leaders, have been responding to changes that present challenges to the profession (Reilly & Perrin 1999). The future of intellectual disability nursing depends on RNs adopting the role of change agents to lead the profession (Menix 2000). Leaders are necessary to facilitate change, however nurses must be willing to "try and think of a new way despite the multiple barriers to change that they confront" (Grossman & Valiga 2000, p. 144).

There is a need to promote intellectual disability as a career option for RNs and more education is required at tertiary level. Without appropriate education, nurse managers may lack the competencies to effectively manage accelerated change (Menix 2000). As previously stated, there appears to be a need for a nurse practitioner to lead the nursing team and such an addition could enhance relations with the allied health team (see chapter 8).

In addition to the delivery of a high standard of health care to clients, the RN will continue to play a crucial role in health promotion and incorporating the principles of evidence based practice into service delivery. Clearly there is a future for RNs interested in taking up the challenge of research in the field of intellectual disability. Furthermore, the RN will continue to support and educate unregulated workers and liaise with general hospital staff promoting an understanding of the needs of clients with intellectual disability.

7.9 Impact of the Culture

A description of culture, its history and the socialisation of nursing demonstrates the manner in which the RN’s role is constructed by culture. Two main conceptualizations of culture, *behavioural/materialist* and *cognitive* are useful in discussing the study. The behavioural/materialist perspective observes culture through a group’s patterns of behaviour and customs, what they produce, and their way of life.

The cognitive formulation considers culture to consist of the ideas, beliefs, and knowledge that are used by a group of people as they live their lives (Roper & Shapira 2000).

This study found the RN’s role in The Centre was affected both by forces within the culture and external forces. Nevertheless, the powerful non-nursing management, tradition, policy, disorganisation and poor communication were found to be overarching concepts. Moreover there was a clear division of the culture between residential services (accommodation services) and health services.

7.10 Internal Forces

The client, nursing practice and other workers have been described as affecting the RN role. In addition study findings showed other internal forces affecting the RN's role were the culture itself, management and the system of health care. These are detailed below.

7.10.1 The Culture Itself

The word "culture" implies human thought patterns, communications, actions, customs, beliefs, values and institutions of racial, ethnic, religious or social groups (Sutton 2000). Culture influences the way people respond to medical services and preventative interventions (Sutton 2000). The role of the RN in the study was observed to be determined by a culture that had limited knowledge of nursing. In fact the nursing service appeared to be a sub-culture of the dominant culture of the organisation (Taylor, Lillis & Lemone 2004).

According to participants in the research, the ways of living this culture had been transmitted over the 30 years since the Centre's inception. In effect, the culture had developed with little regard to societal changes and alterations in health care delivery; this limited the RN’s role.

7.10.1.1 The Culture's History

Throughout history nurses have examined and analysed their role, however little has been written about the evolution of nursing specialties (Nehring 1991). The field of intellectual disability nursing is an example but as Nehring (1991) explained, in the USA intellectual disability nursing had its origin in mental health "asylums" (p. 259). This is also the case in Australia; indeed the Centre was built in a bid to separate people with intellectual disability from those with mental disorders (Hoff 1971).

Notwithstanding that the 1970's advent of deinstitutionalisation meant "opportunities for nurses have changed", there is a stigma associated with intellectual disability nursing (Nehring 2004, p. 1). In fact, the historical development of intellectual disability nursing was found in this research to have impacted on the role of current RNs who supported people with intellectual disability. The model of nursing used at the time of The Centre's inception is understood to have aligned with the medical model and provided basic care, and because the clients were children, there was an emphasis on training (Burness 1970). The introduction of deinstitutionalisation brought the promise of community style living and use of "normal" community health facilities for people with intellectual disability (Hassam 2002). After a brief time, during which nurses at The Centre were replaced by unregulated workers, the organisation found clients needed a nursing service. The resulting nursing service was the subject of this research.

Intellectual disability, as it is now known, was described as embracing a "whole range of facets" that create a "fascination and challenge to the workers" according to The Centre's medical officer (Burness 1970, p. 5). The nurse was described as assisting doctors in diagnosing client illnesses and this aspect of intellectual disability nursing was observed during the study (Burness 1970).

Ten years after The Centre was opened the Superintendent of nurses, McElwaine (1981a) made reference to the discipline as it was in 1971. He stated there was debate about whether the nurse should in fact bear the title of residential care worker or social trainer as in other states of Australia. He revealed the role had not changed since the opening of The Centre and "the important thing is their skills and attitudes" (McElwaine 1981a, p. 15). The years that have ensued have brought many changes to the nursing structure at The Centre; nevertheless historical traditions were found to permeate the culture. For example, McElwaine (1981a) described the discipline at the time the Centre opened, in 1971, as follows:

> Rules and regulations must be made known as should the nature of disciplinary actions which may ensue if these are contravened (p. 19).

Admittedly at that time, the workforce comprised mainly nurses and Centre RNs have appeared slow to liberate themselves of the age old subservience that was observed to continue to impact on their role. General hospital nurses, who have a similar history of subordination, were observed to be decades ahead in relation to acceptance of their knowledge and skills (Madsen 2000).

7.10.1.2 "The Way it's Done"

Ways of thinking and doing at The Centre are passed on to the next generation of staff and as the "family" (the culture) moves into the community, the same practices were observed. In fact, despite modern technology and the introduction of computers to assist the RN in recording statistics, The Centre continued to use the report book of the 1970s as a means of communication. Villa staff relied on the RN to "write in the report" because that was proof the RN had "done something" (3. 4).

The entire culture's rigid, inflexible adherence to routine was observed in client meal times, as mentioned previously, but also in staff meal breaks. This impacted on the RN who was often kept waiting or had to reschedule a credentialing appointment because the care worker had "gone to tea" (3.9). Not surprisingly, due to the expectations of the management, new staff developed the same practices as those who had been employed at The Centre for 30 years. The organisation's policies and rules required staff to comply with its belief system, regardless of their own. This style of conditioning is described by Foucault (1977) who uses the term "the gaze" to describe an ever present authoritative figure to ensure conformity (p. 195).

7.11 Management

The most powerful influence on the RN's role was the strong management depicted in the theme “Hierarchical structure” (see Table 6-1). Subthemes are *Ad Hoc system* and *Management’s role in constructing the nurse’s reality.* The organisation appeared to lean toward management rather than leadership; classic examples were "Standing Orders" and the short lived attempt at leadership training (2002). Leaders may or may not be successful as managers and Menix (2000) found that managers could find it difficult to promote change effectively without appropriate education. The management appeared to dictate the style of "leadership" displayed by Health Services and nursing managers. Notwithstanding the International Council of Nurses (2000) Position Statement on Management of Nursing and Health Care Services that states that whether nurses report to nurse or non-nurse managers, it is the nursing profession that is accountable for the scope and standards of nursing practice.

The International Council of Nurses (2000) describes leadership as an essential component of management. Likewise, Australian experts believe nursing needs a national approach to nursing leadership (Armstrong 2002, Jones & Cheek 2003). Drawing on the research which informed the National Review of Nurse Education in Australia in 2001, Jones and Cheek (2003) described contemporary nursing as an "increasingly complex concept" and revealed that flexibility and educational preparation are necessary to facilitate change (2003). Indeed, research suggests nursing may hold the key to transforming health care and "dragging it into the 21st century in terms of work practices and reform" (Thyer 2003, p.73).

An Australian study that addressed skills mix and client outcomes in nursing homes found management and leadership style to be significant determinants (Pearson, Hocking, Mott & Riggs 1992). The study involved gathering data from 200 nursing homes in four Australian states using questionnaires and a case study approach (Pearson et al 1992). The senior nurse's attitude, commitment and interpersonal skills were found to be conducive to good quality care (Pearson et al 1992) and this would seem to have implications for the role of the RN in other settings.

The Centre is large and was seen to have many leaders including those based at The Centre (the main focus of the research). In particular, the RN's practice was significantly influenced by the Villa managers who were extremely powerful within the Centre. Nursing management personnel as previously stated were "of the culture" and determined nursing practice for the RN.

RNs were also subject to The Centre's policies, which impacted on their day-to-day practice. Organisational management dictated policy with little understanding of grass roots practice: management issued directives in the form of "Standing Orders" and there were serious consequences for any worker who was found to be in breach of these rules, ranging from being "spoken to", to receiving an official warning.

Foucault (1977) described the processes of *surveillance* and *normalization*. For Foucault, surveillance supports an institution's power structure by promoting control and making the individual visible. Normalization is seen as reinforcing conformity by maintaining acceptable standards and issuing punishments to highlight failures (Foucault 1977), a very different interpretation of the term to that described by Wolfensberger (1975). An example of surveillance and normalization in this in the study was the circulation of internal memoranda highlighting breaches of the rules and warning of the consequences (M. 3. 01).

