“JUST LITTLE THINGS”:
NURSES’ PERCEPTIONS
OF
QUALITY OF LIFE
FOR
PEOPLE WITH SEVERE MULTIPLE IMPAIRMENTS

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ABSTRACT

Notions of quality of life dictate philosophies and policies for services for people with developmental disabilities. There is an abundance of research on quality of life, much of which has influenced the significant amount of study of quality of life for people with developmental disabilities. According to specialist developmental disability nurses, however, this research has little meaning for one group of people with developmental disabilities with whom they work - people with severe multiple impairments. Nevertheless, judgements and decisions about the lives of this group continue to be driven by the idea of quality of life.

While the literature review found that researchers are urged to seek the perceptions of people regarding their own quality of life by asking them, some authors have noted the difficulty in pursuing such a method with people, such as people with severe multiple impairments, who are unable to communicate in the usual ways. Given, then, that it is difficult to directly determine the views of people with severe multiple impairments, this study sought the perceptions of nurses about the quality of life of the people with whom they work.

In order to discover and conceptualise nurses’ views, a symbolic interaction perspective was chosen to guide this study and data were analysed using the grounded theory approach. The study was conducted in two stages. Stage One consisted of semi-structured indepth interviews with
expert nurses to explore their perceptions of quality of life for the people with whom they worked. A significant finding in these interviews was that perceptions of quality of life are mediated by interaction. Consequently, Stage Two involved a participant observation study in which the interactions of nurses and people with severe multiple impairments were examined.

Specialist developmental disability nurses have a unique view of quality of life for people with severe multiple impairments. They refer to it as “just little things”, a phrase which masks complex nursing knowledge and skills, and which can be described by four interrelated categories which emerged from the data: humans being, supporting, becoming intimate, and situated belonging. As nurses become more intimate with individuals, they perceive that people with severe multiple impairments are humans being as they wish, and that quality resides in supporting their everyday lives in a context of situated belonging.

This thesis represents a new conceptualisation of quality of life for people with severe multiple impairments, a conceptualisation which may have significance for other groups and, indeed, for the whole quality of life enterprise. This conceptualisation draws on knowledge not usually related to quality of life, that is, knowledge of the body, of the emotions, of identity and of humanness. Such findings demonstrate the power of an interpretive approach in explicating the meanings nurses have regarding quality of life. Further, these findings have implications for how the question of quality of life is approached, for how different ways of thinking about people impact on quality of life, and for the importance of the life in quality of life.
ACKNOWLEDGMENTS

While research and writing can be lonely occupations, the completion of this work would not have been possible without the help and encouragement given to me by so many people over the last ten years.

Ms. Penelope Kearney was always there. She read and commented on so many drafts of the work and challenged so many of my ideas that the thesis is more than it could ever have been without this discourse. Ms. Kay Plymat and Dr. Keith Bennett, my supervisors, assisted me to clarify ideas and to write them down in a way which would be meaningful to others, remaining patient and sensitive and helping me keep my sense of humour. Dr. Jillian Maling and Dr. Judith Christensen both read an early draft of the thesis and their comments helped to guide my path. Dr. Rene Geanellos engaged me in intellectual debate over the years and her insightful comments on the final draft gave me the confidence to finish.

The production of a thesis is the conclusion of the assembling of words, their dismantling and reconstruction over and over again. This was made possible by the patient and endless hours Ms. Ann Crowley, in particular, as well as Ms. Robyn Hopson and Ms. Karen Williams spent at their computers. The words were often inspired by the literature which was made so accessible by an extraordinary librarian: Ms. Margaret MacIntosh. The work was supported financially by generous scholarships from the University of Western Sydney, Nepean, the Edith Cavell Trust, and the Professional Association of Nurses in Developmental Disability Areas (Australia) Inc.

Accessing the world of people with severe multiple impairments can be difficult in this time of ethical dilemmas. My thanks to the Directors of
Nursing in the Department of Community Services who trusted me with the delicate issues in the lives of the people in their care.

Qualitative research can never be the property of the researcher alone; it is the participants who made this thesis a reality. For the time they gave, the trust they had, the thoughts they shared, I will always be grateful. I can only hope that this work will be useful to them as they continue to strive for a place for people with severe multiple impairments.

Finally, as a thesis tends to consume much of one’s life, the practical help and the unconditional love given to me abundantly by my family will never be forgotten.
DEDICATION

For

Joan, Phillip and Kevin

who, first and last, taught me about

people with severe multiple impairments

and

quality of life
STYLE KEY

“*Italics*” are used to refer to the participants’ words.

*Italics* are used to refer to my fieldwork notes.

**Bold** is used for emphasis.
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The reasonable man [or woman] adapts himself [or herself] to the world; the unreasonable one persists in trying to adapt the world to himself [or herself]. Therefore, all progress depends on the unreasonable man [or woman] (George Bernard Shaw, cited in Vohs, 1993, p. 62).

This chapter describes why and how I went about this research. It introduces nurses’ disagreement with the two commonly held views of quality of life for people with severe multiple impairments which gave impetus to the study. The chapter states the research problem and the purpose of the study, and concludes with an overview of the direction the research, and this resultant thesis, took.

**IMPETUS FOR THE STUDY**

As a specialist developmental disability nurse, my work with people with severe multiple impairments led me to note that there is considerable controversy concerning their quality of life. This controversy seemed to emerge from three different views of the people themselves. The first view focussed on the difference of people with severe multiple impairments from other people and their apparent inabilities. The second view centred on the similarity of these people to others and, hence, their repertoire of abilities. The third view was that of other specialist developmental disability nurses who only expressed their view as a disagreement with the other two views. Each of these views has consequences for how quality of life is conceptualised. The following section examines these three views of people with severe multiple impairments and the implications for their perceived quality of life.
Quality of Life from the View of Difference

From the view of the difference of people with severe multiple impairments, there is no potential for quality of life, and the solution is exclusion, including euthanasia. The debate in the ethics literature proceeds on the following basis: we now have the technological ability to save the lives of people who just a short time ago would not have survived (Thomas, 1987); the outcomes of this technology are not always as we would hope, as some people are left with an array of mental and physical impairments (Knepfer & Johns, 1989); in a society which values beauty and strength, people with impairments are not valued (Wolf, 1990); impairments have been associated with limited, or potential for limited, quality of life (Barber, 1990); in a society which values productivity, treatment of people who may not be productive is not cost-effective (Wright, 1983); so the question is raised of whether treatment should be withheld from those who have, or are likely to have, impairments (Bailey, 1986; Gordon, 1984); and finally, it opens the debate for active versus passive euthanasia (Kuhse & Singer, 1985).

Nurses’ Disagreement with the View of Difference

This debate has serious consequences for people with severe multiple impairments. Let me provide an example from my own experience.

David and my story.

When I was first working with people with severe multiple impairments, I met a young man named David. It is difficult to explain the feeling that I had for him. To say that I liked him seems so inadequate: I looked forward to seeing him, I enjoyed being with him, we had wonderful
days together. I helped him to be clean and well-groomed and dressed him to enhance his attractiveness. I gave him food and drinks that he liked. We went on picnics, and to films and concerts together. We played together. We laughed together. One day he became ill. His ventriculo-atrial shunt (a tube to reduce intracranial pressure) was blocking. His doctor decided not to treat David. This meant certain death.

I had dealt for some years with sudden death and with prolonged dying in other areas of nursing and in my personal life. I had assisted at abortions and I had followed "Not for Resuscitation" orders. I had been able to make sense of these events. But I could not make sense of this! A young man who delighted in life, who had not hurt anyone, condemned to death. I argued, pleaded with, harangued the doctor with no success. I appealed to the nursing and medical management of the residential centre but essentially I was told that I was being unreasonable. I was given lectures about being "emotionally involved" and "learning my place" as a nurse. I began to realise that if I continued to argue, I would not be able to be with David when he was dying. David quickly became comatose and, without parenteral feeding, took twenty five days to die. His death certificate probably says multi-system failure; I say he starved to death. Twenty years later, my anger and my sadness about this cruelty is as vivid and passionate as it was then. I am still unable to make sense of it.

Those who agreed that David should not be treated were said to adhere to a quality of life philosophy while I was accused of holding to a sanctity of life doctrine. It only became clear to me later that this was not so. I would not have argued to extend David’s life for the sake of it. Rather I argued for treatment for David and so I too was arguing from a quality of life perspective. That David would be dependent on others for all of his life did not translate into reduced or nil quality of life, since doing the things that other people do does not necessarily mean quality of life. David had his own
life to live, not the life other people thought he would not be able to live. Szalai (1980, p. 18) puts it this way: "The life of an individual is, of course, unique and incomparable in a certain sense. It is his irreplaceable property which he cannot exchange for anything else". Referring to people with disabilities, Dovey and Graffam (1987) found that the experience of disability differs significantly from one person to the next, and that an individual's experience varies over time and across contexts. They also found that people with disabilities do not experience disability, *per se*, rather they experience life. I had no illusions about David's condition nor about the paucity of his accommodation. The difference in opinion arose from different perceptions of quality of life as a consequence of different perceptions of people with severe multiple impairments.

**Quality of Life from the View of Similarity**

From the view of the similarity of people with severe multiple impairments, their quality of life should be no different to any person, and the solution has been inclusion, with a focus on community, group home living. In 1983, when the report of the Inquiry into Health Services for the Developmentally Disabled (Richmond, 1983) was disseminated, one of the report's proposals was deinstitutionalisation, a proposal which would move people with developmental disabilities to a more "normalised" living environment. The principle of normalization (Nirje, 1969; Wolfensberger, 1972), a principle frequently misinterpreted (Perrin & Nirje, 1985), was equated with community living which was equated with improved quality of life (Halpern, Nave, Close, & Nelson, 1986; Johnson, 1988; Jones, 1986), despite the absence of definitions or measurements of quality of life. The quality of life debate re-emerged in 1994 with the New South Wales Department of Community Services' transition plan (Campbell, 1994) which
reaffirms that "small is better" but adds that group homes are not the only "small" option.

Nurses' Disagreement with the View of Similarity

In 1983, nurses were opposed to group home living for people with severe multiple impairments (for example, Mowbray, 1983; The Richmond report, 1983). Their reasons were unclear and clouded by the threat to their jobs; in short, it was suggested that they were being unreasonable. Nurses, however, had been engaged since the mid-seventies in supporting people with disabilities in alternative accommodation. The Richmond Report, therefore, was a two-fold insult to them: firstly, there was no recognition of their work over the previous ten years, indeed, deinstitutionalisation was touted as a new idea; and, secondly, the report explicitly recommended the replacement of nurses by residential care workers who were not medically oriented (Richmond, 1983, Part 2, pp. 54-56), an injustice to the register of developmental disability nurses which from the sixties had successfully fought to separate itself from other nursing registers and devise its distinct biopsychosocial programme of study (Nurses’ Registration Board, 1981). Seen as inarticulate about their reasons for disagreeing and as likely to say anything to protect their employment, nurses’ views were dismissed.

Campbell’s (1994) transition plan ignored the report of Le Breton (c1985), a nurse, who had explored the concept of alternative accommodation in much greater detail. Over the years, nurses have watched people with milder disabilities sometimes "succeed" and sometimes "fail" in group home living. Each time people with disabilities “fail”, nurses pick up the pieces of their shattered existence, blaming a situation which does not provide people with disabilities with what nurses believe necessary. Today, nurses are clearer about, not so much their opposition to community living, but their
view of a community which does not understand people with severe multiple impairments and does not provide the necessary resources to ensure that community living does lead to an improved quality of life.
STATEMENT OF THE PROBLEM AND PURPOSE OF THE STUDY

While quality of life continues to be debated from the view of difference versus the view of similarity, nurses disagree that there is no potential for quality of life for people with severe multiple impairments and that community living automatically improves quality of life. While they disagree with other views, nurses have never articulated their view, leaving them open to criticisms of unreasonableness. At the same time, people with severe multiple impairments are now concentrated in large residential centres as a result of the deinstitutionalisation of those who "function better" (Molony & Taplin, 1988). The purpose of this study, therefore, is to explore the view of quality of life for people with severe multiple impairments held by the specialist developmental disability nurses who work with them.

OVERVIEW OF THE THESIS

The structure of this thesis is, of course, imposed at the conclusion of the research process to produce a logic which is now available to the reader but which was not there while the work was in progress. It is the methodology which imposed the order of the research activity. This activity included movement between the literature and the participants as knowledge emerged. There were many dark corners and cul-de-sacs as my attempts at analysis of the data stopped and started again. Many an idea was thrust aside when the data did not support it, and another pursued. My emotional upheavals, as I cried over literature filled with pathos, despaired at my inability to see the world from others' perspectives, and became elated with moments of insight, are not recorded chronologically. I think, however, that the reader will find "me" in the research. It was not until I was confident that the links among the data were clear that the activity came to an end and I was able to construct the story as if I had some explanations from the
beginning. I remain conscious, however, of Rorty's (1991) comment that I may have merely become tired or unimaginative.

Chapter Two defines the term, “people with severe multiple impairments”, as used in this thesis, and explores their world by examining how different views determine different interpretations of these people and their actions. It introduces two models of disability which have emerged from the views of difference and similarity: the biomedical model and the social model, and suggests that nurses may use elements of these two models.

Chapter Three identifies that, while there is no specific research on quality of life for people with severe multiple impairments, quality of life research for people with disabilities impacts on their lives. Quality of life research for people with disabilities is influenced by other quality of life research as well as general and specific issues relating to quality of life. This literature is reviewed, drawing on social, health, nursing and disability research and the views of people with disabilities and their families. It examines developments in the concept of quality of life, measurements of quality of life in the absence of a clearly defined concept, and the particular developments in quality of life for people with disabilities, including people with severe multiple impairments. The review finds a number of issues in quality of life, many of which have implications for people with severe multiple impairments. In particular, the current conceptualisation of, and research on, quality of life may have little meaning for this group. This study, therefore, sought the perceptions of nurses of quality of life for the people with severe multiple impairments with whom they work.

Chapter Four explains why a particular theoretical framework was used. From the literature review it is concluded that little is known about quality of life for people with severe multiple impairments, that quality of
life research has been, in the main, atheoretical and unrelated, and that limiting preconceptions exist in regard to quality of life for people with disabilities. Consequently, the study adopts an interpretive approach, in particular, symbolic interaction, and uses the grounded theory method of analysis. The chapter traces the ideas of symbolic interactionists since George Herbert Mead and examines methodological implications.

Chapter Five describes the methods used in the study. The study was conducted in two stages. Stage One formed the basis of my research for the award of Master of Nursing and involved indepth interviewing. The analysis of these interviews, however, suggested that quality of life for people with severe multiple impairments is to be found in interaction. Therefore, instead of submitting the work of Stage One for examination for the award of Master of Nursing, I transferred to a doctoral programme to complete Stage Two of the study which was comprised of participant observation. The chapter reports how, guided by the symbolic interactionist perspective, I selected the participants, chose the data collection methods of indepth interviewing and participation observation, and decided on the grounded theory method of data analysis. The procedures are reported in detail with particular attention to rigour.

Chapter Six outlines the findings of the study and Chapters Seven to Ten discuss the findings in detail. Combining the data from the participants, the literature and my experiences, the thematic findings seek to articulate nurses’ perceptions. Nurses define quality of life for people with severe multiple impairments as “just little things”, a phrase behind which a wealth of meaning lies, meaning which is found in the four themes of humans being, supporting, becoming intimate, and situated belonging. Each of the themes provides insights into the definition of quality of life for people with severe multiple impairments and points to possibilities in the general concept of
quality of life. Uniquely, the relationships among the themes draws on areas not usually included in quality of life work.

Finally, Chapter Eleven reviews the intention, the methodology and the findings of the study. The chapter then reflects on the strengths and weaknesses of the findings as well as the methodology which was able to elicit nurses' meanings of quality of life for people with severe multiple impairments. Some implications for nursing and for people with severe multiple impairments are then identified. The chapter closes with a return to David and a reconstruction of the sense of our experience, justifying the progress made by “unreasonable” specialist developmental disability nurses.
Chapter Two

THE WORLD OF PEOPLE WITH SEVERE MULTIPLE IMPAIRMENTS

The job of those who want to serve people seen as disabled or different is to get behind the scenes, to know them as they see themselves, not as they are presented. Presentations are artefacts of changing social institutions, organizational formations, and world views. To understand the presentations, to become dislodged from their hold on our reality, we have to trace their origins and understand their place in the world as it is presently constructed

(Bogdan, 1996, pp. 35-36).

The impact of different views of people with severe multiple impairments on their perceived quality of life described in Chapter One led me to examine more closely what is known about their world. This chapter defines the term, people with severe multiple impairments, as it is used in this thesis. It then explores the literature to discover more about the mostly unfamiliar world of people with severe multiple impairments. This exploration finds two discrete and dissonant interpretations which reflect the biomedical and social models of disability. Finally, it examines how nurses who work with people with severe multiple impairments view them.

DEFINITION OF TERMS

There is a discourse which describes people with severe multiple impairments variously as totally dependent, totally handicapped, or with profound or severe multiple disabilities. While it would be preferable not to have to identify this group as anything other than just people (Ashman, 1989), I have used the term people with severe multiple impairments in an attempt to acknowledge the primacy of the person over the impairment (Blackwell, 1979; Zola, 1991) and to be accurate about the population to which I refer. Impairments refer to significant anatomical and physiological
differences, usually present from birth. **Multiple** indicates impairments in more than one organ or system of the body. **Severe** means that the impairments interfere with usual physical function and are chronic in nature.

