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.