At the Leadership Training course (2002) the Director stated that such explicit rules were necessary because workers require direction. Policies were found to range from basic tasks such as instructions for filling a kettle to the justifiable prohibition of personal mobile telephones while on duty. Most policies pertained to client safety and well being and management appeared overly protective of the client and not trusting of the worker. Such is the power of the organisation, that it can even overrule decisions made by family members of the person with intellectual disability if they are not considered to be in the client's best interest. Management's power impacted on the RN and indeed on medical staff who also believed they practised with the client's best interest at heart.

7.12 "Outsider" Status

“The RN’s position” is a theme that describes the social world of the research setting in the first subtheme as *Like a family* and the RN was deemed a parent figure (Table 5-1). However while the RN was often called on by clients to play that role, the relationship was actually observed to be more consistently that of friend or “outsider” (Table 6-1). *Outsider status, Nurses’ power* and *The Infirmary as the nurse’s domain* are also subthemes of “The RN’s position”. Parent figures to clients are the Villa managers who, with a few exceptions, are their guardians. The Villa managers are powerful people who are required to give consent for a client to join an activity, consult a doctor and receive medical treatment. Indeed, Villa managers are involved in every aspect of the client's life, in a similar way to a normal parenting role for young people under the age of 18 years.

On the other hand, the RN was in the culture, but not a part of it and was observed to be an "outsider" (Table 6-1). The RNs who had been employed by the Centre for many years seemed to have relinquished their "insider" status. They did however have knowledge of the culture, which they shared with newly employed nurses. The "older" RNs were also more readily accepted and "in demand because they know how to do things properly" according to the Villa staff (1. 02).

The move away from the medical model had, correctly, changed the nurse’s place from being central to the clients’ world to being peripheral in their lives. Essentially, RNs were visitors in the client's home and needed a reason to be there. This belief made health promotion difficult as the culture only sought nursing intervention when clients were sick. The RN was relied on for health matters ("bandaid treatment") but not afforded any feedback on care. Registered (and enrolled) nurses who attempted to follow through their nursing actions were greeted with suspicion by Villa staff. Indeed, poor communication seemingly stemming from a belief that the RN "does not need to know" was considered to limit the nurse's role (2.10). The effect of poor communication on the role of the RN was clear and the data revealed a system where managers and care workers did not communicate important client health issues to RNs. Nevertheless, RNs communicated with each other and attempted to communicate with other workers. Nurses were seen by management as people to perform tasks and not consulted for their knowledge; only clinical skills and basic assessment skills. This appeared to be due to their "outsider" status and being unable to have their voices heard. The leaders (that is, the Villa managers) were insiders who belonged to the culture and newly recruited nurses quickly realised it was pointless to try and influence any changes.

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Furthermore, the RNs were distinguished from the majority of the culture by the wearing of a uniform, as is the practice in most health settings. Registered intellectual disability nurses found that when visiting clients in hospital or meeting visitors to The Centre, the uniform identified them as health professionals.

7.13 Confusion About the RN Role

The RNs could have had a powerful role within The Centre yet they did not. This was considered to be due to confusion about their role. Indeed “Role confusion”, the final theme, was evident across all levels of workers (see Table 6-1). Subthemes are *Back covering, Attitudes of workers* and *Running around in circles.*

Unlike in health settings where the primary focus is health, workers were observed to assist in organizing the leisure and social activities of clients. While much of the carer's time was spent bathing and feeding clients who could not attend to their own needs, behavioural support and recreation were also important. This impacted on the RN, who often had to wait to implement health procedures because health care was not a priority to them.

The workers were reliant on the nurses and their dependence was considered a blatant waste of the RN's time due to non-streamlining and misunderstanding of roles. RNs were observed to make unnecessary calls to Villas because the staff members were concerned about a client and the Villa staff did not want the responsibility of deciding on a plan of action. Often in these situations the client was not even ill.

The nurses called it "back covering", the practice of calling the RN to examine the slightest abrasion or a client who was not eating, for example. It was felt that this was due to a mandate issued by management that all sick clients must be seen by the nursing service. The shift supervisors and managers stated "we have to let you know" and admitted to covering their own backs (28. 3). "Back covering" is a universal self-preservation technique and the large volume of documentation in use at The Centre could be seen as protecting the writers rather than informing readers (Sundaram 2005).

Another explanation for frequent calls that wasted the RN's time was the Villa staff's lack of knowledge about what constituted genuine illness. Some Villa staff were more knowledgeable and admitted they did not think that the problem was serious, however they did not want to “get into trouble” for not making a report.

In fact the RN's knowledge was considered to be under utilised, which is typical in all areas of nursing in Australia notwithstanding the nursing profession being "highly regarded in the rest of the world" (Sutton 2002). For the registered intellectual disability nurse, this often meant non-participation in planning and using valuable skills on tasks that unregulated workers could perform. For example treating simple wounds and taking observations.

In management's view, it appeared that any power the RN might have pertained to their health related knowledge and skills and the legislation that certain tasks could only be performed by an RN. For example, overseeing the care delegated to unregulated workers and "credentialing" in health care procedures. On the other hand, because of their skills, RNs were afforded a great deal of respect by unregulated workers who relied on them to authorise medication administration and make clinical decisions. These workers included shift supervisors who were loathe to make decisions of a health nature.

Written guidelines provide some consistency and ensure a certain level of patient care, hence policies and protocols provide nurses with "legitimacy of their knowledge in the clinical arena" (Manias & Street 2000 p. 1467). However, notwithstanding that the organisation had many policies pertaining to staff conduct, no clear guidelines existed for nursing procedures such as wound care, catheterisation and stoma care. Evidence based practice was not apparent.

The RN's knowledge of the client was not called on to provide holistic care, nor client advocacy, in health matters where nursing knowledge would have been advantageous. For example, the data revealed the RN playing a subordinate role in much the same way as other workers. This was despite unregulated workers describing RNs as "the big shots" which was perceived to indicate respect for the RN's knowledge and training (2. 4). Remarks such as this example could have been the result of resentment. However, the research demonstrated that the "big shots" were the organisation's managers. This is common in health settings where "lack of managerial recognition" continues to perpetuate the gap between nursing theory and practice (O'Callaghan 2001, p. 39).

7.13.1 Workers' Attitudes to RNs

Attitudes of workers were considered to be embedded in the culture of the organisation and these impacted significantly on the role of the RN. The staff attitudes encountered by the RN on a day-to-day basis seemed to be unique to the setting. Staff had been taught to approach tasks in a certain way and inflexible routines were adhered to despite common sense often suggesting a task should be done differently. There was no room for any risk taking or "thinking outside of the square" and workers' task orientation influenced the nurse's role in terms of time and mode of health care. Moreover, the workers did nothing without first consulting their Villa manager which was frustrating for a RN who, for example, might want a client's meal delayed by half an hour in order to complete a treatment (3. 8).

Although some care workers were polite and obliging, others were found to be uncooperative and seemingly resentful of the RN. There appeared to be confusion among former mental deficiency (MD) nurses about their role and that of the RN. Comments ranged from "you are being paid more than I am" (former MD nurse, 25. 8) to "why should I? That is not my job" (former MD nurse, 15. 10).

Admittedly, it was the unregulated workers' lack of health care knowledge that accounted for the seeming lack of cooperation observed on occasions. For example, when clients were not fasted for general anaesthetics and venipunctures, despite specific instructions to this effect. In one case the carer did not realise that a tub of yoghurt was classed as food (9. 20) and another client was given his breakfast because he was hungry and "could not wait" (11. 12). In fact the workers' lack of knowledge on medical issues and nursing terms was found to impact significantly on the RN's role, unlike in nursing homes, for example, where RNs are able to oversee the work of a smaller number of care workers.

7.14 The System of Health Care

From participant accounts, the introduction of deinstitutionalisation initially appeared to hail a new era for people with intellectual disability. The "medical model" was abandoned and replaced by the "developmental model" and the ratio of minimally trained staff to trained staff (RNs) was reversed. The organisation initially had to be "convinced there was a need for a nursing service" (G. 3. 36). Consequently, nursing did not appear to sit comfortably within the hierarchical structure of the organisation.

The system of health care appeared chaotic with a handful of RNs attempting to deliver care to 300 clients with intellectual disability. The organisation presented the argument that clients were not sick but the higher incidence of illness in this group has been demonstrated in the literature (Chapter 2), and there is also an acknowledged need for specific attention to health maintenance issues (Lennox & Diggens 1999). An ageing population also had health requirements not accounted for when The Centre opened 30 years previously and the clients were children (Bigby 2002). Furthermore, the increasing recognition of dual disability places a burden on the organisation to provide appropriately qualified RNs (Curran 1999).

The research revealed a disorganised system where roles were not clearly defined, workers' job descriptions were out of date and it was unclear who was responsible for what. The culture seemed complacent about the state of affairs although workers in the lower ranks identified that "something is not right" but were powerless to act on their concerns (1. 23). The "ad hoc" system of care is part of the social system/order that has not changed over time according to participants. One participant described the former system of health care where relevant client information was "just picked up along the way" (B. 1. 29). During the research it was observed to be difficult for RNs to deliver a professional nursing service with information they "picked up along the way". Moreover, communication with other players was impossible without having all of the information readily available. A model for nursing practice is recommended (see example Table 8-1).