The term, people with severe multiple impairments, is also meant to indicate that, while impairments are unlikely to alter, handicaps put in people's way, and disabilities, which are an interaction between impairments and handicaps, are able to be changed. To understand how I came to this usage requires an understanding of developmental disability; impairment, disability and handicap; models of disability; and diagnostic conditions and their impairments.

**Developmental Disability**

People with severe multiple impairments are one group of people who are identified as having developmental disabilities. Developmental disability is not, as is often thought, a euphemism for mental retardation or its various synonyms (for example, intellectual disability, mental handicap, learning disability) but an umbrella term for a range of mental and physical impairments and is accompanied by specific functional criteria. The evolution of the term "developmental disability" (Thompson & O'Quinn, 1979) commenced with the appointment of the President's Panel on Mental Retardation in America in 1961, leading to a "Proposed Program for National Action to Combat Mental Retardation". The Panel's recommendations were legislated in 1963 but by 1969/70, revision was needed to extend existing services and provide for people with other neurologically handicapping conditions. This revised legislation struck out mental retardation, replaced it with developmental disability and established a new definition. By 1973, this new definition was seen as just as restrictive in that many people who had developmental disabilities were still excluded from services. Following a
further two acts and a task force to ensure that the definition was broad enough, developmental disability was redefined in 1978, and passed in law, despite concerns that the vagueness of the term and the absence of identifiable categories would result in endless interpretation of who had and who did not have developmental disabilities. A recent definition can be found in Table 2.1 below (Wolfe, 1992, p. 138).

### Table 2.1

**Definition of Developmental Disability**

The term 'developmental disability' means a severe, chronic disability of a person 5 years of age or older which:

- is attributable to a mental or physical impairment or combination of mental and physical impairments;

- is manifested before the person attains age twenty-two (eighteen years in New South Wales);

- is likely to continue indefinitely;

- results in substantial functional limitations in three or more of the following areas of major life activity:
  - self-care
  - receptive and expressive language
  - learning
  - mobility
  - self-direction
  - capacity for independent living
  - economic self-sufficiency;

- reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in a developmental disability if services are not provided.
Impairment, Disability and Handicap

An understanding of the definition of developmental disability is enhanced by considering Wood's (1975) taxonomy of impairment, disability and handicap which has been adopted by the World Health Organization. While there are multiple interpretations of this taxonomy, useful definitions come from a combination of the works of Bowe (1978), Fulcher (1989), and Smyer, McHale, Birkel and Madle (1988). Impairment refers to limitations in functioning or output at the organ-system level; handicap refers to architectural, attitudinal, educational, occupational, legal, political and personal barriers to integration; disability refers to (negative) evaluations of individual capacity or performance in specific contexts. A person is therefore likely to have a disability as a result of the interaction of an impairment and a handicapping environment, for example, a person with a broken leg (impairment) confronted by a flight of stairs (handicap) is unable to traverse (disability) the stairs.

Handicaps are conceptualised as barriers to integration. One does not have to look very far to find numerous examples of such barriers: continuing consideration of euthanasia or withholding of treatment; poor physical access by wheelchair to most public facilities; and exclusion from mainstream housing, education and work. While legislation, such as the Disability Services Act 1986, proclaims that people with disabilities have the same rights as people without disabilities, they continue to be treated differently.

Models of Disability

Bickenbach (1993), in an analysis of disability policy, suggests that the distinct conceptualisations of impairment, disability and handicap have
initiated three separate models of disability: the biomedical model, the economic model, and the social-political model. The biomedical model focuses on impairment, with precise descriptions of the varieties of disablement, and provides clear resolutions of the “problems”, for example, prevention, cure, containment and rehabilitation. The economic model has an emphasis on disability, describing the effects of impairments on an individual’s repertoire of capabilities, and measures the cost-benefit ratio of work-based disability. The social-political model exposes the social injustice of stigmatising attitudes and discriminatory practices. According to Bickenbach, each of these models ignores or reinterprets two of the three dimensions of impairment, disability and handicap. This suggestion is exemplified in the ongoing debate of models, where, for instance, there is a call to reintroduce impairment into the social model of disability (for example, Crow, 1996; French, 1993).

The social model of disability was introduced by the Union of the Physically Impaired Against Segregation (Shakespeare & Watson, 1997) and formalised and extended by Oliver (1983, 1996) and Finkelstein (1980, 1993). According to Oliver (1996), the social model was intended to provide a view of disability other than the view of the individual model which was underpinned by the personal tragedy theory of disability. While it still included psychological and medical aspects, it was not accepted by the professionals whose attention Oliver was seeking but it was enthusiastically taken up by people with disabilities, many of whom could immediately relate it to their experiences (Crow, 1996). The success of the model was based on its insistence that there is no causal relationship between impairment and disability (Oliver, 1996), that “the real cause of disability [is] discrimination and prejudice” (Shakespeare, 1992, p. 40), that is, handicap. As with all debates, radical positions surfaced, for example, Shakespeare (1992) resists any mention of impairment, for to do so “risk(s) the oppressors seizing on evidence that disability is ‘really’ about physical limitation after
all” (p. 40). Crow (1996), however, argues that to ignore impairment is to tackle only one side of the situation of people with disabilities. The body of literature suggests that there is a melding of the views which have emerged from this debate and that the future direction is to develop an all-inclusive, complete and coherent theory of impairment and handicap.

**Diagnostic Conditions**

Impairments are identified by examining particular diagnostic conditions. After the American definition of developmental disability was adopted in New South Wales (Health Commission, 1981), diagnostic groups identified as likely to be at risk included: "persons with intellectual handicap, severe epilepsy, cerebral palsy, brain damage acquired in childhood and those with other neurological disorders needing similar provision" (Department of Health, 1985, p. 1). American scholars were far more specific about diagnostic conditions, for example, the edited works of Gabel and Erickson (1980) and of Johnston and Magrab (1976) identify the following at-risk categories:

(i) mental retardation (with the accompanying causes from the WHO (1967-1969);
(ii) childhood psychoses (for example, autism and schizophrenia);
(iii) minimal cerebral dysfunction - learning disability syndrome complex (colloquially known as hyperactivity / hyperkinesis / minimal brain damage);
(iv) speech and language disorders (for example, dysarthria and developmental aphasia);
(v) disorders of hearing and vision (for example, high frequency deafness and refractive errors);
(vi) neurological and neuromuscular disorders (for example, spina bifida, hydrocephalus, cerebral palsy, muscular dystrophy, epilepsy, limb deficiency, poliomyelitis, clumsiness); 
(vii) personality and psychoneurotic disorders (such as anxiety and phobia); and 
(viii) behaviour problems (such as feeding, toileting and sibling rivalry).

People with severe multiple impairments may have any combination of these diagnoses. Any such diagnosis implies an impairment, but the impairment alone does not automatically mean that the person has a developmental disability. It is the impairment's interaction with handicap which may result in disabilities (or substantial functional limitations in areas of major life activity). Nevertheless, to identify impairments, the next section turns to the diagnostic condition of cerebral palsy.

**Cerebral Palsy: An Example**

To explain severe multiple impairments, as the term is used in this study, I will use the diagnostic label of cerebral palsy as an example, following Capute and Accardo (1991a). A high percentage of people with cerebral palsy have significant multiple anatomical and physiological differences from birth which are chronic in nature and interfere with usual physical function. Cerebral palsy typifies the impairments found in a range of diagnostic conditions and, as such, is a useful exemplar for an understanding of the various concepts involved.

Some information about the condition provides the context in which impairments may occur. Cerebral palsy is a term describing a group of disorders characterised by non-progressive disorders of motion and posture.
due to brain insult or injury occurring in the period of early brain growth (Alexander & Bauer, 1988). An estimated two children per one thousand live births are affected by some type of cerebral palsy (Copeland & Kimmel, 1989). Only sixty percent of cases of cerebral palsy have an identifiable origin (Harryman, 1986): events during the first trimester of pregnancy which may cause cerebral palsy include exposure to radiation or teratogenic drugs, intra-uterine infection and chromosomal abnormalities; in later pregnancy, abruptio placentae and other abnormalities in the fetal-placental exchange and functioning place the foetus at risk; complications during labour, delivery and the neonatal period also result in an increased risk. This apparent etiology, however, is challenged by Blackwell (1979) and Nelson (1988) who discuss the multifactorial and interactional nature of causes and note the difficulty in evaluating the importance of perinatal factors. For example, autopsy reveals damage to the basal ganglia known to be caused by anoxia during the perinatal period but infants who experience difficult births have often developed abnormally in utero. Also, infants at risk for cerebral palsy come from poor socioeconomic circumstances, with more than one third of children who develop cerebral palsy being dysmature, weighing less than 2500 grams at term. Thus, "the birth process is the first of many experiences for which these infants are not adequately adapted" (Blackwell, 1979, p. 60). Early childhood disorders such as meningitis, head injury and lead intoxication may also result in cerebral palsy (Harryman, 1986).

**Impairments**

Continuing to use cerebral palsy as an example, the primary impairment is brain damage. Pyramidal (spastic) cerebral palsy is so called because of damage to the motor cortex or to the pyramidal tract of the brain. On the other hand, in extrapyramidal (rigid, athetoid, ataxic or atonic) cerebral palsy the damage is to the pathways outside the pyramidal tract.
The damage in pyramidal cerebral palsy affects the initiation of movement while the damage in extrapyramidal cerebral palsy affects the regulation of movement. The functional limitations which present in any individual depend on the precise area of the brain where damage has occurred and are summarised in Table 2.2, which is adapted from Harryman (1986).
Table 2.2

**Motor Impairments in Cerebral Palsy**

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Site of damage</th>
<th>Functional limitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>CEREBRAL PALSY</td>
<td>PYRAMIDAL</td>
<td>INITIATION OF MOVEMENT</td>
</tr>
<tr>
<td>Spastic diplegia</td>
<td>Bleeding surrounding lateral ventricles</td>
<td>Legs more than arms</td>
</tr>
<tr>
<td>R spastic hemiplegia</td>
<td>Left pyramidal tract</td>
<td>Right side of body</td>
</tr>
<tr>
<td>Spastic quadriplegia</td>
<td>Cerebral cortex</td>
<td>All limbs &amp; torso</td>
</tr>
<tr>
<td>EXTRAPYRAMIDAL</td>
<td>REGULATION OF MOVEMENT</td>
<td></td>
</tr>
<tr>
<td>Athetoid</td>
<td>Basal ganglia</td>
<td>Arms, legs, posture</td>
</tr>
<tr>
<td>Ataxia</td>
<td>Basal ganglia</td>
<td>Constant resistance to flexion (lead pipe rigidity)</td>
</tr>
<tr>
<td>Rigid</td>
<td>Basal ganglia</td>
<td>Hypotonia</td>
</tr>
<tr>
<td>Atonic</td>
<td>Basal ganglia</td>
<td>For example, rigid arms, spasticity of legs</td>
</tr>
<tr>
<td>Mixed</td>
<td>Pyramidal &amp; extrapyramidal</td>
<td></td>
</tr>
</tbody>
</table>
Impairments listed above are a neutral description of the alterations to usual anatomy and physiology and, therefore, make no judgment about the abilities of the people who have them. It is the interpretations of these impairments which affect the lives of people with severe multiple impairments.

**BIOMEDICAL VERSUS SOCIAL INTERPRETATIONS OF IMPAIRMENTS**

Returning to the different views outlined in Chapter One, the view of difference, with its focus on the inability of people with severe multiple impairments, fits most closely with the biomedical model (Bickenbach, 1993), while the view of similarity, with its emphasis on abilities, is reflected in the social model (Oliver, 1996). While exploring the literature to discover more about the world of people with severe multiple impairments, I found two discourses which underline these two views. They are juxtaposed to highlight their differences in an examination of the movement, appearance, thinking, communication, and health of people with severe multiple impairments.

**Interpretations of Movement**

Biomedical discourse holds that the damage in cerebral palsy to the motor cortex, the pyramidal and the extrapyramidal tracts most likely contributes to the persistence (or absence) of primitive reflexes and consequently, the delay in development of automatic movement reactions. Primitive reflexes, usually present in neonates, are so called because they are controlled by the primitive regions of the nervous system: the spinal cord, the labyrinths of the inner ear and the brainstem. The reflexes pertinent to
this discussion include: the asymmetrical tonic neck reflex which brings about a change in position; the tonic labyrinthine reflex which brings about changes in muscle tone; the positive support reflex which enables support of weight while standing; and the suck/swallow, bite and gag reflexes. All these reflexes are usually integrated into voluntary movement by twelve months of age. In the child with cerebral palsy, they are usually stronger and often fail to disappear (in true atonia, they are often absent). Their persistence delays the development of automatic movement reactions, the more important being the righting, equilibrium and protective reactions which enable control of complex voluntary movement and posture.

The functional limitations resulting from persistent (or absent) primitive reflexes and delay in development of automatic movement mechanisms can be many and varied, for example, they interfere with motor development and smooth motion and are a contributing factor in the lack of sphincter control. Compensatory movement patterns develop, patterns which use the persistent reflexes to increase activity. The picture, then, is one of little movement, and awkwardness in the movement which does manifest.

This view of difference describes individuals as unable to physically act on the environment. The following observation, however, allied with the social model, focuses on what it is that people with severe multiple impairments can do.

Daniel swings a white-handled Fisher Price lawn mower. Thomas crawls across the floor on his back inch by inch, a distance of twenty feet. He positions himself parallel to Daniel. The attendant comes in, looks at the boys and says, "What are you fighting for?" She picks up Thomas and moves him to another mat twelve feet away. She gives Thomas a blue-handled Fisher Price lawn
mower. With the toy, Thomas crawls back across the floor to lie parallel to and behind Daniel. Thomas hits Daniel on the shoulder. Daniel hides his toy underneath him. Thomas hits Daniel on the shoulder again. Daniel turns over to face Thomas with his toy in front of him. Thomas moves closer and grabs at Daniel's toy. He misses. Daniel grabs at Thomas's toy. He misses. Thomas grabs at Daniel's toy. He gets it. He pulls it over to him. Daniel grabs at Thomas's toy. He gets it. He rolls over with the toy...

Together, Daniel and Thomas continued this sequence of play with the toy for two and a half hours ... (Gleason, 1993, p. 161).

The locomotion, the gross movement, the planning, the play, the interaction, and the concentration depicted in this observation contrast sharply with the limited, awkward movement of the biomedical discourse.

Interpretations of Appearance

From the view of difference, difficulty with movement, as well as sensory and neurological impairments associated with cerebral palsy, all add up to a picture of the person as less than human. Persistent imbalanced musculature can lead to orthopaedic deformities, such as dislocation of the hip, flexion contractures of the hip and knee, plantar extension of the foot, arching of the forefoot and spinal curvatures such as scoliosis and lordosis. People with severe multiple impairments may be seen, therefore, as twisted, distorted bodies in lying positions. Moreover, limited control of nose-breathing and exhalation result from poor muscle control of the oropharyngeal area in forty percent of people with cerebral palsy (Jones, 1983): the breathing of people with severe multiple impairments is therefore
often noisy and irregular and punctuated with gurgling and uncontrolled coughing and spluttering.

Visual deficits, such as strabismus and nystagmus resulting from poor muscle control of the eyes, as well as visual-perceptual impairments, occur in more than forty percent of people with cerebral palsy (Harryman, 1986). As a result, people with severe multiple impairments typically do not focus on other people and objects in their environment. Also, hearing impairment, primarily nerve deafness and perceptual deafness, is associated with twenty-five percent of people with cerebral palsy (Jones, 1983). Thus, people with severe multiple impairments do not attend to sounds in their environment. Loss of tactile discrimination (astereognosis) and proprioceptive sensation is common, probably due to lesions in the sensory nerve pathways and the sensory cortex (Blackwell, 1979) with the result that people with severe multiple impairments do not appear to differentiate among objects within their reach and do not seem to know where their bodies are situated in relation to the environment.

Epilepsy occurs in about thirty percent of people with cerebral palsy. Epilepsy is a term describing a condition where two or more seizures occur unrelated to acute provocation by an underlying disease such as meningitis, drug or alcohol withdrawal (Hermann, Desai, & Whitman, 1988). The primary impairment of epilepsy is brain damage in the form of scarring. Individual neurons near the lesion become hyperexcitable and cause neighbouring neurons to discharge in hypersynchrony. The observable result is a seizure. There are many types of seizures which present differently. During any seizure, however, the individual's function is limited in some way: uncontrollable body movements; altered consciousness; impaired respiratory function; impaired bladder and bowel function; impaired sensation (tingling, numbness); and impairment of the special senses (unusual smells, tastes). In addition, the anticonvulsant medications
used to control seizures potentially cause further impairments, for example, drowsiness, paradoxical excitement, lack of concentration, a reduction in fine motor skills, ataxia, gum hypertrophy, weight gain, loss of hair, and tremor of the hands.

This overwhelmingly technical description of how impairments relate to appearance is tempered by a social view of the person:

"Oh, I see you've found Johnny, my favourite. I've been here three and a half years and he's my special favourite. He's eighteen and I'm his mommy during the day. I wake him when I come on shift, wash him and dress him. We have our routines ... He loves rock and roll, I usually open the window up so it's bright and put on the music loud. He loves when I take his hands and clap them to the beat. He has his likes and dislikes you know. He loves his red flashlight ..." As I listened I could only ask myself, what happened to the person I had seen? This description did not 'jive' ... a deaf-blind, completely paralysed, grotesquely hydrocephalic person with 'likes and dislikes', his own routine and who someone calls her 'favourite'? ... I was ... convinced that this nurse knew something which I did not about disabled persons (Goode, 1984, pp. 230-231).

**Interpretations of Thinking**

From a biomedical view, it is usually assumed that a person with the previously discussed physical impairments resulting from cerebral palsy does not think. This is reinforced by the fact that some degree of intellectual disability is associated with sixty percent of people with cerebral palsy (Capute & Accardo, 1991b). The term intellectual disability is, however, a confusing label at the best of times - associated with cerebral palsy it becomes even more so. If intellect is conceptualised as adaptation, rather than as some
constant held within the brain which is able to be measured, it is more valuable at this point to examine the effect of the motor, sensory and neurological impairments identified thus far on the development of a person with cerebral palsy.

Hogg and Sebba (1986) provide exhaustive discussion on the research to date of the delaying effect of impairments on development. A motor impairment, for example may affect sensorimotor, fine motor, gross motor, language and perceptual development. For the forty percent of people with cerebral palsy who have visual impairments there are potentially further delays in the areas of fine and gross motor development, cognitive and language development as well as exploration of the environment, sensorimotor understanding and social adaptation. Moreover, for the twenty five percent of people with cerebral palsy who have hearing impairments, there may be further delays in cognitive and motor development, as well as language and communication.

These delays in development may constitute a picture of someone who cannot think. Whether there is intellectual disability or not, however, remains uncertain. Part of the uncertainty arises from the difficulty in assessing cognitive capacity in the absence of usual ways of communication. The stories of Kristy Brown (1989) and Annie McDonald (Crossley & McDonald, 1980), who both broke through the communication barrier and demonstrated their cognitive abilities, exemplify this situation. Part of Annie's story is her assertion that some of her peers have a cognitive capacity similar to her own, but to my knowledge, no one has been able to validate this.

Further uncertainty exists in relation to levels of arousal. The research (Guess et al., 1988; Landesman-Dwyer & Sackett, 1978; Sternberg & Richards, 1989) suggests that people with severe multiple impairments spend
considerable parts of their waking hours in a low state of arousal where they may not be alert to input.

Another source of uncertainty as to whether there is intellectual disability comes from the influence on relatives and others of the visibility of a physical impairment, that is, condition visibility. Condition visibility can affect relationships between the person with a physical impairment and others. Thomas and Wicks (1987) identify two aspects of a condition's visibility: apparentness and location, and three categories of visibility: visible to all; non visible to all; non visible to social others but visible to family and the wise. While the research (Mercer, 1974; Richardson & Royce, 1968; Shere & Kastenbaum, 1966; Wright, 1983) is not always clear, there is enough evidence to support that there is a potential for some degree of social distancing from people with physical impairments. This distancing may be a confounding factor in any study of the relationship between development and impairment.

Despite dominant biomedical discourse, and consideration of social distancing aside, it is not unusual to find that people with severe multiple impairments are attributed thinking, as evidenced in the following:

In the television film a nun was attending one of the patients, a full-grown man whose mental retardation was so severe he had spent his whole life in a cot-like bed. His frail skeletal body was ageless. He lay naked and unmoving ... I watched entranced. I was a secret communicant again. The eyes of the paralytic mesmerised me. They stared at the nun with such questioning intensity. They were asking 'What are you doing? What do you want?' Those eyes, so big and bright in that dark face, were staring right through the nun and beyond her. In that instant I knew the nun's need of this pathetic creature was greater than his of her. The intensity of his eyes
watching her told me that somehow he knew it too. They were creatures in symbiotic relationship. Each was meaningless and lifeless without the other ... I was dimly perceiving a new world of meaning (Keenan, 1992, p. 252).

**Interpretations of Communication**

Why people with cerebral palsy often cannot talk is a combination of many factors: difficulty with oropharyngeal musculature control; limited ability to explore the environment; altered perception via vision, hearing, touch, smell, taste and proprioception; altered levels of consciousness; problems with concentration; and social distancing. That their non-verbal expression is in question as to its communicative intent is also multifactorial due to: difficulty initiating and/or controlling movement of any part of the body: neck, mouth, limbs, torso; virtual absence of fine motor activity; poor control of facial and eye muscles; limited breathing control; and reflex activity. Nevertheless, despite this biomedical discourse centred on communication, most people who spend time with people with cerebral palsy give meaning to their verbal and non-verbal communications:

"Kai, Kai", she called in a lilting voice that carried reservoirs of confidence and affection. She collected the boy, who was dressed in jeans and a red shirt, from a low bed where he had been lying on his back. His cry of surprise turned into one of delight as she swooped him around the room. His contorted little mouth grinned ... He laughed and she laughed with him (Gustaitis & Young, 1986, p. 232).

**Interpretations of Health**
Biomedical discourse holds that people with severe multiple impairments get sick from time to time: they have similar risks for infectious diseases and minor surgeries. They are also unable to initiate health promotion or disease prevention strategies. As a consequence of their impairments, they are at greater risk for skin breakdown, malnutrition, constipation, and upper respiratory tract infections, including aspiration pneumonia. Their orthopaedic deformities can lead to conditions such as degenerative arthritis, spinal cord and nerve root compression, as well as cardiopulmonary failure (Rangaswamy, 1983). In addition, people with severe multiple impairments are at high risk for asphyxia and other accidents; for those with epilepsy this risk increases. While the lifespan of people with severe multiple impairments has been greatly extended by advancing medical technology, it would be rare to see someone live till age forty.

In contrast, social discourse is emphatic that people with disabilities are not sick. This emphasis finds its roots in a reaction to the exposure of a medical model of care as inappropriate for people with disabilities. A social model of care replaces the notions that people with disabilities require "hospitalisation" and "treatment", and proposes that services should be based on "living a normal life in a normal environment ... being able to take the risks associated with a normal life ... [with] emphasis ... on education and training" (Richmond, 1983, Part 1, p. 19).

HOW NURSES VIEW PEOPLE WITH SEVERE MULTIPLE IMPAIRMENTS

Services for infants and children with developmental delay and/or disability have improved in Australia over the last twenty years. Early identification and intervention, for instance, have improved these children's
chances of entering school, mainstream or special, and commitment to education has ensured that they complete school. There are also a number of post-school programmes emerging. With regard to accommodation, while most children with disabilities live in their family home, a different set of circumstances exists for adults. Those with milder disabilities are finding varying degrees of success in alternative accommodation outside the family home, while the majority of those with significant disabilities live in government or government-subsidised residential settings of varying sizes.

Specialist developmental disability nurses were, until recently, primary caregivers for older children and adults who have not had the benefit of early intervention, have no post-school organised learning, whose families often have little contact, and who live in large residential settings. Changes to models of care with the implementation of the Richmond (1983) and similar reports have altered the profile of primary caregivers who now include other registered nurses, enrolled nurses, residential care workers, residential care assistants, social educators and youth workers. The world of people with severe multiple impairments is now inhabited and influenced by a range of disciplines from the social sciences and health.

In the debate between a biomedical model and a social model of disability, specialist developmental disability nurses fall somewhere in the middle, using elements of both models when referring to people with severe multiple impairments. I have often heard examples of both models in their conversations about the care of the people with whom they work. On the one hand, nurses discuss the critical nature of knowledge of impairments in relation to an understanding of their implications for function and health. They criticise people who work with people with severe multiple impairments without knowledge of those impairments because they may be incorrect in their interpretation of a situation: they may interpret poor oromuscular control as spitting or not hungry; they may interpret poor eye
muscle control as not looking or not interested; a person with poor trunk and limb control may be said to be not co-operating; and, the grimace associated with hypertonicity may be seen as a smile or as an expression of pain. On the other hand, they say that a focus on impairments may make invisible the potential ability of individuals because it may be assumed that all people with severe multiple impairments are unable to perform certain activities.

**SUMMARY**

This chapter has defined the term, people with severe multiple impairments, by examining some of the vast literature which impacts on the lives of this group. In this examination of their world, it can be seen that how others view people with severe multiple impairments determines how they interpret them. For some time, biomedical discourse has been the only discourse on disability and it remains the dominant discourse for people with severe multiple impairments. Social discourse on disability holds that it is handicap that is the greatest barrier for people with disabilities and that biomedical discourse, or discussion of impairments, is disabling in itself (Fulcher, 1989). It may be, however, that biomedical and social discourses are not mutually exclusive. Essentially, biomedical discourse implies the **inability** of people with severe multiple impairments to do what people without impairments can, and social discourse implies the **ability** of people with severe multiple impairments to do what people without impairments can, given that barriers to integration are eroded. All people have certain abilities and disabilities; people with severe multiple impairments usually have more disabilities than most and, in the dominant biomedical paradigm, their abilities are often overlooked. Gleason (1993, p.160) notes, for example, that a comprehensive universal definition of the ability of persons with severe multiple impairments is difficult to achieve solely through the use of
traditional clinical and psychometric measures; the archive records reveal no simple or consistent description of this population. It is only when both biomedical and social discourses are considered together that the question arises as to the validity of people with such significant impairments wanting to do what those without such impairments do. Such a question opens the way to a new discourse (Rorty, 1990), one that respects difference and focuses on different abilities - what O'Halloran (1993) terms *difability* - against a background of impairment which is very difficult to change (Anderson, 1988). This new discourse is reflected in the work of Oliver Sacks as the following quotation shows:

When I first saw her - clumsy, uncouth, all-of-a-fumble - I saw her merely, or wholly, as a casualty, a broken creature, whose neurological impairments I could pick out and dissect with precision: a multitude of apraxias and agnosias, a mass of sensori motor impairments and breakdowns, limitations of intellectual schemata... A poor thing, I said to myself... The next time I saw her, it was all very different. I didn't have her in a test situation, 'evaluating' her in a clinic. I wandered outside, it was a lovely spring day... and there I saw Rebecca sitting on a bench, gazing at the April foliage quietly, with obvious delight. Her posture had none of the clumsiness which had so impressed me before. Sitting there, in a light dress, her face calm and slightly smiling, she suddenly brought to mind one of Chekov's young women - Irene, Anya, Sonya, Nina - seen against the backdrop of a Chekovian cherry orchard. She could have been any young woman enjoying a beautiful spring day. This was my human, as opposed to my neurological, vision. As I approached, she heard my footsteps and turned, gave me a broad smile, and wordlessly gestured: 'Look at the world' she seemed to say. 'How beautiful it is' (Sacks, 1985, p. 171).
Chapter Three
IDENTIFYING ISSUES IN A REVIEW OF THE QUALITY OF LIFE LITERATURE

In a harbour on some western coastline in Europe a poor fisherman is dozing off in his fishing boat, looking out at the sea. An elegantly dressed tourist is approaching; taking pictures and trying to build up a conversation. "You will have a good capture today", the tourist says. The fisherman shakes his head. He had been out fishing that day. "I already captured enough fish for today, tomorrow and the day after tomorrow", he says.

The tourist then tries to convince the fisherman that if he went out fishing two, three, perhaps even four times every day, he could capture enough fish to buy an engine for his boat. After two years he could buy a bigger boat, and after some years he would be the owner of several big fishing vessels. Then he could catch so much fish that he could build a canning company. He could point out where the fish was located by helicopter and radios, open a fish restaurant, and export lobsters directly to Paris.

Then what?" the fisherman asks.
"Then", the stranger says with silent enthusiasm, "You could sit quietly here in the harbour, dozing off in the sun, and look at the sea."
"But that is exactly what I am doing now", the fisherman said.
The stranger left the scene with some reflection. He had also thought that he worked with the aim that he one day wouldn't work any more. He didn't any longer feel pity for the fisherman - only a little envious

(Heinrich Boell, cited in Kolstad, 1994).

Quality of life for people with severe multiple impairments is defined differently, depending on the view which is taken. As described in Chapter One, the biomedical view implies that, because people with severe multiple impairments are different, they have no potential for quality of life and society should be protected from them through the use of exclusion in such forms as segregation and euthanasia. The response of the social view is that quality of life is dependent on a philosophy of inclusion where people with disabilities are integrated into society, and society is obligated to dismantle the barriers to integration. As previously stated, nurses disagree with both of these views, particularly in relation to people with severe multiple impairments. There is no research, however, on quality of life for people with severe multiple impairments, but the research on
quality of life for people with disabilities is applied in practice to them. The research on quality of life for people with disabilities is influenced by how quality of life is conceptualised and by how it is measured. This chapter, therefore, identifies issues in quality of life which impact on people with severe multiple impairments by reviewing: the concept, measurement of quality of life in the absence of a well-defined concept, and the particular development of the concept in relation to people with disabilities. It concludes with a summary of the issues from which the formulation of the research question was derived.

EXPLORATIONS OF THE CONCEPT

Quality of life is the guide for policies and services for people with severe multiple impairments. But what is this thing called quality of life? Each of us seems to know what it might be for ourselves, but an all-inclusive concept seems elusive. Given that there is no clear agreement on the concept of quality of life, this review of the concept examined the multidisciplinary literature for issues which impact on people with severe multiple impairments and found three: approaches to quality of life, the ‘life’ in quality of life, and the ‘quality’ in quality of life.

Approaches to Quality of Life

It is important to note that, despite endeavours in the areas of social science, health, and disability to explore the concept of quality of life, the underlying approaches in these fields are different. Social science’s conceptualisation is an expression of opposition to the
widespread use of economic growth as an indicator of human well-being and is associated with an evaluation of gratification (Szalai, 1980). In the area of health, however, "... we have a restricted concept of quality of life in mind. We do not mean happiness, satisfaction, living standard, climate, or environment. Rather, we are speaking of health oriented quality of life: those aspects that might be affected positively in clinical studies and the clinical situation" (Fries & Spitz, 1990, p. 25). In this regard, health-related disciplines assume that disease and its treatment have an impact on quality of life (de Haes, 1988) and that health and quality of life are synonymous (Bech, 1993; Fallowfield, 1990). In the area of disability, it was assumed that people with disabilities would experience an improved quality of life in smaller settings (for example, Hemming, Lavendar, & Pill, 1981; Scheerenberger, 1976), without first defining quality of life. An underlying assumption of this approach is that disability and a philosophy of inclusion both have an impact on quality of life.

The concept of time is another issue in quality of life. While there is little discussion of time in the quality of life literature, it is clear that all agree that time has to be considered in any conceptualisation of quality of life. As Szalai (1980) points out: does quality refer to everyday life, to the whole course of life or only a certain stretch of it, or to its present state? If quality of life is conceptualised as a state that humans possess, then it is perhaps different at different times. Naess (1974, cited in Kolstad, 1994) and Schipper, Clinch, & Powell (1990), in a review of concepts contributing to quality of life, note the variability over time as one property of quality of life, while Parmenter (1992) cites a number of authors who argue for longitudinal studies of quality of life to ascertain temporal changes.
Implicit in health and disability-related research is that quality of life changes over time. The utility, or time trade-off, concept from which such measures as quality-adjusted life-years (QALYs) (Goodinson & Singleton, 1989) are derived, assumes that quality of life is higher, lower, or absent at different times. Reintegration to normal living, a proxy for quality of life (Schipper et al., 1990), is based on an assumption that quality of life will improve for people with disabilities from the time of "abnormal living" to that of "normal living". This, however, is challenged by Edgerton (1990) who found, in a review of the longitudinal research on the quality of life of people with disabilities, that there is one striking pattern: that people who were hopeful ten, twenty and thirty years ago remain so regardless of life events, and that people who were negative about life do not change with differing circumstances.

The 'Life' in Quality of Life

While little attention has been paid to the concept of 'life' in the quality of life literature, people with severe multiple impairments are subject to the vagaries of different perspectives on life. Meeberg's (1993) dismissal of 'life' as generally quite easily understood is indicative of the underlying assumptions of most of the work in this area. Unfortunately, the implication that there is a unilateral view of life detracts from the potential richness of the concept of quality of life. Meeberg, however, at least raises the question of the 'life' in quality of life, a question which is usually overlooked, and she also provides some analysis from dictionary definitions. She concludes that humans and animals, but not plants, have life and that "life pertains only to living beings and to the course of their existence, or to the manner of their living" (Meeberg, 1993, p. 33). That she includes animals,
although not explored in the remainder of her paper, is an extension of the usually-assumed position that quality of life refers only to human life (Bestuzhev-Lada, 1980; Szalai, 1980). Conversely, in traditional Chinese culture, the life in quality of life is conceptualised as a balance between Yin and Yang, harmony between human, heaven and earth (Zhan, 1992). Similarly, ecologists equate the life in quality of life with a spiritual respect for the earth (Wright, 1992), an idea which is very strong in older cultures such as Australian Aboriginal and American Indian cultures.

From an interpretive perspective, Bestuzhev-Lada (1980), in attempting to create a conceptual framework in which 'quality of life' can reside, proposes that the context for quality of life is the life of human society and that human society encompasses the entirety of historically evolved forms of the co-existence and joint activity of people; one of the most important characteristics of social life is activity which takes place under definite natural and social conditions and is essentially aimed at purposeful transformation and remodelling of the world. Benner (1985), drawing on Heideggarian phenomenology, claims that life can only be understood by studying people in context, how they constitute and are constituted by a shared history, tradition, and social network. Draper (1992) agrees with Benner and states that "the 'life' whose quality is in question is not some theoretical principle, but always and in every case the characteristic of human being" (p. 966), thus, "in order to understand the nature of quality of life, we need to understand what it means to be a human being" (p. 968).

Different views of life have implications for the conceptualisation of quality of life and, as has already been seen in Chapter One, for the consequences of those conceptualisations. Some authors ponder
whether evaluation of quality of life is related to aspects of life or to life as a whole and, while Szalai (1980) only raises the question, de Haes (1988) concludes that quality of life should be measured as a whole because aspects are only relevant within the context of the whole. Johnson (1988), it is noted, conceptualises quality of life as consisting of two aspects: quality of being and life activities. He reasons that quality of being varies with life situations and develops a number of indicators for each aspect which can be measured and put back together as one score of quality of life. Benner (1985), on the other hand, points out that hermeneutic phenomenology, rather than isolating person and situation variables and then trying to put them back together, seeks to study the person in the situation. She argues for a conceptualisation of quality of life as quality of being, an argument taken up by Draper (1992) who notes that "there is a tendency to conceptualise quality of life in terms of isolated fragments of the human experience" (p. 967).