7.15 External Forces

Health, social and political trends naturally impact on the culture and subsequently on the RN's role. External forces affecting the culture are now addressed.

7.15.1 Current Trends in Nursing

Intellectual disability nursing has changed but there have also been considerable changes in other nursing sectors. The National Review of Nursing Education (2001) highlighted that reduced hospital stays have meant a need for more qualified nurses and there has been a shift in the location of nurses’ work. This was found to be the case in the research setting and in the aged care (Gilmore 2004) and mental health sectors (Armstrong 2005). Community nursing is not confined to these areas as there is a trend toward providing nursing care in the home (Shepperd & Iliffe 2005). RNs also work in general practice settings delivering a wide range of health initiatives "which support the work of Australia's GPs" (Armstrong 2002 b).

Furthermore changes in the work structure of hospitals have made demands on the "flexibility and adaptability of nurses" (The National Review of Nursing Education 2001, p.19). The nursing profession has been responding to changing technological, educational and social forces throughout its history (Reilly & Perrin 1999). Moreover nursing has seen considerable changes in recent years. Where nurse training was once hospital based, today's registered nurse is a tertiary educated professional and this has impacted significantly on nurses and nursing in Australia (Reilly & Perrin 1999).

7.15.2 Political Influences

Political influences were found to significantly impact on the culture ranging from mandates concerning health and deinstitutionalisation to individual politician's views on intellectual disability. Indeed, one participant felt personal experience with intellectual disability would give a politician a more empathic view (L.11.05). In particular, deinstitutionalisation is moving the "family" into the community and this will affect the state's disability budget in much the same manner as the budget will determine the future lifestyle of people with intellectual disability.

An example for future generations of people with intellectual disability and their carers was the October 2005 Australian Government announcement of a $200 million package that will allow parents of people with intellectual disability to establish private trust funds for the future care of their children (Howard 2005). Naturally as a government organisation, the research setting is continually affected by “the budget”. Lack of funds, increased workloads and a shortage of university places for nurses affect nursing across all sectors (Armstrong 2004).

7.15.3 Hospital Substitution (In-Home Care)

The term hospital substitution is used to describe nursing care received by patients in their own homes. Hospital substitution can facilitate early discharge from hospital or it can prevent the need to go to hospital. At times when The Centre RNs were very busy, hospital substitution was used for sick clients who wished to remain at home (Advanced Community Care 2005). It was considered necessary for registered intellectual disability nurses to initiate the use of this service as there is a perceived danger of undermining their role by using other agencies. For example, shift supervisors could arrange nursing care that was within the scope of the RNs employed in The Centre's nursing service without consultation.

7.16 The State of Health Care in Other Nursing Sectors

Nursing research, evidence based practice, and innovations in technology have seen nursing forge ahead leaving the areas of mental health, aged care and intellectual disability lagging behind. These sectors appear to be subjected to stereotyping which affects client and nurse alike. In fact, Shanley (2001) describes a shared feeling of powerlessness and sense of being undervalued by both nurses and clients in the mental health sector. This is notwithstanding that mental health is recognised as a nursing specialty by the Nurses Board of South Australia and the educational preparation for registered mental health nurses is a graduate diploma.

The introduction of deinstitutionalisation has significantly impacted on mental health care, creating a system that Groom and Hickie (2003) described as grossly inadequate. Furthermore, funding is less than adequate and an increase is required to bring Australia's mental health care expenditure in line with other developed countries (Groom & Hickie 2003).

Overwhelming concerns were expressed by nurses in the aged care sector where The Australian Nursing Federation (2004) reported issues such as "lack of staff, lack of time and poor wages" (electronic source). Moreover, Gething (1999) suggested that education is a "major source of negativity" and the result can be students who regard aged care as "undesirable, unpleasant and unrewarding" (p. 2). While research was found to be lacking in the discipline of intellectual disability, other nursing sectors are conducting research into their practice.

7.17 Comparison with Overseas Trends

The Scandinavian model of normalisation and deinstitutionalisation, developed in the 1970s, has been adopted by many countries around the world (Merrick et al 2004) and Parmenter (1992) observed that the normalisation principle "did not emerge as a result of research efforts" but rather as a result of values held by society at the time (p. 187). Regardless of the motivation for these changes, in the USA, several states have completely closed down their institutions and transferred care of people with intellectual disability to the community (Merrick et al 2004). Nehring (1991) described the evolution of intellectual disability nursing in the United States and suggested current medical technology mandates a need for improved nursing education in the field of intellectual disability. The process of deinstitutionalisation has not been without complications such as health problems, earlier deaths and lack of health services, therefore a combination of community and institutional care is suggested by some (Merrick et al 2004).

Indeed, throughout the world changes in care provision for people with intellectual disability in recent years have impacted on the nurse's role (Seal 1998). The past two decades have seen the ratio of nurses to unregulated workers dramatically reduced in South Australia (Flett 1992). However with the process of deinstitutionalisation now well established in most English speaking countries, the world trend is to increase nursing numbers in the care of people with intellectual disability (Griffiths, 1999).

In South Australia, the advent of deinstitutionalisation marked the removal of the intellectual disability nurse qualification (Bottroff et al 2000). In fact, across Australia there is limited education at tertiary level about the health needs of people with intellectual disability (The New South Wales Council for Intellectual Disability 2005). The University of Wollongong in NSW is the only university campus of 19 in NSW that has a compulsory subject on intellectual disability in its Bachelor of Nursing curriculum (The New South Wales Council for Intellectual Disability 2005). However, in most overseas countries, intellectual disability nursing is acknowledged as a nursing specialty that holds many career opportunities (Tidby 1999).

Furthermore, overseas literature reveals a plethora of learning opportunities for registered intellectual disability nurses at tertiary level. The UK and Ireland offer intellectual disability nursing at pre-registration level (Barr 2004). Moreover, in Ireland a Nursing Education Forum was established to address emerging trends in intellectual disability (McKeon 2001).

However, the role of the intellectual disability nurse has not been "constructively debated" and Sheerin's (2004) study attempted to identify the foci of interest in Irish intellectual disability services (p. 59). The study highlighted a possible gap between the "philosophical underpinnings of professional nursing practice" and of service provision (Sheerin 2004). As my research revealed a similar gap, a need for further research from this perspective is indicated.

The field of intellectual disability has not been well researched in Australia (Parmenter 1992) although Parmenter (2004) revealed an increase in the sharing of research efforts concerned with people with intellectual disability across the world over the last 50 years. This is due in part to the growth of scientific journals, international conferences and the sophistication of information technology. The field has also benefited from the establishment of major affiliated research centres dedicated to the study of intellectual disability in Europe, North America and Australia (Parmenter 2004).

7.18 Meeting Research Objectives

In describing the role of the intellectual disability RN from the perspective of a range of other stakeholders the objectives of this research (as outlined in chapter 1) were met. It was however the nurses themselves to whom I turned for a description of their role and how they might view the future of this nursing specialty.

Aspects of the culture which was created by many players, nurses and non-nurses, were considered to impact on the RN’s role. Thus the role of others in the setting was explored. Benefits of the research are detailed in the following section (7.17).

7.19 Contribution to the body of knowledge

This research contributes to the wider body of knowledge in the disciplines of intellectual disability and nursing by describing the role of the registered intellectual disability nurse. This has not been attempted in quite the same way before. Clear differences have been demonstrated between intellectual disability nursing and nursing in other sectors. In this setting the culture had a significant impact on the ability of the nurse to practise at an optimal level. In particular, organisational management circumscribed the RN's role despite moves made to empower the nurse. However the study had an effect on the interest shown among workers at all levels in the field of research; communication has improved, and partnerships formed between interested general hospital staff and other researchers about the work.

Innovations stemming from this interest include the development of education sessions for care workers, the delivering of health lectures to disability studies students, and promoting role awareness among staff through communication. I have campaigned widely to professionalise the role of the intellectual disability nurse and in 2001 a nurse specialist position in psychiatric nursing was established. The position has relevance due to the high incidence of dual disability.

In 2005 two RNs successfully applied for reclassification as level 2 RNs. One RN has also expressed an interest in the role of nurse practitioner and there is a keen interest in developing a nursing model for the field of intellectual disability. In 2005, changes to the nurses' rosters at The Centre gave the RNs an opportunity to "design" their own practice and principles of inclusion and improved communication have been applied. The RNs have now moved their base to the Health Centre where they provide a community outreach service. Similarly, community mental health nurses have applied this concept to their practice since the devolution of mental health services from psychiatric hospitals to the community commenced (Muir-Cochrane 2001).

As a result of these developments, the number of "back covering" calls has fallen as unregulated workers reluctantly learn to take more responsibility. RNs are now much more assertive about what is and is not their role and in providing training and support for care workers.