The 'Life' of People with Disabilities

Researchers such as Goode (1990a) and Keith (1990) assert that quality of life for people with disabilities should be no different from that of people without disabilities. Perhaps so, but this view tends to ignore both the history and valued differences of people with disabilities, thus working against an understanding and explanation of the quality of life of people with disabilities.

Cartesian dualism, which separated mind and body and influenced twentieth century thinking, has grave consequences for people with disabilities. Within such a framework, they are perceived as without mind, and through a generalised response to deviancy
(Wolfensberger, 1972), as without emotion, sensation, soul - in short, without humanity. Their lives, therefore, are not discussed in terms of human experience, but rather in terms of problems to be solved. The typical question asked in relation to people with disabilities is not “what do you want to do?” but rather, “what are we going to do about?” Instead of seeking answers to the wishes and interests of individuals with disabilities, society seeks answers to the problems of the group’s appearance, behaviour, communication, accommodation, and so on. Their lives, consequently, are carved up by the specialists into aspects with few of these specialists seeing the whole.

People with disabilities are frequently perceived as deviant and the history of their lives is one of stigmatisation, discrimination and social control. Moreover, elements of Wolfensberger’s (1972, pp. 15-25) analysis of the imputed roles and societal management of people with disabilities persist today. Destruction of “the deviant individual as subhuman organism”, for example, is evident in abortion following prenatal diagnosis and in euthanasia, while segregation of “the deviant individual as menace or as object of dread” is demonstrated in residential placement, large or small. Further, services arising from a sense of duty, rather than compassion, and which have no respect for people with disabilities, perpetuate the image of “the deviant individual as object of pity and as diseased organism” rather than as people entitled to human services. “The deviant individual as an object of ridicule” is not taken seriously.

The plans to reverse or prevent deviancy by social redefinition, that is, by not attaching negative values to certain types of differentness (Wolfensberger, 1972) have fallen miserably short of their goal. Moreover, the principles of normalization (Nirje, 1969; Wolfensberger, 1972) have been interpreted and misinterpreted
(Perrin & Nirje, 1985) in an endeavour to make people with disabilities as like people without disabilities as possible, rather than highlight and value their differences. Therefore, people with disabilities are still not welcome in their communities (Barlow & Kirby, 1991) and perceptions of people with disabilities as deviant continue to exclude them from a place in society, despite their physical presence (Borthwick-Duffy, 1987).

In short, the life of people with disabilities is different from the life of people without disabilities. Thus, people with disabilities, until recently absent from disability discourse, are telling their stories. They are questioning "able-bodied" assumptions about problems of body image and so on when the problems they experience are of others' response to their disability (Dartington, Miller, & Gwynne, 1981).

**The 'Quality' in Quality of Life**

While first expressed, in 1956, as an extension of an economic view of life, 'quality' changed over the next twenty years to refer to its original lexicographic sense, that is, 'good' or 'satisfactory' character of people's life (Szalai, 1980). 'Quality' is used in two senses: firstly, as an attribute and secondly, as a comparison. As an attribute, quality is an essential feature of life (Meeberg, 1993), a non-evaluative term (McCall, 1975): just as quality garments may be different but equally excellent, no life is better or worse than another. Quality, however, is more often used in a comparative or an evaluative sense (Meeberg, 1993). It is qualified on a continuum from high to low, from best to worst: there is a comparison (implicit or explicit) with other things of the same kind (Draper, 1992). There is no argument that quality is
desirable but its indisputable goodness (Kolstad, 1994) has been questioned by Goode (1991, cited in Parmenter, 1992) who expresses concern about its quantification and development as a standard for application across all populations.

'Quality' for People with Disabilities

When quality is used in an evaluative sense, it becomes related to solutions to problems of difference rather than to the person. The goal becomes achievement of what the mainstream desire, for example, looking good, behaving acceptably, speaking well, having a job, a home, a car, and so on. What occurs is that the quality of society and, hence, the quality of services is privileged over the quality of the individual. The quality of society is preserved when genetic differences are erased and deviant individuals are placed at the periphery of society (Wolfensberger, 1972). The quality of services ensures that deviancy is kept under control or eradicated through, for example, segregation and euthanasia.

The dilemma is that, except in rare circumstances, the qualities of people with disabilities are not valued, unless they are extraordinary qualities. "Heroes" with disabilities are few - for example, Alan Marshall (1971), John Roarty (1981) and the fictional Tim (McCullogh, 1979) and Forrest Gump (Finerman, 1994). Wolfensberger (1988a; 1988b) has recognised that there is little written by professionals over the years about the qualities of people with disabilities. He notes from his experience a range of "strengths, virtues, gifts, capacities, prosocial dispositions, and resources, here called 'assets' " (Wolfensberger, 1988a, p. 63), which many people with disabilities share, for example,
spontaneity, generous response, trust, direct and concrete honesty, and relating to the 'heart qualities' of others rather than to their status.

Any comparative measure of quality of life, therefore, potentially excludes people with disabilities, unless it considers such assets. The major fear associated with comparative measures is that people with disabilities, and other minorities, may be unable to reach the devised standards and, in the circular logic of society, may then be seen as having no potential for quality of life.

Summary of Issues in the Concept of Quality of Life

This review has identified three issues associated with the concept of quality of life which impact on people with severe multiple impairments. Firstly, within the number of approaches to quality of life, it is important to note that there are two assumptions in the area of disability: that disability itself somehow impacts on quality of life, and that improvement in quality of life is somehow associated with deinstitutionalisation. These assumptions, however, are challenged by others: Dartington et al. (1981), for example, submit that disability itself may have little to do with quality of life, and Edgerton (1990) suggests that environment may not be related to quality of life. Secondly, little attention has been paid to the ‘life’ in quality of life but assumptions about life are implicit in a concept of quality of life. These assumptions tend to render invisible the life of people with severe multiple impairments. Thirdly, the ‘quality’ in quality of life, when used in its comparative sense, may suggest that people with severe multiple impairments have no potential for quality of life.
In the absence of an agreed upon and clear conceptualisation of quality of life, "some vaguely circumscribed meaning" (Szalai, 1980, p. 9) has been attributed to it and "researchers have generally ended up analysing as empirical referents the various indicators used to define quality of life" (Meeberg, 1993, p. 36). The next section, therefore, turns to an examination of these indicators.

MEASUREMENTS OF QUALITY OF LIFE

The history of quality of life shows its movement from a subjective perspective to an objective measure to a debate between the two, as the term has been adopted by disciplines in human services. Without agreement on a definition or concept of quality of life, the range and selection of indicators is typically based on the values of the investigator, leading some to argue that measurement should be subject-authored. There is also a developing relationship between indicators of quality of life and outcomes of quality of care. Finally, the shift to a subjective perspective of quality of life is producing difficulties concerning who can answer questions about an individual's quality of life.

Subjective versus Objective Perspectives

"Quality of life is not a revolutionary idea ... But quality of life has caught on as the challenge - or the shibboleth - of the 1990's" (Landesman, 1986, p. 141). While the phrase may be relatively new, the idea has been with us for some time. Plato's Republic, for instance, was concerned with a good life for all (Schalock, 1990a) and wars have been justified throughout time by the need to defend a valued way of
life. The notion of quality of life was implicit in a happy life, for example, when James Cook met the Australian Aborigines he wrote that they were "far more happier" than Europeans (Clark, 1980). Black (1911) related happiness to good health, enjoyable work, simplicity, intellectual stimulation and affection and Cooksey (1916) stressed friendship, affection and industriousness for a good life. Thus, quality of life has been associated historically with a subjective measure of how satisfied we are with life. When politics entered the debate, another dimension was added: an objective measure of how good life is.

In 1956, in a climate dissatisfied with economic growth as the indicator of human well being, 'quality of life' was coined as a political slogan in America (Stensman, 1985), and became a researchable concept which was assigned objective indicators. Since then, in attempting to incorporate financial, welfare and other indicators of the well being of individuals in society, quality of life has its roots in economics, sociology and psychology (Kolstad, 1994).

The first effort to measure quality of life was in 1960 with the American President Eisenhower's Commission on National Goals (Flanagan, 1982). Since that time, debates about the concept and ways to measure it have proliferated to the degree that every town and city has seemingly had its quality of life compared to that of every other (Zautra & Goodhart, 1979). Moreover, comparative social research has evaluated the quality of life of social groups, strata, age cohorts, societies and nations (Szalai, 1980).

Health and disability-related disciplines adopted the phrase 'quality of life' shortly after its initiation. In medicine, Karnofsky is credited with proposing in 1947 a non-physiological outcome
parameter for cancer while the first use of 'quality of life' is attributed to Priestman and Baum in 1976 (Schipper et al., 1990). In nursing, there was developing work on satisfaction with life (for example, Laborde and Powers, 1980) but the initial use of the phrase ‘quality of life’ seems to have occurred in oncological nursing (see Presant, Klahr, & Hogan, 1981). In the area of disability, Edgerton contributed the pioneering work in 1967 and 1975 on issues related to quality of life among people with mental retardation (Schalock, 1990b). The adoption of quality of life as a measure of human well being has resulted in debates concerning the perspective to be taken.

It is to be noted that, while it may be more appropriate to refer to subjective perspectives and objective measures, much of the quality of life literature does not differentiate between perspective and measure. According to Halpern (1993), the subjective perspective refers to the individual's point of view, while the objective perspective refers to a societal point of view. Nevertheless, there is considerable debate concerning whether quality of life is the sum of objective indices determined by society, or at least by the majority view, or an evaluation by the person whose quality of life is in question. One view is that quality of life can only be an objective measure of living conditions because, regardless of the individual's perception of or satisfaction with these, they can be better or worse (Rodgers & Converse, 1975). The alternative view is that only the individual can assess their own quality of life based on personal values rather than another's values (Flanagan, 1978; Johnstone, 1988).

Most authors take the position that there are both objective and subjective aspects of quality of life (Kolstad, 1994) because both types
of measures "can provide interesting, potentially useful, and complementary information" (Andrews, 1980, p. 278). Use of both measures is apparent in current quality of life research (Charlton, 1994; Hart & Wearing, 1994; Kolstad & Vikan, 1994) despite some unease among those who adhere to the objective method (Schipper et al., 1990). Campos and Johnston (1990) note, however, that even among these adherents to objective approaches there has been a dramatic increase in the use of subjective measures. Similarly, Evans, Dingus, and Haselkorn (1993) found in a review of the health-related quality of life literature that of fifty-two studies, thirty one percent used subjective criteria only, forty percent objective criteria only, and twenty one percent used both. Most disability-related models of quality of life use both objective and subjective indicators, while Schalock (1993) proposes, in an analysis of current models, that some indicators are interactional, and that the three indicators: subjective, objective and interactional, are vital to an holistic approach.

Subjective versus Objective Perspectives and People with Disabilities

An objective measure of the quality of life of people with disabilities would find their living conditions, on the whole, substandard. While children with disabilities usually enjoy the same living conditions as their parents (which may be objectively measured from high to low), adults with disability have a different experience. Those living in large residential settings, for instance, are subject to conditions which most of us would not tolerate (Blatt, 1981), for example, dormitory-style sleeping arrangements, bathrooms without doors, and routinisation. For those in group home living, while the house may reflect the standard of its neighbours, and four or five
people may be easier to live with than dozens, on many other indicators, for example, friends (Vitello, 1986) and choice (Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988), their quality of life would be low. For those without the supports of home or placement, their poverty negatively influences their living conditions (Giddens, 1989).

A subjective perspective suggests that people with disabilities rank their quality of life equally with people without disabilities. Satisfaction with particular dimensions, such as social life and autonomy, may differ (Barlow & Kirby, 1991) with place of residence but these seem related to the importance of the dimension to the person whose perception of quality of life is being measured. A study by Ramund and Stensman (1988) found similarly that, for people with mobility impairments, social abilities are more important, while for people without mobility impairments, motor functions such as sport are more important.

Different perspectives also determine the indicators used. Halpern (1993) provides an example when he identifies a number of dichotomies in the quality of life literature and purposely uses them to expose the underlying assumptions in a quality of life model. In his discussion of personal choice versus universal entitlements, for instance, he notes that personal choice is presumed by any quality of life model which includes a subjective perspective and that universal entitlements, as difficult as these may be to agree on, are presumed by an objective perspective. He argues the case similarly for personal needs versus social expectations, and for personal intervention versus social policy development.

Dennis, Williams, Giangreco, and Cloninger (1993) move beyond such a fragmented view of individuals in adopting a model of quality
of life drawn from the optimal theory of Speight et al. (1991, cited in Dennis et al., 1993). Their model consists of three overlapping circles depicting individual, common and culturally-specific values and needs. In the individual circle, "every person is like no other person" (p. 500): unique experiences contribute to a unique world view. In the common circle, "every person is like all other persons" (p. 500): common values arise from the context of perceived common needs. In the culturally-specific circle, "every person is like some other person through experiences and meanings that groups of people share" (p. 502). The area of overlap holds the key to understanding a person's world view. The interactions among individual, common and culturally-specific needs and values influence individual and group perceptions of quality of life.

Who Selects the Indicators?

There are as many different indicators of quality of life as there are people who have developed them. Most quality of life research utilises multidimensionality (Schipper et al., 1990) as a property of quality of life, although it has been noted that many studies are unidimensional in their representation of quality of life (Parmenter, 1994; Zhan, 1992). While Spilker (1990) carefully considers the ethical implications of the choice of indicators to be measured, this way of thinking leads to an ever-increasing number of indicators of quality of life, which are then measured and presumably account for the person's amount of quality of life. The next section outlines a number of the indicators used by different disciplines and notes the emerging link between quality of life indicators and quality of care outcomes.
Social Science Indicators

Social science indicators of quality of life are generally extremely broad ranging. The first measure of quality of life of the total population of America, in 1960, included social and environmental factors such as education, concern for the individual, economic growth, health and welfare, and defence of the "free world" (Flanagan, 1982). Domains identified by Campbell, Converse, and Rodgers (1976), in another study of the American population, included marriage, family life, health, neighbourhood, friendships, housework, job, non-work, life in America, city or country, housing, amount of education, usefulness of education, standard of living, and savings. The American Government's report (1977, cited in Flanagan, 1982) on social indicators of quality of life includes objective indicators such as economic productivity, crime rates, family income, health indices, and accident rates, as well as subjective indicators such as satisfaction with housing, health care, and recreational opportunities. Flanagan (1982) attempted to develop a comprehensive list of the domains of quality of life through the use of a critical incident technique where he condensed 6,500 critical incidents, collected in interviews with three age groups of 3,000 Americans, to five dimensions (with fifteen factors): (1) physical and material well being; (2) relations with other people; (3) social, community and civic activities; (4) personal development and fulfilment; and (5) recreation. In the main, it can be noted that the indicators from the social sciences reflect the private and social lives of people interacting with the world.

Health Indicators
In the health-related quality of life literature, domains of quality of life are, not surprisingly, more consistent with concepts of health. While there are different operationalisations, most include physical, activity and psychological aspects and fewer include social and material aspects (de Haes, 1988). Spilker (1990) and Fallowfield (1990), in reviews of the health-related quality of life literature, agree that the general consensus on domains is that there are four: physical, psychological, social and economic. This does not mean, however, that each researcher uses all four domains nor do they use these four exclusively. Lehman and Burns (1990), for example, use only social and psychological indicators. Schipper et al. (1990) employ all four domains but add a fifth: somatic sensation, meaning unpleasant feelings such as pain and nausea which detract from quality of life. A closer examination of the four domains demonstrates that they are also interpreted differently and therefore have different dimensions - the domain of somatic sensation (Schipper et al., 1990), for example, is included within Fallowfield's (1990) physical domain.

Early work in nursing on (implicit) quality of life is characterised by individuals engaged in life:

Smiles ... what fun it is to lie on my tummy ... that feels more comfortable ... they wheel me around ... I begin to laugh ... pots and brushes and paint ... I feel the grass ... they are wearing lovely bright colours ... moves my arms and legs ... sing and laugh and hug ... I am learning ... (Horton, 1980, pp. 18-19).

I have learned to love the feel of the rain on my face, the wind in my hair, the warmth of the sun ... the perfume of flowers ... the cat comes to me for a cuddle ... feel the plants in the pots ... the true and real company of my friends (Patton, 1981, p. 17).
This picture of the individual engaged in life with others was soon to change, however, as nursing followed medicine's lead and developed indicators of quality of life including, for example, independence, a sense of security, and relationships with others (Burckhardt, Woods, Schultz, & Ziebarth, 1989). It is interesting to note that, while indicators were and continue to be used, the nursing literature (for example, Ferrans & Powers, 1985; Goodinson & Singleton, 1989; Simmons, 1994) repeatedly asserts that the importance of particular indicators to individuals is essential to the measurement of quality of life. More recently, there are attempts to distance the use of indicators and view life as a process (Holmes, 1989; Zhan, 1992) or life as being (Draper, 1992).