In addition, progress has been made toward creating a better system of education for the intellectual disability RN. For example, consultation with one of South Australia's universities has resulted in curricula revision to include intellectual disability in the Bachelor of Nursing course. Recently an orientation to the Centre was introduced for second year students enrolled in the Bachelor of Nursing course from that university. I have also presented several papers on aspects of the role of the intellectual disability nurse and a conference paper available online (Paech 2003) has attracted inquiries from overseas intellectual disability RNs. This work has raised appreciation of the contribution intellectual disability nurses make to the setting.

7.20 Summary

The role of the registered intellectual disability nurse in the research setting has been described as "totally different" to that of nurses in other health settings. Special qualities are required and indeed it would not be a job suited to every nurse. The RN, in caring for people with intellectual disability, provided a proactive and a reactive health service (health promotion and health maintenance). These nurses were resourceful in terms of often removing the need to consult other health professionals because of their knowledge of the client and ability to conduct assessments and make clinical decisions independently.

While good communication was observed within the nursing team, the allied health professionals were observed to largely exclude the RN from their world. The research setting's communication problems were exacerbated by a strong non-nursing leadership and management, and supervisors and care workers who did not have a health focus. Indeed, the role of the nurse was unclear and the RN was seen to be an "outsider".

The RNs in the current research were operating in a model other than health and were "outsiders", as management set them apart. Notwithstanding these issues, the RN is clearly the overseer of health care at The Centre and crucial to client care. However, it seems they were not afforded sufficient decision making power in the system and also appeared to have their time wasted performing tasks that did not require an RN qualification. *Managerialism* discounted nursing's professional knowledge and skill and there was little or no collegiality between the two groups which, at times, had effects on clients' health. The RN was in a difficult position and there were long standing tensions that hampered any attempts to improve the situation. As a result the nurses became complacent and accepting of the situation.

Despite the constraints imposed on their practice, the nursing role was found to be essential and, importantly in light of ever changing systems of care, the study found there is an important place for the RN in the care of people with intellectual disability. It was quite clear that health care would become even more fragmented should the RN be removed from the support system. The introduction of progressive deinstitutionalisation has meant that RNs play valuable roles in formulating health plans, liaising with general practitioners, and in health promotion for people with intellectual disabilities. This study demonstrates the potential for intellectual disability nurses to expand their role and take a more active part in determining future care for people with intellectual disability. Recommendations based on the research findings are detailed in the next chapter.

CHAPTER 8
SUGGESTIONS FOR PRACTICE
and
CONCLUSION

8.1 Introduction

In the previous chapter the findings of the study were summarised and integrated. Drawing on the literature the discussion chapter reiterated some of the key features that distinguish the role of the intellectual disability nurse and the way the cultural context impacted on that role (see Tables 5-1 and 6-1). The current study found that intellectual disability nursing is different to nursing in other sectors. The aim of this chapter is to present suggestions for practice change based on the study findings.

The ethnographic approach I adopted as the researcher, from both an emic and etic stance, has enabled me to produce a descriptive explanation of the intellectual disability nurse's social world of work and of the behaviour, values and meanings of given groups within that context, which have served to construct her/his role. After all, ethnography aims to make sense of the local situation by examining the lifeways of a group or culture and describing these. This cultural knowledge obtained through first-hand observation and conversation with key informants has made explicit that which was previously implicit including areas in need of development. The ethnographic account of the field should benefit the nursing service, the organisation and ultimately the clients. Areas of need have been identified including the involvement of RNs in health care planning and clarification of the roles of different workers, including RNs. There is a need for education as appropriate education for various roles in the care of people with intellectual disability appeared to be minimal.

Furthermore a more effective general hospital liaison is required as general hospital nurses often have no knowledge of intellectual disability which can have adverse effects on clients during hospital admission. Moreover, lack of understanding by staff in general hospitals about the services offered by the Centre can result in early discharges which are not always appropriate and have proven detrimental to some clients. Indeed the planned closure of the Infirmary is discussed and it is suggested that a "Drop in clinic" would assist in meeting the health needs of many clients.

The addition of a nurse practitioner and a sorely needed emphasis on evidence based approaches to practice are suggestions that would add value to the RN’s role. It is also suggested that a model of nursing service delivery should be designed and an example is included (see Table 8-1). The chapter concludes with recommendations for further research which were highlighted by the current research and a concluding statement. The contribution of the ethnographic approach to the understanding of the field and the role of the RN is included in this section and the limitations of the study are discussed.

8.2 Relevance for Nursing Practice

This study highlights the need for more involvement of nurses in planning health care, as opposed to simply delivering health care treatments. Given that the culture exuded well meaning toward the clients, the inclusion of nurses as a part of the team would bolster that intent and would align with the Health Services' aim for the nursing service to be proactive, rather than reactive. Admittedly this would require a change of attitude by the organisation which is currently unclear or ambivalent about the role of nurses (G: 2. 6).

A new nursing rostering system (commenced in 2005) encouraged greater participation by the RN including their attendance at specialist client appointments and accompaniment of clients to hospital in times of acute illness. It seems that RNs could also be involved in case conferences and time made available for them to attend other Centre meetings and be representatives on committees to provide nursing input. The multidisciplinary team hold a monthly meeting and have formed committees including a medication advisory committee, mortality review committee, and wound management committee. Now (at the time of writing) there is an RN who sits on the mortality review committee (examines the circumstances of all deaths), and two RNs have representation on the wound management committee. The "registered nurse presence" reinforces the value placed on the knowledge and skills of the RN and assists in keeping communication channels open (6.1).

8.3 Clear Definition of Roles

The study highlighted a need for clearer role definitions (see Table 6-1). The RN’s (1999) job description is outdated and states in fact that the no longer recognised mental deficiency nurse certificate is a desirable educational qualification.

Furthermore, the description was written at a time when all RNs at the Centre were at level one, but currently some are level two nurses and there are different RN jobs. It is suggested that the nurse's job descriptions be rewritten and improved guidelines and communication are needed to describe their roles.

The EN role has also changed and their job description ought to reflect their increased levels of autonomy and responsibility and that they work solitary night duty shifts. Indeed, clearer role definitions of all staff are required in order to explain, for example, why some shift supervisors are able to consent to PRN medication administration and others are not. The supervisors need to know what their role is in health care matters and the RN needs to know when care can be delegated and to whom. In fact (at the time of writing) the managers routinely make unqualified medical decisions and clarification of their role is needed particularly for new RNs who do not know the culture.

It is suggested that supervisors and managers be encouraged to make simple judgements regarding client health issues to ascertain a genuine need to call an RN. Unnecessary calls accounted for much of the RN's time and it was noted that these calls were solely for clients living within the institution; care workers of clients living in the community seemed able to make accurate assessments about the need to seek medical treatment. In the UK where there is a higher ratio of RNs to care workers, clinical supervision has proven effective in supporting carers of people with intellectual disability and enhancing the carers’ self confidence in making appropriate health care decisions (Malin 2000).

Improved communication between Villa staff and nurses would enhance client care which was observed to be very disorganised. As a result of the new rostering system where each RN had charge of an area, the situation has improved. Nevertheless, there was clearly a need for Villa staff to keep the RN updated on health matters. Moreover, RNs should be clearer about their role so they can provide optimal care without any confusion about "whose job it is to do what" (9. 42).

8.4 Educational Needs

The main finding of the current study was to highlight the very different educational needs of RNs in the field of intellectual disability and in basic care for unregulated workers (see Table 5-1). In fact RNs in all settings would benefit from education to meet the challenges faced by the people with intellectual disability with whom they are increasingly likely to come into contact, particularly as this client population ages (Smith 2002).

8.4.1 Introduction of Health Subject for Disabilities Studies Students

During the current study occasional lectures on health issues were delivered to undergraduates of disability studies at a metropolitan university. The input of a specialist RN has proved useful in preparing the students for the roles they will undertake and it is suggested that this become a part of university curricula wherever disability studies are taught (Edwards & Matthews 1996).

8.4.2 Intellectual Disability Education for Nurses

In this setting the care of people with intellectual disability is reliant on nursing knowledge passed on from one "generation" of nurses to the next. However the future of intellectual disability nursing depends on the teaching and learning of more appropriate knowledge. Evidence based practice as an approach to service delivery is mandatory in the 21st century and nurses need to be trained to access and broker knowledge in order to be equipped with up to the minute evidence on aspects of care. In addition it became clear training is needed in epilepsy, the various syndromes and common disorders, and behaviour management. Initial and ongoing training could be conducted in universities, at the Centre or at TAFE colleges.

8.4.3 Graduate Certificate in Intellectual Disability Nursing

Currently, in Australia one university offers a Graduate Certificate in Disability Studies but it is not specific to nursing practice. A one year graduate certificate in intellectual disability nursing is suggested, introduced at tertiary level to prepare RNs for the role; this would also provide the required education for a nurse practitioner. The curriculum could include an introduction to the potential health problems encountered by people with intellectual disability and associated syndromes. The role of the RN could be expanded to include health promotion and carer/self management of illness issues around “ageing in place”.

Intellectual disability nursing in Australia could be presented as a possible option to other nursing specialties which offer graduate certificates such as emergency nursing, infection control and community nursing. Much of the stigma attached to intellectual disability, and nurses who work in the field, could be removed by promoting intellectual disability nursing as a worthwhile field of study. This could be achieved by offering more student placements and a graduate nurse program could be introduced for RNs who choose to work in the intellectual disability sector. The introduction of clinical supervision in England during the 1990s proved to be a very supportive measure for RNs working in this sector (Malin 2000).

8.4.4 Training in Health Issues for Care Workers

It is suggested that care workers receive basic health care training because many of those newly employed have not previously worked in a health setting. This can be achieved by equipping them for the role without necessarily making them "untrained nurses". A health training course could prevent situations where care workers make poor decisions due to a lack of basic knowledge and would assist care workers in supporting the RN in his/her care of the client. Training could be conducted by RNs in the care workers’ work settings or in a classroom environment.

8.4.5 Enforcement of First Aid Certificate for all Workers

A first aid certificate would appear to be essential for all workers in the health care industry and in particular care workers who work with a vulnerable population prone to choking, epilepsy and injuries (Beange 1996). A random survey of villa managers and shift supervisors toward the end of the field work phase revealed that workers are not maintaining their first aid certificates. Some senior staff were unaware that this is mandatory and most did not know where the care workers could go to update these skills. However, in the other states of Australia and in overseas countries, while first aid training is available, it is not mandatory for intellectual disability care workers (Personal Communication: F. Walsh 2.2.06).

8.5 General Hospitals

There appeared to be confusion about the role of the intellectual disability RN when clients were admitted to general hospitals (see Table 5-1). The following suggestions are designed to ease the burden surrounding hospitalisation on clients, their families and the nurse.

8.5.1 Better Liaison with General Hospitals

Despite efforts to forge partnerships with the general hospitals by the Centre's health services management, understanding to nursing staff in general hospitals about the role of the intellectual disability RN appears clouded. Individual RNs need to explain their role in order to facilitate involvement of the visiting RN and this would benefit the client.

The Centre has a limited number of beds in the infirmary for sick clients and during the current study some acutely ill clients were returned to the Centre from general hospitals. In most cases this practice did not result in positive health outcomes and clients were sometimes readmitted to hospital for lengthy periods of time. Therefore it is considered important to inform general hospital staff of the types of services available at the Centre when clients are discharged from hospital, so that they too can make informed decisions.

In fact an intellectual disability liaison RN attached to each of the general hospitals could eliminate some of the problems associated with client hospital admissions. The concept is used by psychiatric nurses in Australia and is reported to provide a positive contribution to the confidence of general hospital nurses (Sharrock & Happell 2002). The role, which was successfully introduced at two metropolitan hospitals during the current study, is to advocate for people with intellectual disability, to educate hospital staff and liaise with care workers and house staff. In South Australia organisations, such as RDNS, can co-ordinate discharge planning for clients (see Appendix 1) however nationally and internationally this would appear to be the role of the intellectual disability RN (Alaszewski et al 2001, Beange 1996, Malin 2000, Merrick et al 2004, & Sheerin 2004).

8.5.2 Centre RN on Hospital Liaison Committee

During field work I observed there was no Centre RN representative on the hospital liaison committee whose numbers included level three nurses from other agencies. Health services management could not see the need but it would be advantageous as RNs are often the ones who send clients to hospital, visit them and care for them on their return. During the current study Centre RNs provided feedback on Hospital Visit Report forms, and directly to their manager. Although nurses generally are not well represented on decision making bodies, a Centre RN on the hospital liaison committee could provide up to date information on services available and liaise with ward staff. People with intellectual disability usually need another person to negotiate health care "which only works successfully if their agent is trained and empathic" and understands their health needs (Beange 1996, p.159).

8.6 The Future of the Infirmary

During the current study, in line with the organisation's future plan to close the seven bed Infirmary, a closure was trialed. The result was an outcry from villa managers and care workers who argued that the Infirmary nurses offered an essential service. The unit was reopened because a client with nursing needs, that could not be met on his villa, required admittance. The Infirmary is perceived by a senior manager as a "step down unit" for clients who are discharged from hospital prior to being well enough to return to their homes (5. 20).

However, during the current study the Infirmary appeared to be a "dumping ground" for clients who were awaiting accommodation (6. 4). Similarly to the acute sector where the aged can be left waiting for weeks for placement, the problem of finding accommodation for people with intellectual disability is ongoing. What is more it appeared to be more difficult to place people with comparatively high IQs and dual disability (psychiatric and intellectual). Some clients were particular about with whom they would share accommodation particularly if some of the other people in that setting had behavioural problems (6. 27). The RN was not included in planning for client accommodation needs although some clients were cared for in the Centre's Infirmary for long periods while they awaited placement.

The reduced length of hospital admissions meant that many clients were treated in the Infirmary during the current study. In fact hospital discharges appeared to be hastened because it was known the Centre had such a facility staffed by nurses. Given the care workers’ lack of medical knowledge and the seriousness of some of the clients' health conditions, it is inconceivable to workers that the Infirmary be removed.

The current study has shown the need for a nursing service to continue to provide nursing care to clients in the Infirmary who are discharged from hospital. Many clients are not well enough to return to their homes on discharge from hospital and unregulated workers do not have the skills to care for them. Some clients have complex nursing needs following hospital admissions. The Infirmary provides an alternative to hospital for sick clients. Retaining the Infirmary or providing a similar facility would assist in reducing hospital admissions as it did during the current study.

Furthermore, the findings of the current study clearly demonstrate a need for a "health" focus in the model of care provided, rather than just a "social" model. There is a need to bring back "health" to service delivery in its rightful position and produce a new hybrid of worker.

8.6.1 "Drop in Clinic"

A recent study found that people with intellectual disability can experience loneliness and have limited supports (McVilly, Stancliffe, Parmenter & Burton-Smith 2005). In fact during the field work I observed a number of clients "dropping in" to the Centre's Infirmary on a regular basis to visit the nurses. The Centre offers clients a range of diversional activities but some clients tended to seek out the nurses to talk over a cup of tea. An important discovery was that these clients were much more likely to comply with health care treatments because of the rapport they had with the nurses. Acknowledging that intellectual disability nursing can be challenging, Barr (2004) stresses the value of the therapeutic relationship.

The inevitable closure of the Infirmary presents concern about where clients would have these needs met and a "drop in clinic" could provide a solution. A clinic, staffed by an RN, could provide health care such as vaccinations as well as the "someone to talk to" that clients seek. The clinic would need to be located in an easily accessible location because persons with an intellectual disability may have "a variety of physical and sensory impairments" (Evenhuis et al 2001, p. 183). This idea was trialed in Scotland where research has been conducted into intellectual disability nursing and the study found that such a clinic bridged a gap in health care provision (Allan 1999).

8.7 Need for a Nurse Practitioner

The current study has identified intellectual disability RNs as different to nurses in other settings and, as experts in their field of practice; they provide a valuable nursing service to a distinct group of people (see Table 5-1). The role could be examined in terms of whether there is a need for a nurse practitioner working in this area.

Nurse practitioners have been commissioned overseas where studies have shown that in some settings they provide better care than doctors (Sweet 2005). Indeed USA nurse practitioners in the 1960s and 1970s were "pioneers" and research shows they faced many obstacles and stresses, including "intense resistance" (Brown & Draye

2003). Brown and Draye (2003) describe the early nurse practitioners as designing their own roles and forging new relationships with employers, clients and colleagues.

In Australia, the process for developing the role began in 1990, in NSW, and in 2001, a generalist community nurse and an emergency department nurse became Australia's first two authorised nurse practitioners (Armstrong 2001). Nurse practitioners now work in many specialist areas, and are proving to be an "outstanding addition" to the health workforce and the community they serve (Kearney 2005, p. 56). Nurse practitioners are not a substitute for doctors, rather they work within "multidisciplinary frameworks that include doctors" (Kearney 2005, p. 56).

In South Australia, a nurse practitioner is an RN, endorsed by the Nurses Board of South Australia, who has advanced education and clinical experience in a specific area. The role of a nurse practitioner is autonomous, and the nurse practitioner requires good assessment and management skills.

The introduction of a nurse practitioner to the research setting would be cost effective and would minimise the need to call doctors as the role of nurse practitioner extends to therapeutic regimes including ordering pathology and radiology tests and prescribing medication. The RNs in the current research were observed to diagnose illnesses but their practice was limited by the number of people they needed to seek permission from. In this setting, nurse practitioners would provide much needed leadership.