Disability Indicators

The factors which were thought to be important in community adjustment studies following deinstitutionalisation formed the basis of current quality of life measures in the area of disability (Borthwick-Duffy, 1992). A number of researchers have attempted to devise reliable instruments to assess satisfaction with community life, after deinstitutionalisation, of people with disabilities. Heal and Chadsey-Rusch (1985), for example, identify the dimensions of residence, community environment, friends and services while the factors of social network, residence, occupation and client satisfaction were identified by Halpern et al. (1986). On the other hand, as previously mentioned, Johnson (1988) defines quality of life in terms of quality of being and life activities. He identifies indicators of quality of being as: choice, emotional well-being, privacy, community interaction, adequacy of resources, physical health, aesthetic interests, flexibility,
and support networks. Life activities are broken down into two main categories, leisure and personal management, which are then further subdivided. Indicators, therefore, are related to aspects of life thought to be important in community integration, and as such, are more like social science indicators, such as neighbourhood and friendships, than health indicators, such as physical function and symptom control.
Values and Indicators

The overwhelming conclusion from asking about who selects indicators of quality of life is that such selection is value-based. Individuals and the discipline focus determine which indicators will be used in a particular study.

Quality of life is a value-laden concept because it refers to attributes that are 'desirable' or 'undesirable', selected out of all the qualitative attributes and their duly quantified indivisible elements which are involved with or respond to the life process of human beings (Mukherjee, 1980, p. 189).

How indicators are measured also impacts on quality of life. Guadagnoli and Mor (1990) provide an interesting example. A problem with measurement of social interaction is that individuals' preferences for interactions with others differ. The solution has typically been to assess the quantity of social interactions and to operate under the assumption that more social interaction is better. This implies that not only is social interaction valued but also that the amount of social interaction is valued, thus ignoring individual preferences.

Such an example raises questions about whether selected indicators are valid measures of quality of life. Indicators are reflected in the numerous standardised scales available for measuring quality of life, for example, the ‘Quality Of Life Index’ (Spitzer et al., 1981, cited in Parmenter, 1994), the ‘Lifestyle Satisfaction Scale’ (Heal & Chadsey-Rusch, 1985), and the ‘Quality of Life Questionnaire’ (Bigelow, McFarland, & Olson, 1991). Such standardised, as well as non-standardised, scales are typically investigator-authored, thereby
reflecting, to a greater or lesser extent, the values of those who devise them. Heal and Sigelman (1990) question the validity of investigator-authored indicators and propose rather that indicators could be authored by the subjects of investigation. An example of how this can be done is found in Flanagan's (1978) work where he used questions such as the following to select indicators:

Think of the last time you did something very important to you or had an experience that was especially satisfying to you. What did you do or what happened that was so satisfying to you? Why did this experience seem so important or satisfying? (Flanagan, 1978, p. 138).

There is no differentiation here between importance and satisfaction. Ferrans and Powers (1985) as well as Cummins (1991), however, attempt to overcome the dilemma of imposed values by using two-dimensional responses to their indicators: the importance of an item, and satisfaction with it.

The Relationship between Quality of Life and Quality of Care

Increasingly, quality assurance outcomes are reflecting quality of life indicators (Schalock, 1993). While quality of life and quality of care have probably always been implicitly linked, it is not until recently that that link has become explicit. This is because quality of life and quality of care have arisen from different roots and quality assurance programs preceded quality of life research. While quality of life finds its beginnings as a political slogan which developed into a researchable concept, quality of care has an economic history. It began when supply exceeded demand, business had to become competitive
and cost-effective, and 'quality' of goods and services began to dominate. This was more than the traditional notion of quality; it became "fitness for use, [a term which] encompasses both freedom from defects (conformance to specifications) and the multiple elements required to meet the total needs of a customer" (Fortuna, 1990, p. 4). The economic situation had a direct impact on human services which also took up the various quality measures. Quality assurance is a common facet of health and disability services today and, without demonstration of quality assurance programmes, there is little likelihood of accreditation and/or funding.

In the area of health services, there is clearly a link between quality assurance and health-related quality of life. Quality is an abstract concept, and as such, requires tools to measure it: the tools used are standards which name and discuss the properties of the concept. Because they are developed by people, they reflect people's norms, values and expectations. Criteria, used to operationalise standards, provide measurable quantitative guidelines. Both standards and criteria may be written, retrospectively or concurrently, for three dimensions of evaluation: systems, process and outcome (Cuthbert, Duffield, & Hope, 1992; Sullivan & Decker, 1992). It is the evaluation of outcomes which provides the link between quality of life and quality of care since outcome criteria are often synonymous with quality of life indicators, for example, independence, health, and social relationships.

In the area of disability, Knoll (1990) describes three eras in the definition of quality, each related to residential programmes: institutional reform, deinstitutionalisation, and community membership. Exposés of appalling conditions for people with disabilities living in institutions in the United States of America led, in
1972, to an injection of federal funding which was tied to minimum treatment standards (Chafee, 1990). Since that time funding for programmes is dependent on an evaluation of quality of service. With the evolution of values regarding people with disabilities, the focus of that evaluation has gradually changed from system to process to outcome (Pearce, 1990), that is, from evaluation of the structure of services, to the ways in which services are provided, to the outcomes for the recipients of services. Thus, "society is finding that achieving a high quality of care is inextricably entwined with providing a better quality of life for those with disabilities" (Chafee, 1990, p. 97). In this regard, the leading proponents of quality assurance programs, Bradley and Bersani (1990), recognise that quality of life is dependent on quality of care while Borthwick-Duffy (1992, p. 58) says that "there is a general consensus that quality of care is a necessary but not sufficient aspect of quality of life".

**Who Can Answer Quality of Life Questions?**

Regardless of who authors the questions, there remains the debate about who answers them. The view that only the individual can answer questions about their quality of life raises some problems for people whose self-reports are seen as unreliable (Bech, 1993) and for those who cannot communicate in the usual way (Borthwick-Duffy, 1992; Heal & Sigelman, 1990). The usual course in this situation is to introduce a third party who speaks on behalf of the person who is presumed unable to provide valid answers, and who is "mindful of what is good for the individual and what he [or she] would choose" (Lachs, 1986, p. 96). Bech (1993) cautions, however, citing a number of studies, that there is, at best, only fifty percent concordance between "unreliable" patients and relatives' perceptions
of the patient's quality of life. Similar results were found for staff-resident agreement by Budd, Sigelman, and Sigelman (1981, cited in Heal & Sigelman, 1990).

If, however, people cannot answer for themselves, how can decisions be made about their lives? Should it be left to the policy makers, or should the direction come from intimately involved third parties? According to nurses who work with people with severe multiple impairments, leaving decisions to the policy makers is not working for this group. Taylor and Bogdan (1990) suggest that it may be unprovable whether people with disabilities, who cannot speak, experience the world as other people do, but that it is just as reasonable to assume that they do as they do not. They note that people close to those with severe multiple impairments talk at length about what the latter think, feel, like, and so on, based on an interpretation of subtle gestures and signs not necessarily apparent to an observer.

**Summary of Issues in Measurement of Quality of Life**

Unable to agree on a concept of quality of life, researchers have nevertheless attempted to measure it. This has resulted in a massive number of different indicators dependent on the view of quality of life of the researcher and the reason for the measurement. As the work progresses towards a more subjective view of quality of life, there is an emerging link between quality of life indicators and quality of care outcomes. There is, as well, concern regarding the ability of people, whose self-reports are seen as unreliable or who cannot speak, to express what they mean by quality of life.
QUALITY OF LIFE AND PEOPLE WITH DISABILITIES

The next section of this chapter focuses on issues in the developments in quality of life related to people with disabilities. In doing so, it examines (a) the early work in the area, (b) more recent quality of life models, (c) the views of individuals with disabilities and their families, (d) quality of life for people with severe multiple impairments, and (e) ethical considerations in the quality of life enterprise.

The Early Work in Disability and Quality of Life

For the most part, the early work on quality of life for people with disabilities must be drawn indirectly since most researchers, before 1990, were caught up in addressing another more general question: Are traditional institutions or community-based programs the most appropriate setting for people with developmental disabilities? (Knoll, 1990).

Deinstitutionalisation and Quality of Life

Research in the 1980s, during the time of deinstitutionalisation, focused primarily on the size of the residence in relation to quality of life. Hemming et al. (1981), for instance, summarise research pertaining to quality of life for residents in institutions under five separate but interacting categories: institution size and practices, institution practices and beneficial staff-resident interaction, participation in culturally normative activities, effects of the
institution on behaviours, and measurement of the behaviour of residents. They found that reduction in institution size does not necessarily improve quality of life but does provide an opportunity for change in management practices which could improve quality of life. Butler and Bjaanes (cited in Hemming et al., 1981) found that free institutions were often better places to live than small group homes with rigid practices. Landesman-Dwyer (1981), quoting a number of studies, dismisses the belief that "small is better" and, while agreeing that large institutions are more prone to depersonalising practices, she concludes that size is not related to quality of care. Deinstitutionalisation, it is argued, is little more than an exercise in depopulation unless there is an accompanying effort to examine the constituents of quality of life (Bachrach, 1985). The study by Hemming et al. (1981) is the only one, in the 1980s, which assessed quality of life for people with intellectual disabilities both while they were living in a large institution and after transfer to new small units. Using multiple methods, they found that quality of life after transfer improved on most indices for the majority of residents, although residents with moderate to mild disabilities from relatively "free" large institutions improved the least. Hence, it seems that little was known about the quality of life of people living in large institutions in the first place and the literature is therefore inconclusive about the differences in quality of life in institutions versus group homes.

**Community Living and Quality of Life**

There are many American studies which concentrate on improvements in quality of life following the move of people with disabilities to community living. McDevitt, Smith, Schmidt, and Rosen (1978), for instance, report that people with mild disabilities,
who were deinstitutionalised during 1963 to 1974, had made some quality of life adjustments as evidenced by vocational, economic, social and personal dimensions. Edgerton, Bollinger, and Herr (1984) found that aged people, with moderate disabilities, who were deinstitutionalised twenty years before, are less dependent, and more hopeful and confident than previously. A study by Schalock and Lilley (1986) of eighty five people with moderate disabilities, who were deinstitutionalised eight to ten years previously, concludes that significant correlates in quality of life include increased family involvement, increased income, reduced number of disabilities and lower age. In an Australian study, Jones (1986) reports that residents with severe disabilities, deinstitutionalised five years previously, were satisfied with living in a group home, with their level of competence and independence, and with the people with whom they lived. Kishi et al. (1988), however, compared the decision making of groups with and without mental retardation. They found that the subjects with mental retardation had significantly fewer opportunities to make decisions on what to eat or wear, how to spend free time, and with whom to live.

Two authors have provided an overview of the community living research. In America, Vitello (1986) found that changes in adaptive behaviour were mixed, that is, there was some evidence of increased family contact but little evidence of interaction with the wider community. In addition, the subjects reported that they were much happier in the community than in an institution and that support services were improving but there remained a demand for social and recreational services. In Australia, Moloney and Taplin (1988) found positive effects on the general quality of life following deinstitutionalisation but the outcomes for those with profound and multiple disabilities were less positive. They conclude that:
In reality, a range of programs may need to be established for a group of people as heterogeneous as those who have a developmental disability. Special populations such as the medically frail, profoundly and multiply handicapped, and the seriously behaviour disordered and psychotic, require special provision (p. 118).

Quality of Life Models for People with Disabilities

Between 1986 and 1993, a number of disability-specific quality of life models were developed. Five of these have recently been extensively reviewed by Parmenter (1992). Drawing on Parmenter’s works, a brief summary of these five, and another two, are included here to document the progress in thinking about quality of life for people with disabilities.

The model developed by Halpern et al. (1986) provides a direct link between early community adjustment work and current quality of life models. It is a model of community adjustment derived from an empirical base and contains four domains of community living: occupation, residential environment, social support, and personal satisfaction, each domain having a number of dimensions. The significant finding, in its application to adults in semi-independent living programs in America, is the strong relationship between occupation and opportunities for community integration.

Drawing on a number of community psychology models, Borthwick-Duffy (1987) developed and evaluated a model of quality of life for people with mental retardation which consists of four domains of quality of life: residential environment, interpersonal
relationships, community involvement, and stability. The relationships among the four domains, each with a number of dimensions, are examined. The significant finding, on evaluation of this model with children and young adults (aged five to twenty one years) in family foster care programs in America, was that residential environments appear to determine the degree of community involvement. While different from the Halpern et al. (1986) study, both concluded that improved quality of life in one domain does not necessarily affect quality of life in another domain.

The model of quality of life for people with disabilities developed by Parmenter (1988) draws on a symbolic interactionist/ecological framework. It identifies and describes three domains: self, functional behaviours, and social influences, which interact with and influence one another. In a trial with adults who had recently moved from a large residential setting to group homes in Australia, support was found for some aspects of the model (Parmenter, Briggs, & Sullivan, 1991). Empirical validation using longitudinal ethnographic methodology is planned (Parmenter, 1992).

A client-driven, ecological, quality of life model was developed by Goode (1988) from a review of the literature. It is a client-centred, nonlinear, process model which depicts relationships, rather than causative pathways, between subjective and objective indicators. This ethnomethodological perspective implies a circularity between the person and the environment. The essential point of this approach is that quality of life is experienced and influenced by people interacting in particular settings and thus, quality of life is specific to the setting under discussion. A discussion framework drawn from this model includes five essential quality of life factors: client needs, social expectations, behavioural outcomes which satisfy needs and
expectations, client resources to meet demands, and resources needed by others in the setting to facilitate clients' abilities to meet demands. This framework is used in focal group discussions with people with disabilities as part of the ongoing National Quality of Life for Persons with Disabilities Project in America. Such discussion identifies particular needs, expectations and resources in specific settings from which recommendations are made regarding the national agenda for enhancing quality of life for people with disabilities.

Brown, Bayer, and MacFarlane (1989) developed a model of the measurement of quality of life for disabled persons to assist their analysis of data collected from adults in community based agencies in Canada. Objective quality of life is measured on the dimensions of environment, growth and mastery of skills, health, and economic stability. Subjective quality of life is measured on the dimensions of life satisfaction, psychological well being, and individual perception of skills and needs. A number of variables are identified to reflect the objective and subjective evaluations. While the gap between an individual's achieved and unmet needs and desires formed the basis for a measure of high to low quality of life, the researchers did not report a global quality of life measure. As with Goode (1988), the perceptions of the participants were used to formulate a set of recommendations regarding services.

While not strictly speaking a model, Cummins' (1991) work on the comprehensive quality of life scale - intellectual disability (ComQol-ID) is included here for its domains. It is an adaptation of the general ComQol scale and, thus, can be directly compared with data from the general population. It has subjective and objective components on seven domains generated from a review of the literature. These domains are material things, physical well-being,
productivity, intimacy, safety, place in society, and emotional well-being. Each item within the domains requires two responses: the importance of the item, and the extent of fulfilment with it. The scale is administered to both the client and a carer to detect discrepancies between their perceptions. The client's ability to use Likert scales is tested through the use of wooden blocks of ascending size on an item known to be important to the client. The number of discrimination points are modified in relation to ability. There is also a "faces" version of the fulfilment scale. The carer completes objective information.

Schalock's (1993) multidimensional quality of life model has four components: cultural factors, aspects of life experiences, perceived quality of life, and quality of life indicators. Aspects of life experiences, that is, personal characteristics, objective life conditions and perceptions of significant others, are influenced by cultural factors and have a marked effect on perceived quality of life. Indicators of quality of life have been developed from the testing of a standardised forty-item 'Quality of Life Questionnaire' (Schalock, Keith, & Hoffman, 1990 cited in Parmenter, 1992) which cluster into four domains: independence, productivity, community integration, and satisfaction.

On the whole, these models reflect the philosophy of inclusion and, more often than not, focus on setting. Elements of some of the models, however, are beginning to incorporate the stories of people with disabilities and their families.

Views of Individuals and their Families
Amidst all the activity of the development of quality of life measurements, people with disabilities and their families have often felt ignored. As development continues, they are being asked to express their views about their quality of life.

Crutcher (1990), a parent of a sixteen year old girl with Down Syndrome, is disenchanted with quality of life research because her daughter's "quality of life would never be questioned if you only knew her" (p. 17). Turnbull and Brunk (1990), both parents of people with disabilities, extensively explore seven ways of conceptualising quality of life for people with disabilities and their families and conclude that:

For all of us, as well as for the public philosopher, there is an underlying measure of quality of life. It is the measure that ascribes quality of life according to the extent to which people choose to be with each other, the ways in which they give form to their choices to be with each other, and the nature, extent, and duration of their relationships. Quality of life is indeed measured by relationships (p. 207).

Individuals with disabilities are beginning to point researchers towards new research directions. Martinez (1990), for example, claims that quality of life is having a dream for herself. Ed's meaning of quality of life is related to his struggle "not to give in to that mental retardation image" (Taylor & Bogdan, 1990, p. 39) while Ward (1990) defines quality of life as seeing herself as a person.

Quality of Life for People with Severe Multiple Impairments
While the discussion to date has in the main dealt with the generalised concepts of quality of life and their applications to people with disabilities, there is less work directly related to people with severe multiple impairments. One who has highlighted people with severe multiple impairments and drawn attention to the particular issues related to their quality of life is Borthwick-Duffy (1990). She comments on this group's unique disabilities and suggests that, while the generally accepted domains of quality of life may be applicable, the specific criteria by which those domains are defined and measured may be different. She recognises that this group's particular needs result in the majority of their time being spent at home (regardless of the dedication of carers) and asserts that quality of life and quality of care may be inseparable. Borthwick-Duffy confronts the dilemmas of this group's inability to communicate in the usual way, and third party judgements about the quality of life of people with severe multiple impairments. She cites the work of Rochelau, Spolar, and Yang (1988) which found that caregivers reported no differences in their ability to assess the preferences of people with severe multiple impairments, and the study by Cirrin and Rowland (1985) which found that a sample of people with severe multiple impairments were capable of intentionally communicating through non-verbal means, with great diversity in communication styles and frequency.

Borthwick-Duffy's (1990) conclusion is that professionals should concentrate on improving the communication skills of people with severe multiple impairments in order that they can convey their concepts of quality of life, and that quality of life for this group should be taken into account before generalisations are made about quality of life for all people with intellectual disabilities.
Goode and Hogg (1994) also note the challenge in assessing quality of life when people do not participate in formal language systems. They remark on the number of projects all over the world which are attempting to devise a suitable assessment for people with severe multiple impairments. They conclude that such an assessment will take a long time to develop, that it will be shaped by social policy in human services, and that it will probably never qualify as hard science.

Due to the complexity of QOL, and especially due to the differences in countenance and experience between the assessors and those being assessed, determining the quality of life for people with profound cognitive disability will probably always rely on very fine judgments and forms of empathy, which are not easily operationalized and put to paper (Goode & Hogg, 1994, p. 205).

**Ethical Considerations**

A chronological review of the disability literature demonstrates that, for about a decade, there was a perceived urgency to give meaning to the concept of quality of life, and eager anticipation of its usefulness for services. This feverish activity slowed to more considered advances as research directions and their implications unfolded.

In the 1980s, there was a call for research to map the constituents of quality of life for people with disabilities. Professionals were interested in a definition of the concept (Ellis & Luckasson, 1984; Neale, 1988; Zaner, 1986), the identification of factors pertaining to
quality of life (Anderson, 1982; Landesman, 1986) and its possibilities for enhancing services (Landesman, 1986; Wortis, 1988). By the end of the decade, despite voluminous work, there was still no clear conceptualisation of quality of life, no agreement about its indicators, and no clear strategies for its use in services. Rowitz (1989, cited in Ashman, 1990) predicted that quality of life for people with disabilities, including the clarification of its definition and the determination of its factors, would be one of the issues which must be faced within the next decade.

In the 1990s, there is growing caution about quality of life research. While Schalock (1993) claims quality of life to be the new paradigm with the potential to enhance well being and satisfaction through policy development, program practices and habilitation services, others are not so sure. There is a fear that, if criteria for quality of life are standardised, people with disabilities may not be able to meet the criteria. Unable to meet the criteria for quality of life, people with disabilities may lose their battle for any life, based on the argument that they have no potential for quality of life. Goode (1991, cited in Parmenter, 1992) warns that imposed standards may bring about a "tyranny of quality", while Luckasson (1990) urges the disability community to reject the use of the phrase because her experience as a lawyer tells her that it may be used as a shorthand justification for denial of rights to people with disabilities.

A number of others encourage research, but with reservations. Borthwick-Duffy (1990), for example, insists that quality of life data not be used to define personhood or humanness. Taylor and Bogdan (1990) agree that quality of life may be used to justify discrimination but argue that this is not inevitable. Further, they challenge researchers to study quality of life in ways that emphasise our
common humanity. Similarly, Edgerton (1990) appeals to researchers to stop perpetuating the myth that white, middle class culture is to be cherished by all. Different cultures express their preferences for alternative ways of living and people with disabilities, "like the rest of us, should have the right to strive for satisfaction in life in their own way" (Edgerton, 1990, p. 158).

**Summary of Issues in the Quality of Life of People with Disabilities**

On the whole, despite the mixed findings in the early work regarding large versus small residential settings, research continued to revolve around the setting and, while indicators broadened and increased in number, there was little agreement on which were indicators of quality of life. As a result, the focus on setting and the lack of agreement about indicators spill over into the quality of life models. The models devised by Halpern et al. (1986) and Borthwick-Duffy (1987) explicitly link community adjustment and quality of life while the influence of the community living literature is evident in the models depicted by Brown et al. (1989), Cummins (1991) and Schalock (1993). While Parmenter (1988) and Goode (1988) bring theoretical frameworks to their work, the application of their models is still in the early stages. These latter models, however, appear to fit more with the views of people with disabilities and their families than the other models. Borthwick-Duffy (1990), nevertheless, suggests that whatever quality of life measurement is used for people with disabilities, there must be consideration of the particular issues for people with severe multiple impairments. Further, in any measurement of quality of life, researchers urge caution: no measure should put the lives of people with disabilities at risk.
SUMMARY OF ISSUES IN QUALITY OF LIFE

The debate over what constitutes quality of life continues. There is little consensus about the concept, about what influences quality of life, or about how to measure it. From its beginning as a political slogan, it has grown into being one of the most prolifically researched areas today. This research has primarily taken the form of comparing the 'quality' in the quality of life of different groups of people, using objective measures and, more recently, subjective perspectives.

While there has been little attention paid to the 'life' in quality of life, assumptions, usually implicit, about life, exist in the conceptualisations of quality of life. Different assumptions and values also underpin the selection of indicators of quality of life: health-related quality of life research has implicit assumptions based in utility concepts, while disability-related quality of life research has arisen from pre-formed notions about the virtues of community integration. Given the many differences among researchers regarding indicators, it is unclear which, if any, are measuring quality of life. Indeed, it is wondered whether quality of life can be, or even should be measured.

A large part of the problem with quality of life research is its tendency to be atheoretical (Emerson, 1985; Parmenter, 1988), although theoretical assumptions are always implied. The extensive work done, therefore, lacks direction. The focus of the research is epistemological rather than ontological, on how to measure quality of life rather than on what quality of life is. Discussion of the concept, therefore, "is limited to methodologically difficult but philosophically trivial reliability and validity questions of the various scales ... and to
debates of future measures" (Rosenberg, 1992, p. 76). Tentative efforts
to create a conceptual framework in which quality of life can reside
have been ignored (for example, Bestuzhev-Lada, 1980) or are still in
their early stages (for example, Draper, 1992; Goode, 1988; Parmenter,
1988).

Life for people with disabilities is often one of devaluation and
exclusion. The selection of indicators which presumably reflect
quality of life ignores the history and the differentness of people with
disabilities and urges them to be more like other people, despite
evidence that such a pursuit does not guarantee them a place in
society. Because the differences of people with disabilities are not
valued, quality of society and quality of services are privileged over
the qualities of individuals. Holistic explanations of the lives of
people with disabilities are present in the stories of people with
disabilities, those close to them, and, more recently, some researchers.
These views and experiences are often in conflict with society and
with disability services and, because it is asking society and services to
change, the emerging link between quality of life and quality of care is
fuelling this conflict.

Recently, in the area of disability, questions have been raised
concerning the ethics of studying different groups because of possible
negative outcomes for some groups, such as people with severe
multiple impairments. The inherent message in this debate is that any
quality of life research with people with disabilities must adopt a view
which respects the humanity of people with disabilities and the
different views of individuals.

Despite the growing comparative research, we seem no closer to
a definition of quality of life. Definitions which do exist always
exclude some people. Indicators of quality of life are infinite. The research to date suggests that different aspects of quality of life are important to different groups (Ramund & Stensman, 1988) and to individuals (Taylor & Bogdan, 1990). There is also some evidence to support the notion that quality of life is domain specific (Borthwick Duffy, 1987; Halpern et al., 1986). Alongside these issues is the concern that the dependence of people with severe multiple impairments may affect the conceptualisation of their quality of life (Fretwell, 1990; Janicki, 1990). There may be implications for quality of life related to the extent of disability both in terms of the constituents of quality of life and the method by which those constituents can be identified. The recent suggestions that quality of life for people with severe multiple impairments may have to be defined and measured differently (Borthwick-Duffy, 1990) concur with this view.

The current research on quality of life may have little significance for people with severe multiple impairments. What relevance is there in work and independence for people who cannot initiate movement? What do accommodation and access mean to people who have random and unpredictable awareness of the environment? Referring to people with severe multiple impairments, Lachs (1986) said that more is known about the quality of life than is supposed and that the worth of a life should not be measured by the rare peaks of achievement but by "the tone and temper of its everyday" (p. 95). He claims that although we cannot articulate a defensible concept of quality of life we make complex decisions about it every day and with considerable skill - all the choices that affect our daily life are quality of life decisions in miniature. When Nirje (1969) first described normalisation, he conceived that life should be concerned with the normal rhythms of the day, the season, and the year. It is the
"everyday" which has meaning for people with severe multiple impairments and is therefore probably linked to quality of life.

People with severe multiple impairments cannot articulate their concepts of quality of life. Nurses are the one group, apart from families, who are in constant contact over a long period of time with people who have severe multiple impairments. Schipper et al. (1990) noted that nurses, among others, are, not surprisingly, good at estimating a patient's psychological state. Thus, nurses who are in constant interaction with people who have severe multiple impairments may hold explanations about the meanings of quality of life to individuals in that group.

THE RESEARCH QUESTION

Numerous people with severe multiple impairments remain living in large residential settings yet little attention has been paid to quality of life for this group. On the other hand, researchers working with people with mild disabilities have increasingly addressed quality of life issues by recognising the need to ascertain the perception of quality of life from carers and, more importantly, from people with disabilities themselves. People with severe multiple impairments, however, are not able to communicate their notions of quality of life in the usual way. Nor might its conceptualisation or measurement in the usual way be appropriate for people with severe multiple impairments. This study, therefore, aims to explore quality of life for people with severe multiple impairments by seeking the perceptions held by nurses who work with them.
Chapter Four
THEORETICAL PERSPECTIVE: UNDERSTANDING THROUGH INTERACTION

It is seldom, if ever, easy to understand what any person feels and experiences. But without an understanding of how people with mental retardation view and experience their lives, quality of life becomes at best a hollow concept and at worst a justification for treating them in ways that we ourselves would not like to be treated


Given that I knew that nurse practitioners disagreed with the views of quality of life found in the literature and that their views had not been articulated in any coherent way, the issue for this study became one of finding a theoretical perspective through which nurses' views could be articulated. The only obvious reasons for nurses' different views seemed to be that they interact with people with severe multiple impairments, as opposed to society which excludes them and to disability advocates who are usually only familiar with people who are more able than people with severe multiple impairments. This interaction between nurses and people with severe multiple impairments, therefore, provided the key to a research perspective which identifies interaction as the context for meaning. This chapter, then, outlines the thinking which led to the choice of symbolic interaction to guide the study and the use of grounded theory to analyse the data.

SYMBOLIC INTERACTION

There were a number of methodologies which could have been used to address this research problem. The adoption of a qualitative method in general, and symbolic interaction in particular, in pursuit of an answer to the
research question, was indicated by reference to studies similar to the current investigation - to explore perceptions, meanings, and definitions - where a similar method was adopted. Hutchinson (1984), for example, used qualitative methods in an interpretation of nurses' meanings in their work in neonatal intensive care units, as did Clements, Copeland, & Loftus (1990) in their study of parents' perceptions of specific periods viewed as difficult while caring daily for a chronically ill child. Weinberg (1984), too, used qualitative methods to assess quality of life for people with physical disabilities, an approach supported by Parmenter (1988), who proposes that a quality of life model, derived from a symbolic interaction perspective, has the potential to provide a set of measures which can capture the richness of the concept.

Apart from support from related studies for the adoption of a qualitative method, there are a number of other arguments in favour of this decision. Firstly, the literature review demonstrated that little is known about the concept - quality of life - for people with severe multiple impairments and qualitative methods are particularly appropriate when there is little known about an area of investigation (Field & Morse, 1985; Stern, 1980). Secondly, investigation of the quality of life concept has been largely atheoretical, with much of the research on quality of life being conducted in an "atheoretical vacuum" (Emerson, 1985). This investigation, on the other hand, attempted to remedy that situation by using symbolic interaction as the conceptual framework for the study. Thirdly, this investigation sought to elicit the meanings nurses have about quality of life and symbolic interaction's fundamental assumption is that humans live in a world of meanings where the way inside those meanings is through interaction and interpretation. Moreover, the literature review demonstrated a tendency to mechanically apply pre-formed meanings to quality of life. For people with severe multiple impairments, who cannot articulate quality of life issues, the applicability of pre-formed meanings may be misleading. An
interpretive perspective challenges the mechanistic view of applying pre-formed meanings. Fourthly, the literature suggests that quality of life can be related to the everyday world and qualitative approaches are concerned with the situations of the everyday life world which people construct and give meaning to. Fifthly, qualitative approaches address the ethical concerns regarding the humanity of people with disabilities in quality of life research by respecting the character of the world under study. Finally, a symbolic interaction perspective provides a means of "getting at" the whole reality of nurses' perceptions of quality of life for people with severe multiple impairments, thus enabling the development of a new conceptualisation of quality of life.

Among the diversity of perspectives encountered in qualitative approaches are the interpretive perspectives which are those in which the researcher seeks to understand the meanings that people give to their actions. They are a reaction to a view which assumes that people are more "acted upon" than "acting": interpretivist thinking rejects the scientific explanations of positivist inquiry and aims to understand the meaning of social phenomena (Schwandt, 1994). Rather than studying and explaining human actions entirely in terms of externally perceived events, therefore, interpretivists study and explain social actions in terms of their situations and their meanings to the actors themselves (Douglas, 1970). From an interpretive perspective, the "why" question is replaced by the "how" question (Denzin, 1983): the concern is not with why actions occur but rather with how they occur. The interpretive approaches include symbolic interaction, phenomenology, ethnomethodology, existentialism and, more recently, structuration theory, among others. While there is debate in the literature about whether these perspectives are different and how they are different (see, for example, Denzin, 1989; Gallant & Kleinman, 1983; Malhotra, 1987), all have shared key assumptions. Ryff (in Marshall, 1986, pp. 44-47) provides a list of these assumptions:
1. ... interpretive approaches emphasise a person that is active and intentional. People construct their own meanings and identities: they exercise control over their lives and are guided by internal convictions and goals.

2. ... the emphasis is not just on behaviour but the meaning of behaviour, or action, as constructed by the person.

3. ... human conduct must be understood from the point of view of the person ...

4. ... [there is] a concern for studying the "Lebenswelt", the life-world ... to get away from empty word abstractions and into the world as it is actually experienced ... calls for understanding the world as we actually live in it.

5. The contextual and historical relativity of what we know is emphasised in ... interpretive works ... knowledge about human experience and social structure is time and culture bound ... rather than search for sweeping generalisations about human experience or social structure, we must content ourselves with the unending task of monitoring changing human experiences in changing social worlds.

These assumptions do much towards answering the call from the disability field (for example, Heal & Sigelman, 1990; Taylor & Bogdan, 1990) to attempt to understand how people with severe multiple impairments view their lives. It was necessary, however, to explore the different interpretive perspectives in more detail before finding that symbolic interaction may be able to explain how nurses and people with severe multiple impairments
develop meaning in their interactions with each other. This exploration, and its conclusion, was vital to the acceptance of nurses’ perceptions as valid interpretations of the views of people with severe multiple impairments. The following, therefore, is a more detailed examination of symbolic interaction.

"Symbolic interaction is a theory about human behaviour. In addition, it is an approach to the study of human conduct and human group life" (Chenitz & Swanson, 1986a, p. 4). Symbolic interaction is therefore both a theory and a method. A fundamental assumption of symbolic interaction is that humans live in a world of meanings and they respond to events and objects in terms of meanings they have attributed to these events and objects (Lauer & Handel, 1977). "Symbolic interaction focuses on the meaning of events to people in natural or everyday settings ... [and is] concerned with the inner or ‘experiential’ aspects of human behaviour, that is, how people define events or reality and how they act in relation to their beliefs" (Chenitz & Swanson, 1986a, p. 4).

It is difficult to define what constitutes symbolic interaction as a theoretical perspective. It is not, however, a singular perspective: Denzin (1992) finds as many as thirteen theoretical varieties of symbolic interaction and a dozen methodological approaches. Its proponents believe that symbolic interaction offers the promise of incorporating and integrating other perspectives. In his lecture to the Society for the Study of Symbolic Interaction, Farberman (1991, p. 480) describes the accomplishments of symbolic interaction and points to its future:

Indeed, there is now every reason to believe that, Symbolic Interaction, precisely because of it's (sic) blend of revolutionary political values, Hegelian philosophical values, and pragmatic epistemological values has become the first truly enlightened, post-modern, social science, the very hub into which the redeemable
features of phenomenology, ethnomethodology, ordinary language philosophy, hermeneutics, critical theory, and structuration theory are now beginning to fit, like spokes in a wheel.

There continues to be a high level of activity within symbolic interaction with postmodern theorists (for example, Denzin, 1992; Farberman, 1991; Perinbanayagam, 1985a; Shalin, 1993) debating the perspective in the literature. So while symbolic interaction is not stuck in the past, it is to the past that we turn for an understanding of the perspective. Most of those identifying with the perspective trace its principal origins to the works of George Herbert Mead, a pragmatist and social behaviourist.

**Mead's Contribution to Symbolic Interaction**

Mead's lifelong work was the development and elaboration of the pragmatist theory of mind. He posed the classical sociological question: how is society possible? (McPhail, 1989). His thinking, which stressed developmental change rather than structural constancy, was said to have been chiefly influenced by Darwin's evolutionary theory, although Manning (1989) claims that Mead's "I" was a reworking of Bergson's "élan vital", and Meltzer, Petras, and Reynolds (1975), and Mead (1934) himself, note the influence of Wundt's theories of the gesture. Mead's contemporaries included Peirce, James, Dewey, Cooley and Thomas, pragmatists who "stepped out of the world of academe into the world of practical affairs" (Farberman & Perinbanayagam, 1985, p. 3) and no doubt influenced each other's thinking.