8.8 Evidence Based Practice and Intellectual Disability Nursing

There is a dire need for evidence based practice in the study setting and, indeed, in the care of people with intellectual disability more broadly. From a mental health perspective, for example, there were a significant number of clients in the current setting with dual disability and it is estimated that 30 - 40% of people with intellectual disability will experience mental health disorders during their lives (Raghaven 2005). Raghaven (2005), a consultant psychiatrist in the UK revealed many intellectual disability nurses and a significant number of mental health nurses are in daily contact with this group but their complex needs are often not well understood. It seems, therefore, that mental health nurses need to be aware that their knowledge does not exist "in isolation from other cultural practices" (Lines 2001, p.169).

Evidence based practice aims for the best client outcome based on available research and current practice (Selim, Lewis & Templeton 2001). However it was observed to have limited application in the research setting and mostly in the area of wound management where RNs were observed to employ methods that had been researched and proven to be effective in other sectors.

In fact RNs in the current study did not initiate research due to perceived lack of support by the organisation. Research in Northern Ireland was conducted to assess nurses' attitudes to research and found much work needed to be done for the goal of evidence based practice to be achieved in intellectual disability (Parahoo, 2000). This is consistent with Parmenter's (1991) observation that throughout history the most significant influences on service delivery for people with intellectual disability have been related to social movements, cultural phenomena and political and economic forces, rather than science. The virtual absence of evidence based practice in intellectual disability nursing is an oversight that needs to be addressed.

8.9 Formulation of a Nursing Model for Intellectual Disability Nursing

A model of health care delivery impacts on how nurses practice and traditionally nurses were trained by doctors, using the medical model, which was supplemented by nurse educators in both classroom and clinical settings (TAFE Frontiers 2003). The Centre used the traditional medical model until a developmental model was introduced in the mid 1980s. This major paradigm shift appears to have removed the responsibility for client care from the nurse and, subsequently it appears that no effective model for nursing practice has developed and the health aspects of caring for people with intellectual disability has taken a steep decline. This study has shown, and the literature suggests, that the move to deinstitutionalisation and lack of focus on health has had ramifications for client wellbeing (New South Wales Council for Intellectual Disability 2004). Indeed there is a much reported push by mental health advocates for a return to institutional care of the mentally ill and an emphasis on health (Groom & Hickie 2003, Hassam 2002, Muir Cochrane 2001 & Shanley 2001).

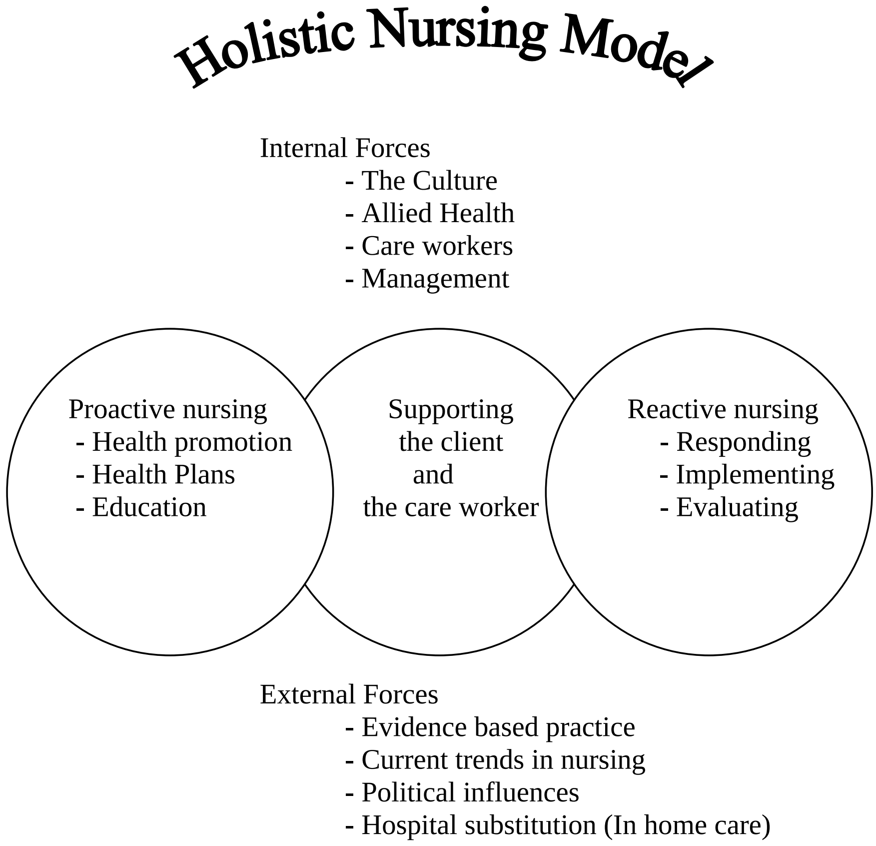
There is an obvious need for registered nurses working with people with intellectual disability to develop a model for nursing service delivery in light of contemporary contexts. A nursing model is defined as:

> A conceptual framework of nursing practice based on knowledge, ideas and beliefs. A model of nursing clarifies the meaning of nursing, provides criteria for policy, gives direction to team nursing thereby obviating conflicts in approach and giving the framework for continuity of care. It identifies the nurse's role, highlights areas of practice where research is needed and can be a basis for the nursing curriculum (Burr et al 1991, p. 334)

The use of evidence based practice is imperative in the proposed nursing model which recognises the impact of internal forces such as the way of life embedded in the culture and external forces such as current trends in nursing and political influences. Forces that impact on the RN role were identified in the second part of the research question (see Internal Forces, 7.10, and External Forces, 7.15). There is clearly a need for: open communication; mutual respect; multidisciplinary team work; recognition of the nurse's valuable role; and equal emphasis given to support and health. In addition to the obvious benefits to clients, creating a healthy workplace culture is of interest to researchers who have identified a link between organisational culture and stress (Peterson & Wilson 2002).

A beginning concept map for a nursing model appears in Table 8-1 below:

Table 8-1. An example of a nursing model that could possibly provide effective outcomes for clients with an intellectual disability



Holistic Nursing Model

Internal Forces
- The Culture
- Allied Health
- Care workers
- Management

Proactive nursing
- Health promotion
- Health Plans
- Education

Supporting
the client
and
the care worker

Reactive nursing
- Responding
- Implementing
- Evaluating

External Forces
- Evidence based practice
- Current trends in nursing
- Political influences
- Hospital substitution (In home care)

8.10 Recommendations for further research

The overarching organisation, of which the Centre is a part, acknowledges the importance of research and RNs who wish to conduct research in the area of intellectual disability need to be encouraged and supported. The literature suggests that research has been conducted by overseas nurses in the field of intellectual disability and some Australian studies have been conducted. During the current study issues such as pressure area care and wound management were informally researched by RNs in the nursing service. A number of issues arising from overseas literature are thought to be worthy of research in Australia. They include: day programs and activities, respite, ageing, general accommodation for people with intellectual disability, and informed consent (Parmenter 1992). These are all areas of research in which intellectual disability RNs could be involved.

Furthermore the current study has demonstrated a need to examine the experiences of general hospital nurses who care for people with intellectual disability to determine measures to assist them to provide appropriate care in the acute sector. This study has clearly demonstrated an institutional culture and the community houses were observed to be "mini institutions". Therefore another group of people who would benefit from research are care workers making the transition from working in an institution to community living. This could throw light on the experience from the carer's point of view and information gleaned from such a study would benefit clients. In fact research is needed to examine the culture in the community setting and its impact on health care.

More research is needed into dual diagnosis particularly as researchers believe mental health concerns should be considered when the client presents with challenging behaviours (Chan, Hudson & Vulic 2004). Moreover it is suggested mental health services need to address their understanding of clinical practice with clients with intellectual disability and mental illness (Chan et al 2004).

Indeed many research possibilities exist for nurses who specialise in intellectual disability. For example the use of physical and chemical restraint in the research setting was periodically the subject of debate. This subject was recently examined in the acute-care setting and it was argued the use of restraints was detrimental to rehabilitation outcomes (Mott, Poole & Kenrick 2005).

The current research has examined the complex network of discourses that make up intellectual disability nursing (Walker 1993). Further research could be conducted around the role of intellectual disability nurses and the culture in which they work in light of recent changes to the structure of the nursing service. A nursing model (see Table 8-1) needs to be applied, tested and further developed. This could result in ideas for service delivery, which could be tested through research, including the need for a nurse practitioner.

I have developed a model which could be used within the cultural context (see Table 8-1). The model, which takes into consideration external and internal forces, such as management, allied health and family, needs to be tested and built on through research. The current research has shown that internal and external forces are inter-related and influence the nurse's role.

The main finding of this research was the need for education specific to intellectual disability. Educational programs for care workers could be introduced and tested and, in light of developments in disability care, the findings need to be tested in other areas of disability.

8.11 The Contribution of using an Ethnographic Approach

The ethnographic approach I adopted as the researcher has enabled me to produce a critical and descriptive explanation of the intellectual disability nurse's role. The choice of ethnography was reliant on a research methodology that could be used to examine the entire culture and the sub-culture of nursing within that social milieu.