Darwin advanced the notions of adaptation and adjustment. The impact of Darwin's naturalistic, evolutionary theory was to allow consciousness (or mind) to move from the philosophical and abstract to
within the reach of naturalistic observational methods (Franks, 1985b, p. 30) and the pragmatists have undertaken the task of reinterpreting the concepts of mind in biopsychosocial terms following Darwin's groundbreaking theory. In the introduction to Mead's (1934) work, its editor, Morris, affirms that this undertaking, while not complete, has achieved "a naturalism which sees thinking man (sic) in nature, and which aims to avoid the inherited dualisms of mind and matter, experience and nature, philosophy and science, teleology and mechanism, theory and practice" (p. x).

The written history of pragmatism belongs to James (whose influence is found in phenomenology) and Peirce (whose thoughts are the foundations of semiotics). While there are many forms of pragmatism, it is "a humanistic movement in philosophy whose proponents sought to undercut the extremes of classic rationalisation through the renewed emphasis on the role played by humans in the production of reality as objective and meaningful" (Shalin, 1991, p. 224). Farberman and Perinbanayagam (1985) state that while James and Peirce did not always agree, their great achievement was to transform the principle of antecedents to the principle of consequences, that is to move from the "why?" to the "how?" Denzin (1992), however, attributes this transformation to Dewey who held that "truth and meaning lie in the consequences of an action that receives confirmation or verification in practical, or experimentally controlled, situations" (p. 6). Denzin further says that Mead aligned himself with Dewey's instrumentalism (or experimentalism) against James' phenomenology but, while Dewey and James were cultural pragmatists, Mead's pragmatism was political - aligned with a politics which sustained a liberal-minded version of the status quo.

It is often said that Mead published no systematic version of his theories. While this is so, Lowy (1986) points to Mead's seventy five published articles and four posthumous texts collected from his notes and correspondence made during the four decades in which he taught and
formulated his theory. Baldwin's (1989) reading of Mead's works led him to conclude that Mead constructed "a unique and distinctive theory that unifies evolution, physiology, socialisation, mind, self, behaviour, micro-social interaction, and macro-societal structure" (p. 54).

The aspects of Mead's work that are generally considered to have had an influence on symbolic interaction include his theories of the act, self, society, mind and emergence. Mead posited that mind (or meaning) emerges from the interaction between self and society. He disagreed with Wundt's theories of the origins of society, which were based on the presupposition of the existence of individual minds. Mind, he argued, develops out of an existing process of social interaction, and that development is dependent on reflexiveness - the turning back of the experience of the individual upon self (Meltzer et al., 1975). According to Mead (1934), the self, as well as the mind, emerges in the social process. He is clear that the body is not a self: it only becomes a self when it has developed a mind in the context of social experience. Mead's self, then, is embodied meaning. It is a social object in the field of experience and is structured by taking the attitude of the other (Denzin, 1992). It is a dialogue between the "I" and the "me".

Farberman (1985) most coherently gives an account of Mead's "transformative breakthrough" in the approach to social psychology. It is James, Farberman reports, who first identified two distinguishable aspects of self: "I" - the self as knower, and "me" - the self as known. Cooley went on to argue that James' ideas suggested the illusion of a personal identity (individualism) and that the self lives in the interaction between people. His "looking glass self" describes the self arising in one's own imagination of others' imagination of one (mentalism). Mead rejected both James' individualism and Cooley's mentalism and proposed a theory of "self" and "mind" as inherently social and behavioural and consequently open to external (intersubjective) examination. Perhaps the most basic element in the
interactionist image is the idea that the individual and society are inseparable units:

The behaviour of men and women is 'caused' not so much by forces within themselves (instincts, drives, needs, etc.), or by external forces impinging on them (social forces, etc.), but [by] what lies between, a reflective and socially derived interpretation of the internal and external stimuli that are present (Meltzer et al., 1975, p. 3).

This was the basis of Mead's (1934, 1938) integral philosophy of the act: mind (or meaning) connects to other (objects) in the world through social behaviour (the act) and therefore, the ideal unit of analysis is the behavioural act. This behavioural act is not the behaviourism of Watson, who "sought to expunge all references to psychic phenomena from psychological discourse" (Shalin, 1989, p. 37) but it is a behaviourism which gives primacy to action over thoughts and rejects the introspection of the psychoanalytic theories (Denzin, 1992; Shalin, 1989).

Mead's (1938) act has four stages: impulse, perception, manipulation and consummation. Impulse refers to inner impulses for survival; perception uses the senses to selectively attend to objects in the environment; manipulation consists of moving towards, or away from, perceived objects to analyse them; and consummation is a thorough examination of the object. These stages occur in what Mead calls the inner and outer phases of the act. Impulse and perception form the inner phase, and manipulation and consummation the outer phase.

Farberman (1985) again provides an illuminating description of the phases of Mead's act. The act has both inner and outer phases, the inner being the beginning of the outer phase. The inner phase consists of physiological mechanisms, tendencies of response and imageries, and the
outer phase of natural and symbolic gestures. The inner and outer phases connect in the attitude, or incipient act, which can be conceptualised as an inner mobilisation of energy preparatory to the external act, which sometimes may be observed in the gesture. Of particular interest to this study involving people in non-speech interactions is that,

"where incipient actions are observable, interaction between people is facilitated as each individual can make appropriate adjustive responses to others and, also, anticipate the adjustive responses of others ... If the goals that are carried in the incipient action of the actor can be apprehended by other, then other can make some kind of approximation of how actor will behave ..." (Farberman, 1985, p. 23).

The assumption of other people's future actions underlies and allows for social organisation. Thus emerges an action logic which, when understood by others, becomes the basis of meaningful response. This, according to Mead, is only possible through symbolisation. "Gestures become significant symbols when they implicitly arouse in an individual making them the same responses which they explicitly arouse, or are supposed to arouse, in other individuals" (Mead, 1934, p. 47). The interpretation of symbolism is only possible by taking the role of the other, by, in Mead's terms, placing oneself in the attitude (incipient act) of the other. Nursing is not unfamiliar with taking the role of other in its practice. Mead's theory, therefore, suggests that nurses observe the gestures (incipient acts) of people with severe multiple impairments, take the role of the person with severe multiple impairments, interpret the symbolism and adjust their responses.

Blumer's Contribution to Symbolic Interaction
The acquaintance with Mead's works has come through the teaching and writings of his best known student, Herbert Blumer, who coined the term "symbolic interactionism" in 1937 to describe his methodology (Blumer, 1969). This methodology, according to Denzin (1992), was defined by Mead's pragmatism but Baldwin (1989) cautions readers that there are major differences between Mead and Blumer, primarily arising from their differing opinions regarding empirical methods: Blumer's method of naturalistic inquiry is sceptical of the experimental methods of pragmatism.

The purpose of Blumer's (1969) classical text on symbolic interaction was to outline the nature of symbolic interaction and to contrast the methodological position of symbolic interaction with that of empirical science. Symbolic interaction rests on three basic premises: firstly, humans act towards things on the basis of the meaning that those things have for them; secondly, the meaning of such things is derived from, or arises out of, social interaction with other humans; and thirdly, these meanings are handled in, and modified through, an interpretive process used by humans in dealing with the things they encounter (Blumer, 1969).

These premises suggest that nurses' speech acts regarding quality of life for people with severe multiple impairments are based on the meanings that quality of life for people with severe multiple impairments have for them; that nurses' meanings arise out of social interaction with people with severe multiple impairments; and that nurses' meanings of quality of life for people with severe multiple impairments are not present at the outset, but are modified through an interpretive process used by nurses in dealing with the lives of people with severe multiple impairments.

Similarly, the meaning of quality of life for people with severe multiple impairments is not an external phenomenon imposed on nurses - meaning emerges from interaction with people with severe multiple impairments. In
the interpretative process, nurses take the role of people with severe multiple impairments and interact with themselves to modify or change their definition of the situation. As Meltzer et al. (1975, pp. 26-27) state: "the concept of the definition of the situation implies ... that the past and the future are often defined with respect to an emergent present ... the 'real' facts are the ways in which different people come to define situations". Thus the meanings that guide action arise in the context of interaction via a series of complex interpretive procedures.

Blumer (1969) describes six basic ideas or images on which symbolic interaction is grounded and which together represent the way in which symbolic interaction views human society and behaviour. Summarised, this view is that human society exists in action and this action is the starting point for analysis of society. Social interaction which constitutes society is significant in its own right: it is the process which forms individual and joint behaviour and occurs through non-symbolic and symbolic interaction. "Worlds" are composed of "objects" - anything which can be indicated or referred to - and are the products of symbolic interaction. Each person's "world" has its own "objects" which may or may not be shared with other people, and changes in "objects" are reflected in changes in individual's behaviours. Thus, humans interpret their worlds and construct their actions based on that interpretation, both individually and collectively. Joint action is an interlinkage of the separate acts of the participants, which, even in its well-established and repetitive forms, is formed anew in each instance of it.

The implications of this are that social life creates and upholds the rules, not vice-versa; social institutions are created through joint action; and joint action is related to previous actions, that is, it has a history. Thus, from a symbolic interaction perspective, nurses and people with severe multiple impairments are involved in a social life which uses joint action to create and
re-create itself. This action is therefore the starting point for analysis of that social life and its meaning.

This action also “takes place in and with regard to a situation ... [and]... the action is formed or constructed by interpreting the situation” (Blumer, 1972, p.151). The actor has to identify aspects of the situation, assess them and make decisions about their actions. According to Blumer (1972), symbolic interaction requires the researcher to capture this process of interpretation which W. I. Thomas (Thomas & Znaniecki, 1918; Thomas, 1972) called the definition of the situation. Definitions of situations are not fixed but rather, dependent on the interpretations of particular people in particular interactions (Daniels, 1972). Therefore, the task of this research is to capture nurses’ definitions of situations in regard to quality of life for people with severe multiple impairments.

**Further Developments in Symbolic Interaction**

Developments in symbolic interaction since Mead and Blumer have been extensive. A number of papers (for example, Denzin, 1992; Kuhn, 1964; Maines, 1986) provide interesting descriptions of the building of theory, the impact of postmodernism, changes in methodology, and substantive contributions made by this perspective. Rather than deliberate on all of these changes, this section turns to those developments of particular interest to this study.

One of the potential criticisms of this work could be the reliance on meaningful interaction between nurses and people with severe multiple impairments. Given that people with severe multiple impairments do not use language and are usually considered to have severe cognitive deficits, it became important to find some theoretical explanations of how nurses and
people with severe multiple impairments communicate. Several ideas emerged from my reading of the symbolic interaction literature. Firstly, it has been postulated that communication may involve language but that the meaning is inherent in the situation. Secondly, it has also been suggested that meaning is communicated not only through language but also through various other methods, for example, gesture, facial expression, in fact, any instance of human conduct. Thirdly, some theorists argue that meaning is linked to the body and emotions. Fourthly, many agree that communication and meaning exist within the context of knowing the other and knowing the situation - what is taken for granted. The emergence of these ideas, as central to the constructed integrity of this thesis, is traced in the following sections.

Meaning is Inherent in the Situation

Mead (1934) explicitly says that meaning can be found in language, but language "simply lifts out of the social process a situation which is logically or implicitly there already" (p. 79). Meaning, he says, "arises through communication by a conversation of gestures in a social process or context of experience" (Mead, 1934, p. 52). Gestures are the phase of the act - the incipient act - which brings about the adjustment of the response of the other. The adjustive response of the other is the meaning of the gesture. Similarly, Perinbanayagam (1985b) states that if gestures are successful in eliciting the required interpretation, it is because they can be connected by any individual to certain universal experiences of the members of a community. The entire gamut of gestures from the actor connect with each other to convey messages to the other to aid the other in taking the role of the actor, just as the verbal and non-verbal gestures from the other enable the actor to take the role of the other.
How Meaning is Communicated

Mead (1934) argues that there is the language of speech, of hands, of expression of the countenance, and of contact (touch). Symbolism is not simply language, it is any aspect of human action. This is not a new idea but language has been so privileged in the work of symbolic interactionists that Stone and Farberman (1986) prefer to use the term communication. They argue that language is social and that the meaning of language arises, is maintained, and changes in communication, another term for symbolic interaction. They credit Freud with the contribution that any instance of human conduct may be construed as symbolically significant. They also note that the actor may or may not be aware of the symbolism: in any interaction, the actor presents or gives off symbolism to which the other responds. The notions of "presents" and "gives off" draw on the work on awareness and out-of-awareness contexts (Glaser & Strauss, 1986) and suggests that there is symbolism of which the actor is aware, and so, presents, and symbolism of which the actor is unaware and, thus, is given off. The response from the other is also symbolic and may be presented or given off.

Links with the Body and Emotions

For Travisano (1993), heavily influenced by Foucault, meaning is not verbal but sensate. It is to be found in connection, not in comment on connection. Travisano argues that meaning is in response and response at base is sensate, not symbolic. He says that symbolic interaction has been caught in its own tradition with a resultant overemphasis on the symbolic, when meaning is basically a matter of our bodies. Similarly, Stone and Farberman (1986) think that taking the attitude of the other has an affective component. Indeed, Mead (1934) prefigured this notion in saying that
gestures are expressions of emotion, but then went on to almost exclusively focus on the idea behind the gesture.

A number of researchers are exploring body-emotion relationships and their links with interaction (Denzin, 1992; Franks, 1987; Scheler, 1986). Shott's (1979) work is particularly useful in illuminating "physiological empathy", one of Stone and Farberman's (1986) "empathetic processes". Physiological empathy is a process whereby the expressed emotion emerges from sensation in the body of the actor and the other's perception of this expressed emotion results in a sensation in the body of the other.

**Knowing the Other and Knowing the Situation**

Role taking, according to Stone and Farberman (1986), occurs within the context of knowing the other and knowing the situation, what Altheide and Johnston (1992) refer to as tacit knowledge. Tacit knowledge includes what actors know, take for granted, and leave unexplained and may also include deep structures from the "emotional memory" of past generations. Schutz and Luckmann (1973) argued that, as personal relationships become more tacit, people feel more intimate, feel that they know the other. This knowing, according to Stone and Farberman (1986), is situated in communication where verbal communication has three dimensions of silence: appearance, situation, and circumstance. Appearance draws on Stone's (1986a) work which attempts to show that the self is established, maintained, and altered in interaction as much by the communication of personal appearance as by conversation. Appearance and situation are "read" by the other and they may be more than an existing "scene or arrangement of things in our environment" (Morriione, 1985, p. 163): they may be presented or staged, an idea adopted from Goffman's (1969) work on the presentation of self. In this regard, the collected work on strategic interaction tells of how people
negotiate social constraints by tactics such as bargaining, demeanour and reputation as well as spaces, props, clothing and body (Maines, 1986).

Halas (1985), too, makes some interesting contributions to the concept of situation: she notes that there is no agreement among symbolic interactionists as to what a situation is. It is not, she says, a setting but is constituted by those aspects which are important to the actor, a notion reminiscent of Mead's (1938) "selective attention" in the stage of impulse in the act, and of Glaser and Strauss' (1966) awareness contexts. A situation, then, is a metaphorical scene where time and space can be altered by the actor (Brittain, 1973).

Stone and Farberman (1986), drawing on Stone's (1986b) work on the nature of social status, add that situations occur in larger contexts which they have called circumstances. Circumstances often operate in out-of-awareness contexts and are the taken for granted aspects of interaction.

These theoretical explanations of the communication of meaning lend some credibility to my own, by now, explicit position. Interactions between nurses and people with severe multiple impairments are meaningful since they suggest that nurses do not rely on language alone but also utilise non-speech communications, and the context in which these interactions occur, that is, nurses know the person and the situation. For the researcher to explicate this tacit knowledge, a suitable methodology must be found. I now turn to methodological developments in symbolic interaction to provide the background to my choice of grounded theory to guide the data process.

**Methodological Developments**
Denzin (1972) proposed seven principles demanded by the interactionist perspective to guide research using its methodology. The last of these principles is most relevant to this thesis: begin with a loose definition of the topic under study until the participants give meaning to it, test the common meanings, generalise the examples in the context to all contexts to arrive at formal theory and verify universal interactive propositions, not numbers.

This principle connects theory to method and calls for interaction between the researcher and people who share meanings about the research question. Further, this principle requires a "way of thinking" in the approach to those interactions, during those interactions and throughout the interpretation of the emerging meanings. Despite Denzin’s (1972) principles, however, these and others are so loosely defined that nearly all methods and techniques are represented in symbolic interaction studies (Maines, 1986).

One methodology, which developed from the Chicago tradition of symbolic interaction and is more clear about its methods of data analysis, if not its methods of data collection, is grounded theory. It is seen as a major contribution to the development of methodology, with its effort to close the theory-practice gap (Maines, 1986), and is currently recognised as one of the major approaches in nursing research (Lowenberg, 1993).

**GROUNDDED THEORY**

Originally developed by Glaser and Strauss (1967), grounded theory has come to the attention of and use by nurses through Glaser and Strauss who supervised students in the School of Nursing at the University of California. It is particularly useful for research where concepts have not been developed since, instead of starting with a theory, it allows concepts relevant
Grounded theory is characterised by a systematic collection of data and concurrent analysis, the methods of which have been refined over time. Lowenberg (1993), however, points out that as nursing, in its "scientific" quest, uses more and more systematic methods, other disciplines are moving toward (or back to) less structured work. She goes on to say that part of the reason for nursing's present direction is that excessive attention is paid to technique and insufficient attention to epistemological assumptions. She further states that too many nurses using grounded theory cite Blumer, and the early work in grounded theory, and ignore the developments since that time. In response to her criticisms, this chapter has explored the developments in symbolic interaction, and now turns to epistemological assumptions as well as recent developments in grounded theory.