8.11.1 Advantages

The practice of nursing is "a complex, interactive process" occurring within diverse contexts and ethnography has been widely used in nursing research (Roper & Shapira 2000, p. 25). A focus on the culture is unique to ethnography and its sole purpose is to understand "the lifeways of individuals connected through group membership" (Streubert & Carpenter 1999, p. 149). Ethnography is used to examine different cultures and involves the researcher becoming immersed in the culture through participant observation (Hammersley & Atkinson 1995).

Ethnography not only "helps to understand complex societies", the methodology assists in discovering human needs and ways for meeting them (Rice & Ezzy 1999, p. 154). Rice and Ezzy (1999) describe this concept as "learning from" the people of interest rather than "studying" them (p. 57). Using ethnography as the research methodology enabled me to observe the culture that affected intellectual disability nursing within its natural setting. As participant observer, I became the data collection instrument by making field notes and conducting interviews (Roper & Shapira 2000). This led to a rich description of the intellectual disability nursing culture.

8.11.2 Limitations

Qualitative research methodologies such as ethnography have been criticised as being unscientific (Atkinson et al 2001). Consequently a limitation of the current study was how ethnography could be "sold to an organisation more comfortable with 'quick fix', 'objective' quantitative research" (Atkinson et al 2001, p. 68). Qualitative studies such as ethnography are likely to be dismissed as "stories" with a subjective focus (Koch 1998, p.1182). Nevertheless "it is for the reader to decide if the story is believable" (Koch 1996 p. 175) and the aim of the current researcher is to put the account before members of the scientific community and have them decide.

Furthermore while the current study has produced an "in-depth understanding" of the intellectual disability RN role in the research setting, findings cannot be generalised to other settings (Paley 2005, p. 116). However, Denzin and Lincoln (2005) suggest that qualitative research is descriptive but is not intended to have the capacity to be generalised to other contexts. In fact, the Centre, the focus of the study, is a unique setting that, it is planned, will soon effectively disappear. I have made no attempt to provide the type of sample that would meet the requirements needed to allow generalisation of the results to other settings (Paley 2005).

One of the other possible limitations of the range of views captured in data collection was that members of senior management, with the exception of the Health Services manager, were not formally interviewed. However, their voices are not silent in this work (see Hassam 2002) and their perceived influences on the RN’s role are included, as are those of the allied health team who are a part of the culture that was observed.

A limitation of the participant observation approach itself also meant that workers and indeed nurses may have presented their practice in "the best possible light" (McIntosh 2000, p. 106). However studies reveal that observation does not necessarily lead to the distortion of practice and participants tend to behave as usual after becoming accustomed to the researcher's presence (McIntosh 2000). This appeared to be the case in the current research particularly since I was know to the participants.

Ethnography focuses on individual's interactions rather than their quantification (Savage 2000). Thus, information gathered by means of ethnography in one setting from a relatively small number of people "cannot be generalised to the wider population" (Rice & Ezzy 1999, p. 170). Consequently the resulting dissertation is a descriptive account of the role of registered intellectual disability nurses and the culture that was found to affect their practice.

8.12 Conclusion

The current research answers a two part question examining the role of RNs who care for people with intellectual disability. The first part describes the role from the perspective of the nurse, client and other health care professionals. The ethnographic approach enabled the researcher to ask questions such as "how do things work around here?" and "what does it mean to be a registered nurse in this context?" in order to find out what was happening in the research setting.

Data collected during field work have been presented in themes that describe the role of the intellectual disability RN. A diverse range of skills required by the intellectual disability RN are described and the advantage of a special knowledge of the client is emphasised. The clients held the RN in high esteem. Most general hospital nurses, however, were found to lack understanding about the health care needs of people with intellectual disability.

The manner in which the culture of the setting appears to set the role for the RN was examined in the second part of the research question. The RN appeared to belong to a minority group which was a part of a large non-nursing culture which had existed for thirty years. Rituals and practices within the setting gave the impression of a culture where time had stood still. Unresolved tension was observed between long-time workers who had experienced change in their positions, and the RNs. Newly recruited care workers appeared to readily adapt to the rule bound culture or quickly leave.

This study became increasingly significant as moves were made toward complete devolution of the Centre, in line with deinstitutionalisation which is now popular worldwide. The registered intellectual disability nurse is in danger of being replaced by enrolled nurses and unregulated workers. Nevertheless legislation dictates that an RN make certain decisions and perform nursing tasks. Consequently RNs were found to be the overseers of health care at the Centre and played a crucial role in client care but the managers often affected the care by having the last word on health issues.

The current research has significance for the discipline of nursing as it clearly demonstrates the need for a nursing model that would provide effective outcomes for clients with intellectual disability. I have developed a model which could be used within the cultural context (see Table 8-1).

Nursing leadership is needed to implement the model and the future of intellectual disability nursing will be determined by nurse leaders who can, through research and evidence based practice, guide the profession through inevitable change. In fact the study strongly suggests the need for nurse practitioners to lead teams of nurses who care for people with intellectual disability. The nurse practitioner would take a strong clinical leadership role as opposed to managers who are removed from the bedside. Nurse practitioners base their practice on research findings and therefore would be strong advocates for an evidence based approach to care.

A nurse practitioner would be required to possess appropriate educational qualifications. Moreover the current study highlighted a need for appropriate education in care of the person with intellectual disability for registered and enrolled nurses, and care workers. This is particularly important in light of worldwide moves toward deinstitutionalisation and in order to provide adequate health care.

The current research provides insights for people into the different nature of the intellectual disability nurse and heightens awareness of the need to keep this knowledge and these skills in the system or the client will suffer. Indeed the study found the role of the intellectual disability nurse to be "totally different" from nursing in other sectors and as such the role deserves a different educational pathway.

As I write, in South Australia disability sectors are merging. The time has never been better for examining the role of nurses in the care of people with disability

GLOSSARY

Agency nurses. Registered or enrolled nurses who are employed on a casual basis through a nursing Agency**.**

Allied health team**.** Collective term for a group of health professionals comprising various disciplines.

Annual medical review**.** All clients have a thorough annual medical health check by a medical officer.

Anticonvulsant medications. Usually prescribed as prophylaxis for the prevention of seizures.

Auriscope. An instrument used to examine the ear.

Bachelor of Applied Science (Disability Studies). 3 year tertiary course that provides management and Options Co-ordination opportunities.

Bachelor of Nursing. 3 year tertiary course that leads to registration as a nurse.

Behaviour management. Strategies used to manage challenging behaviour such as self abuse, non-compliance and aggression.

Blood glucose level (BGL). Also described as BSL (blood sugar level), the measurement of glucose in the bloodstream, commonly used in diabetes.

Blood pressure (BP). Measurement of blood pressure using a sphygmomanometer cuff around the upper arm.

Carer. A family member or friend who cares for a person with an intellectual disability.

Care Worker. Unregulated worker (disability services officer - DSO 1). In the context of this thesis, this is sometimes abbreviated to “Carer” as this term is commonly used as shorthand to describe “care workers”.

Catheter. A tube inserted into the bladder to aid urinary elimination.

Client. The terms *patient* and *resident* are also used , and refer to any person who has intellectual disability for whom the organisation is responsible.

Clinical nurse (RN 2). A registered nurse who has additional skills and knowledge and provides leadership in the nurse manager's absence.

Community nurse. A registered nurse (level 1) who is assigned to staff credentialing and delivering health care in the community.

Deinstitutionalisation. The practice of removing people with disabilities from institutions by offering them an opportunity to live in the community.

Developmental model. Strictly, the developmental model states that there is a logical order of behavioural/skill development and that this sequence of order is invariable – simple to complex. Earlier steps provide the basis for later steps to develop. In practice, this model of care emphasises equality and acceptance, giving the person with intellectual disability the opportunity to grow, develop, and enjoy the same lifestyle as any other person.

Diagnosis. Determination of the nature of a disease.

Diagnostic and Statistical Manual of Mental Disorders (DSM-1V 1994). In the medical model of psychiatry, the DSM-1V is used as an accepted classification tool.

Disability services officers level one (DSO 1). Also known as care workers, an unregulated worker who delivers basic care to people with intellectual disability.

Disability services officers level two (DSO 2). Often employed as shift supervisors. Have advanced through length of service and an inservice training course.

Emic. Through the process of participant observation, the researcher discovered the insider's view of the culture.

Enema. Liquid inserted rectally to evacuate the bowel.

Enrolled nurse (EN). May have qualified through hospital-based training, a private agency or within the Vocational Education and Training sector, by undertaking studies usually of one year duration. Operate within a narrower scope of professional practice and are supervised by a registered nurse.

Ethnography. Qualitative research methodology that examines and describes the culture of a group of people.

Etic. Term used to describe cultural studies from the perspective of the outsider (researcher).

General hospitals/ hospital nurses. General hospitals are public or private hospitals that may provide care to people with intellectual disability. Hospital nurses are those employed by the general hospitals.

General Practitioner(GP) A term used in Australia to describe a generalist medical doctor.

Graduate nurses / graduate nurse program. Graduate nurses are those entering the paid workforce after completing their Bachelor of nursing degree. Graduate nurse programs are offered by hospitals and health services to facilitate the transition into the work setting by offering support and ongoing education for the first year of employment.

Infirmary. Small hospital specialising in care of the infirm, sick or injured.

Institute of Medical and Veterinary Science (IMVS). The pathology service used by the Centre.

Institutionalisation. Residential service system where people live in congregate care.

Intelligence quotient (IQ). A ratio of mental age to chronological age. One measure of intelligence.

Intramuscular injection (IMI). An injection into a muscle.

Intranasal (I/N). Route for medication administration via the nose.

Intravenous (IV). Venous route for fluid or medication administration directly into the blood stream.

Medical officer. A doctor.

Medication. A prescribed substance administered to a client for therapeutic purposes, can be by a number of routes. For example oral, inhaled or topical.

Midazolam. Drug belonging to the benzodiazepine group. Found to have therapeutic properties in the treatment of seizures.

Mental deficiency nurse. Completed a three year in-service certificate course to qualify as a registered mental deficiency nurse. No longer recognised by the Nurses Board of South Australia.

Nasogastric tube. Tube passed from the nose to the stomach for feeding purposes or the administration of medication**.**

Neurological observations. Observations of a client's neurological state, conducted frequently following a head injury.

Normalisation/ social role valorisation. Making available to people with intellectual disability the same norms and patterns that are available to the mainstream of society.

Nurse manager (RN 3). Decision maker of nursing team. Largely administrative role with some clinical involvement.

Nurse practitioner. A recently introduced initiative to enhance the career options of more experienced nurses by allowing them to achieve a higher level of clinical practice within a specialty area. The setting does not have a nurse practitioner.

Nurse registration. Nurses are required to apply to and satisfy the registration requirements of the NBSA. Registration is renewed annually for a nominal charge.

Nurse specialist (RN 1). Registered nurse (level 1) who has additional qualifications in a specialised field of nursing.

Nurses Board of South Australia (NBSA). An independent statutory authority responsible for registering nurses (registered and enrolled), determining scope of practice, investigating suspected unprofessional practice and imposing disciplinary action.

Nursing assessment. Gathering information about the health status of a client, analysing it and making a clinical nursing judgement.

Observations (obs). A set of measurements of temperature, blood pressure, pulse and respiratory rates.

Options Co-ordination. Approach to co-ordinating available services for people with intellectual disability in South Australia.

Placebo. Substance used that is not a drug, but has a therapeutic effect because the client believes that it will.

PRN. Medication given only when required.

Registered nurse (level 1). A nurse belonging to Level one of the nursing register**.** An RN 1 may have qualified through hospital-based training or university studies, usually of 3 years duration. The RN 1 is educated to perform and be accountable for a range of clinical interventions and assume a supervisory role when working with enrolled nurses.

Seizure. Sudden onset, involuntary muscle spasms, associated with epilepsy.

Shift supervisor. Has advanced through length of service and an inservice training course. Adopts a supervisory role over care workers within the villas and acts on behalf of villa managers during periods of absence. Often referred to as supervisor.

Suppository. Solid substance which when inserted rectally encourages bowel evacuation.

Sutures. Stitches used to close a wound.

Syndrome. A group of symptoms typical of a distinctive disorder, usually occurring together and forming a clinical picture.

TAFE Colleges. Technical and Further Education Colleges. Provide nationally (Australian) accredited training at Certificate 1, 2, 3 and 4 levels as well as Diploma level training in some cases.

Tonic - Clonic seizure. Epileptic seizure characterised by generalised involuntary muscular contractions and cessation of respiration followed by tonic and clonic spasms of the muscles. Seizures may occur singly, at intervals, or in close succession.

Unregulated/ unlicensed worker. An untrained care worker who is not licensed as a health professional.

Venipuncture. Blood collection.

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APPENDIX 1.

Other Relevant Agencies in South Australia

The SA Department of Human Services Policy (2001) statement stipulates that people with disabilities should receive prompt quality heath care that takes into account their ability to participate fully in the community and maintain an independent lifestyle (p.6). There are a range of other agencies, funded by the South Australian government, providing support to people with intellectual disability in South Australia**.** They include another large institution and many small non government organisations that provide accommodation, respite, day activities, and employment support (Disability Information Directory 2004). While the focus of most agencies is on recreation, education and training, and employment opportunities for people with intellectual disability, a small number specialise in supporting their health care needs (Disability Information Directory 2004).

Minda Incorporated – A Non-Government Centre

Minda (an incorporated body that receives funding from State Government, Federal Government, and community fund raising) was the first specialised service for people with intellectual disability in South Australia. Prior to the building of The Centre (Strathmont Centre), people with intellectual disability were cared for at home or in a psychiatric hospital when the family could no longer cope. Minda, which is still a residential facility for people with intellectual disability, was the earliest institutional alternative that focused specifically on the needs of people with intellectual disability.

Minda has a health service which operates similarly to that of The Centre and they provide support for 544 clients. The service offered by Minda includes aged care and health services both on campus and in the community. The Clinical Heath Care Unit provides sub-acute and rehabilitative nursing care and an outpatient service. Care includes community aged care packages (Minda Incorporated 2004).

Health Care Support Agencies

Disability Health Care Support Services (DHCSS) provide a specialist community nursing service for people with disabilities in their homes, respite, schools and other community services within the metropolitan and regional areas of South Australia. They aim to facilitate appropriate hospital discharge planning for people with disabilities, care workers, other health professionals and service provider agencies to ensure minimal impact on the client's transition back into the community environment. DHCSS also provide support for younger South Australians with intellectual disability and respite care for children with intellectual disability (Gaskin 2003).

The Royal District Nursing Service (RDNS) have been heavily involved in the nursing care of people with intellectual disability in South Australia and played a key role in determining clients' nursing needs since prior to the closure of the western suburbs nursing home, referred to previously. RDNS provides nursing care to people with intellectual disabilities (and many other disabilities) in their homes within the metropolitan area of South Australia.

In addition RDNS work with people with intellectual disabilities and their carers to ensure health needs are addressed in the transition from hospital to home. The trend toward day surgery and early discharge from hospital can have serious health consequences for the person with intellectual disability whose regular care provider could be an elderly family member. As a result comprehensive discharge planning is a key factor for community nurses in the design and coordination of care.

Finally, there are a number of organisations such as Community Access Services (CAS) offering day options for people with severe and multiple disabilities (all of these services are not described as this is not relevant to the thrust of the current research) (Disability Information Directory 2004). CAS provides services to 150 adults across the Adelaide metropolitan region, and to some country clients. Recreational, pre-vocational and educational options are offered. CAS shares resources with a number of agencies such as DHCSS who provide medication credentialing training for care providers (CAS 2004).

Further up to date information on services/ resources is available at:
http://www.dircsa.org.au and http://www.enable.net.au.

APPENDIX 2

Consent Form

This Form was on University Letterhead and contained contact details of the Primary Supervisor

CONSENT FORM FOR INTERVIEWS

I …..

being over the age of 18 years hereby consent to participate as requested in the interviews for the research project on "The role of the registered nurse in disability service - a critical ethnography"

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to my information and participation being recorded on tape/videotape
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my course of study, or results gained.
    - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I agree to the tape/transcript being made available to other researchers who are not members of this research team, but who are judged by the research team to be doing related research, on condition that my identity is not revealed
7. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature……………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………….…………………….

Researcher's signature…………………………………..Date…………………….

APPENDIX 3

Participant Information Sheet

You are invited to voluntarily participate in the following project:

The role of the registered nurse in disability service – a critical ethnography.

Researcher:

Susan Paech RN RPN BN GradDip Psych/Mental Health. Master Nursing Science. PhD candidate

Supervisors Dr Brian Matthews, Flinders University
Dr Sally Borbasi, Flinders University

The purpose of this research is to examine the role of the registered nurse who provides health care for people with intellectual disability. The study could help nurses who are thinking of taking up intellectual disability nursing, enlighten nurse educators and assist the current nurses to provide a better service. This type of research has been used previously by nurse researchers to bring about positive change in the workplace.

The researcher will be observing the registered nurses in their daily routine and their interactions with other staff to get an overall picture of what registered nurses do. Observations will be made over a period of one year. During that time participants will be selected for interview. Those selected for interview will be asked a number of questions and encouraged to talk freely about their understanding of what the registered nurses do. The interview will last no longer than two hours. Interviews will be conducted at a time convenient to participants within Strathmont Centre or the participant's workplace, if they are not based at Strathmont Centre.

Everything you tell me will be treated as confidential – your real name will not be used in any way.

This is a research project and participation is voluntary. Further information will be given on request. My telephone number is **[phone number given]**. If you wish to discuss aspects of the study with someone not directly involve, you may also contact the Secretary of the Flinders University Social and Behavioural Research Ethics Committee **[Details given of how to make contact by phone, fax, and email]**