Nursing epistemology is the study of what nurses know, how they come to know what they think they know and the criteria for evaluating the credibility of that knowledge (Schultz & Meleis, 1988). Symbolic interaction suggests that nurses define the situation (what they know) through interaction with others and through interpretation of that interaction (how they know). Further, their actions (what they do and say) are based on their definition of the situation. Through use of the methods of symbolic interaction, researchers attempt to observe and participate in what nurses do.

to the research to emerge. Nursing has little in the way of substantive theory that explains the everyday world of its work with people, thus grounded theory offers a way to do this (Hutchinson, 1986). According to Stebbins (1972), symbolic interaction researchers, interested in the definition of the situation, should develop grounded theories of recurrent definitions, such as quality of life for people with severe multiple impairments, by studying the definitions of situations of those in a given identity, such as nurses. He claims that such studies provide a theoretical link to the structure of society, enabling an analysis of the findings at the macrosociological level.
and say in order to uncover what they know and how they know it. Thus, symbolic interaction allows researchers to articulate the knowing in the doing, to make the tacit explicit while the criteria for the credibility of that knowledge includes validation by nurses.

Historically, emergence of the initial work on grounded theory was twofold. Firstly, according to Stern (1994), Glaser and Strauss, unable to get at meanings in the research that they were conducting, tinkered with their methods until they worked. Secondly, their grounded theory text arose out of a recognition that other researchers, equally bereft of effective methods, might benefit from this contribution. From there, Glaser (1978) elaborated on theoretical sensitivity. Stern (1994) notes that the demise of the partnership between Glaser and Strauss coincided with Strauss and Corbin's (1990) publication on grounded theory which was met with Glaser's (1992) subsequent publication on the differences between his and Strauss' approaches.

Of course, I knew nothing of this impending split when I commenced this present study in 1988. I found Glaser and Strauss' (1967) work virtually impenetrable and relied heavily on Chenitz and Swanson (1986b), supplemented by two examples of grounded theory research: those of Strauss (1975) and of Christensen (1988, 1990). Glaser (1978), Hutchinson (1986) and Strauss (1987) added little to my understanding while the clarity and coherence of Strauss and Corbin's (1990) publication served as a useful guideline. Stern (1994), however, identifies the essential difference between Glaser and Strauss' approach to data: she says that Strauss asks the data "what if?" while Glaser asks "what do we have here?" Having been introduced to what I now know as the Glaserian approach at a NUDIST workshop conducted by Lyn Richards in 1991, and having used that approach in this work, I have come to realise the pitfalls associated with
trying to "do" grounded theory from reading about it (Morse, 1991) and strongly support Stern's (1994) admonition to find a mentor.

**SUMMARY**

An interpretive perspective challenges the assumptions concerning quality of life found in the literature review since this perspective is open to the meanings people give to their experiences. Symbolic interaction, in particular, "gets inside" the reality of the actor in an effort to understand the reality as the actor does (Meltzer et al., 1975). Central to understanding this reality are the range and variety of symbols and symbolic meanings shared, communicated, and manipulated by interacting individuals in social situations through language, non-verbal gesture and manner of speech. Clearly this requires the researcher to talk with and observe people who share meanings about quality of life for people with severe multiple impairments. Grounded theory offers a way for these conversations and observations to be analysed so that a conceptualisation of quality of life for people with severe multiple impairments might be formulated. It is to this method that the following chapter turns.
Chapter Five

METHOD: UNDERSTANDING QUALITY OF LIFE

It is a disservice to individuals with mental retardation to "slap together" a measure and simply hope for the best. Developing any reliable and valid quality-of-life measure requires considerable effort, effort that promises to result in a fuller understanding of the lives [emphasis mine] of developmentally disabled citizens

(Heal & Sigelman, 1990, pp. 174-175).

So far, this thesis has presented four ideas. Firstly, my experience as a specialist developmental disability nurse led me to believe that nurses in this field have a unique view of quality of life for people with severe multiple impairments. Secondly, the lives of people with severe multiple impairments are different from the lives of others. Thirdly, while much of the quality of life literature influences the lives of people with severe multiple impairments, it may have little meaning for them. Finally, symbolic interaction is a perspective which will assist in understanding the view of nurses.

This chapter, then, outlines how the symbolic interaction perspective was used to uncover nurses' meanings of quality of life for people with severe multiple impairments. The study was conducted in two stages, the second stage being an outcome of the initial analysis at the conclusion of the first stage. The chapter outlines the procedures I used, with particular attention to the data collection techniques of indepth interviewing and participant observation, and to the grounded theory method of data analysis.
Blumer's (1969) explanation of the method of symbolic interaction was used to guide this study. He says that the way to study the world is through the use of naturalistic inquiry which employs exploration (or depiction) and inspection (or analysis).

Exploration is "a flexible procedure in which the scholar shifts from one to another line of inquiry, adopts new points of observation as his [or her] study progresses, moves in new directions previously unthought of, and changes his [or her] recognition of what are relevant data as he [or she] acquires more information and understanding" (Blumer, 1969, p. 40). Thus, exploration implies an initial broad focus which narrows as the research progresses. No particular technique is prescribed, but rather the researcher responds to the data and uses techniques which have the most likely success of finding an answer to the research question. These techniques may include interview, observation and document perusal. While no particular procedure is advised, there are some important points to consider: participants should be well-informed; researchers need to constantly revise their images in response to the data; and the picture of the topic under study should be as accurate and comprehensive as possible.

Inspection, on the other hand, lifts the study to the level of analysis and is "an intensive focused examination of the empirical content of whatever analytical elements are used for purposes of analysis, and this same kind of examination of the empirical nature of the relations between such elements" (Blumer, 1969, p. 43). By analytical elements, Blumer means any general or categorical items used as key items in an analysis. In the case of quality of life, general items may be physical well being and emotional well being, and categorical items would include health and relationships. Blumer says that such elements may refer to processes,
organisation, states of being, happenings, and so on. The procedure of inspection consists of examining the analytical scheme by viewing it from different angles and asking many different questions of it. The researcher must go to the empirical instances of the analytic scheme to do this. Like exploration, inspection has no fixed rules about its procedure. It does not operationalise its analytical elements but rather discovers the nature of the elements by inspection of empirical instances. It also uses empirical instances to validate relationships of analytical elements in the empirical world.

**PROCEDURES**

As already noted, this study was conducted in two stages. The following procedures, therefore, represent both stages of the study, differentiated only when clarity is required. The remainder of this chapter outlines: (a) setting, (b) participants, (c) protection of participants’ rights, (d) entry to the field, (e) data collection, (f) data analysis, (g) rigour, and (h) leaving the field.

**Setting**

The location of the field depends on what is to be sampled (Strauss & Corbin, 1990). Given that I wanted to sample concepts related to nurses’ perceptions of quality of life for people with severe multiple impairments, the setting for the study comprised residential units of three large centres in New South Wales where nurses work with these people. While I had initially intended to include all four residential centres in New South Wales where nurses work with people with severe multiple impairments, the analysis of the data determined that three were sufficient.
Participants

A total of sixteen registered nurses, fifteen female and one male, participated in the study, their education and experience qualifying them as informed participants (Blumer, 1969; Morse, 1991; Taylor & Bogdan, 1990): they all held a Mental Retardation Nursing Certificate or equivalent, eleven held additional nursing qualifications and four were pursuing tertiary qualifications; the participants had been registered nurses for at least five years and for as long as thirty-one years, their experience working with people with severe multiple impairments ranging from one to twenty-five years.

Ethical considerations

The major ethical consideration of the study was sensitivity to the particular concerns for people with severe multiple impairments generally, and in any quality of life study in particular, as discussed in Chapter Three. These concerns were managed in two ways. Firstly, the symbolic interaction perspective, which respects the world under study, was used in this investigation. Secondly, in the absence of Department of Community Services ethics committees at the time, letters of approval for the conduct of the research were received, prior to commencement of the study, from the Directors of Nursing who were legally responsible for the welfare of people in their care who were unable to give informed consent.

The second ethical consideration involved the rights of the nurse participants to informed consent. In order to obtain informed consent, all participants were given an information sheet outlining: the purpose of the
study, the nature of the research method, the time commitment involved, the benefits and risks of the research, and an explanation of confidentiality and of freedom to withdraw (Appendix I, II). An initial interview was held with all participants to clarify these issues prior to their signing an informed consent form.

This project was submitted to the Cumberland College of Health Sciences, The University of Sydney's Ethics Committee and approved in November, 1990 (Approval Number CCHEEC 90/104). The committee applauded the information sheet and suggested two additions: a statement advising participants that they need not answer any questions which they find distressing or are an invasion of their privacy; and a statement regarding the storage of data. These suggestions, included in the information sheet prior to the study, highlighted the participatory nature of research and led me to two further considerations in this regard: participants' control of the researcher's records, and the dubious guarantee of anonymity in small studies.

Minichiello, Aroni, Timewell and Alexander (1990, p. 134) state that "tape recording is one means of obtaining a full and accurate record of the interview. It can enhance greater rapport by allowing a more natural conversational style. The interviewer is free to be an attentive and thoughtful listener. The raw data remains on the record". Nevertheless, Minichiello et al. (1990, p. 135) warn that "problems with tape recording include potential inhibition in the interaction, the feeling that once something is on tape it is indelible and cannot be refuted leading to a possible imbalance in the interaction because of the interviewer's perceived greater power". Participants were, therefore, given control of the recording device in an attempt to redress the balance of power: they could turn it on and off as they wished, which they often did. Participants also were told that they were welcome to read my notes, but only one took up the offer.
I noted, during the study, that the issue of privacy is more complex than I had anticipated. While I was determined to disseminate this work in a manner which ensured the anonymity of individuals, I did not count on the difficulty with anonymity among the participants. There were, for example, group interviews held with the participants who had previously given individual interviews. During those group interviews, it was vital to focus on issues in a way that individuals in the group would not be identified. Further, during the observation period, when there were only three participants, each of whom had access to my notes, any given participant had a fifty-fifty chance of identifying the words or actions of another participant. Therefore, like Kearney (1996), I would be more precise about anonymity in future information sheets.

**Entry to the Field**

Access to the field involves negotiating with the gatekeepers (Wilson, 1989). For this reason, permission to conduct the research in each centre was sought from the Directors of Nursing prior to speaking with the nursing staff. The research was then explained to the Nursing Unit Managers who were asked to talk with the Registered Nurses about the research in order to recruit volunteer participants. The Nursing Unit Managers were also asked to distribute the information sheets to potential participants at both stages of the study.

Part of entering the field is establishing a research role in negotiation with the gatekeepers and with the participants (Wilson, 1989). As I am well known to the staff of the centres, establishing a research role was complicated by my previous roles: for many staff, I had been their nurse educator ten to fifteen years before; for a few staff, I had been a student
nurse who had entered a Mental Retardation Nursing conversion programme from a background of Psychiatric and General Nursing; for some staff, I was a relative because my brother lives in a residential unit which was not involved in the study, my mother has long been heavily involved with the Parents and Friends Association, and my sister had previously worked at one of the centres; and, for the remainder, I was a university lecturer who taught students from an undergraduate nursing programme.

These previous roles worked for and against my research role at different times, but, overall, had a positive effect. An instance of difficulty was encountered, for example, when I was pursuing a participant's knowledge base for a particular interaction: she replied that I should know because I taught her. I explained that she was the practitioner and I was seeking her reasons for her clinical behaviour. She obliged when she felt comfortable that she was the expert, not I. In relation to my "relative" role, I was asked in that capacity by several nurses for my thoughts regarding the Department of Community Services' current transition plan (a ten year plan to integrate residents of large centres into the community). This reflected a greater appreciation of the opinions of relatives than I have previously experienced from nurses. It also gave me an opportunity to add to this study by asking their opinions about the relationship of the transition plan to quality of life for the residents.

Because I was primarily involved with a limited number of participants (those who met the criteria for participants), it was important not to exclude other staff. To this end, I ensured that the information sheet was available to all and listened when non-participants engaged me in their conversations. Most importantly, I continued throughout the period of the study to reinforce my role as researcher.
Data Collection and Analysis: An Overview

In qualitative research, data collection and data analysis occur concurrently. This section, therefore, outlines the data collection methods of indepth interviewing and participant observation, as well as the grounded theory method of data analysis. This overview provides justification for the use of these methods and precedes an outline of how they were used in this study.

Indepth Interviewing: An Overview

One of the major methodological approaches of symbolic interaction is the use of interviews to "get at" meanings. Denzin (1983, p. 132-3) said that:

Every human situation is novel, emergent, and filled with multiple, often conflicting, meanings and interpretations. The interpretivist attempts to capture the core of these meanings and contradictions. It is assumed that the language of the life world can be used to explicate its own structures.

Morgan supported interviews to "get at" meanings, because the processes engaged in during interviews allow a renewed understanding: "... in conversation, as in research, we meet ourselves. Both are forms of social interaction in which our choice of words and actions return to confront us in terms of the kind of discourse or knowledge that we help to generate" (Morgan, 1983, p. 406).

Minichiello et al. (1990) also advocated the use of indepth interviewing to access words and interpretations. They agreed with Taylor
and Bogdan (1984) who said that indepth interviewing is "repeated face-to-face encounters between the researcher and informants directed toward understanding informants' perspectives on their lives, experiences or situations as expressed in their own words" (p. 77). In support of indepth interviewing as an appropriate method Minichiello et al. (1990) said:

If social reality exists as meaningful interaction between individuals then it can only be known through understanding others' points of view, interpretations and meanings. If meaningful human interaction depends on language, then the words people use and the interpretations they make are of central interest to the researcher (p. 100).

Oakley (1981) stated that a non-hierarchical relationship, where the interviewer is prepared to invest their personal identity in that relationship, has success in finding out about people. She added:

It requires, further, that the mythology of 'hygienic' research with its accompanying mystification of the researcher and the researched as objective instruments of data production be replaced by the recognition that personal involvement is more than dangerous bias - it is the condition under which people come to know each other and to admit others into their lives (Oakley, 1981, p. 58).

This approach is important in both individual and group interviews. In group interviews, particularly, it is the researcher's responsibility to create a secure and trusting climate for participants (Peters, 1993). Such a climate encourages expression of ideas and opinions which are the basis for the primary purpose of group interviews: the building upon responses of other members (Minichiello, Aroni, Timewell, & Alexander, 1995).
Indepth interviewing, therefore, could uncover the meanings which nurses held about quality of life for people with severe multiple impairments. In non-hierarchical conversations with nurses, I could listen to their words and interpretations in a way which could discover their perspectives. As the study progressed, however, it became evident that indepth interviewing was only sufficient for a descriptive account of nurses’ perspectives. In order to develop a conceptual understanding of their perspectives, therefore, I turned to participant observation.

**Participant Observation: An Overview**

According to Atkinson and Hammersley (1994), the definition of participant observation is somewhat elusive. Similarly, Adler and Adler (1994) remark on the variety of approaches utilised in observational research, dependent on the practitioners, the stage of a given research project and the relationships of the researchers to the participants. The initial descriptions of these different approaches to observational research can be traced to Gold (1958) who developed the classic fourfold typology: complete observer, observer as participant, participant as observer, and complete participant. The complete observer observes without participating in the social scene; the observer as participant primarily observes “subjects” for brief periods of time while interviewing them; the participant as observer observes and interacts closely enough with the participants to establish an insider’s identity without necessarily participating in the core activities of the participants nor adopting their values and goals; and the complete participant observes in scenes where they are already participants, or where they come to adopt the values and goals of the participants. The observational approach which is most consistently used by symbolic interactionists is the participant as observer, or more simply, the participant observer. Participant observation has strong theoretical roots in the symbolic interaction perspective; symbolic
interactionists want to gather data from their participants while interacting with them (Adler & Adler, 1994).

Turning then to symbolic interaction, Blumer (1969, p. 37) defined observation as "getting close to the people involved in it, seeing it in a variety of situations they meet, noting their problems and observing how they handle them, being party to their conversations and watching their way of life as it flows along". But how was I to do this? Hughes (1992) provided some links with my aim. He said that participant observation depends on the researcher using the senses and cognition as data-gathering tools and "being there, participating (in some acceptable role) in the social scene" (Hughes, 1992, p. 444). Conversations are open-ended with the researcher asking questions "when they are appropriate and when there is something to ask about" (Hughes, 1992, p. 444). "The distinctive feature of this [participant observation] method resides in its ability to grasp the symbolic nexus between thought and action in a particular social milieu" (Schwartz & Merten, 1971, p. 281). Similarly Schwartz and Merten (1971) state that the participant observer focuses on the way the definition of the situation is embodied in the meanings participants give to their actions. Thus, meaning cannot be attributed to actions until the observer asks "Why did you do/ say that?".

These processes of participant observation need to be conducted within a theoretical framework because the researcher "must have a perspective that will help him [or her] see relevant data and abstract significant categories from his [or her] scrutiny of the data" (Glaser & Strauss, 1967, p. 3). While observations and conversations may be structured or unstructured (Burns & Grove, 1993), symbolic interaction calls for unstructured observations and conversations because research aimed at discovering explanations, requires a data collecting technique which maximises the possibility of discovery (Becker & Geer, 1982). Nevertheless,
without a schedule for conducting the observations and conversations, the researcher has to decide on how to record the data. In this regard, three types of notes are recommended: observational (substantive), theoretical (analytic), and methodological (Burgess, 1982; Wilson, 1989), which respectively record the researcher’s observations, ongoing analysis, and methodological issues.

Guided by the symbolic interaction perspective, I was able to be a participant observer in the social life of nurses and people with severe multiple impairments. Conversations associated with particular interactions were unstructured but the three types of note-taking were highly structured. These data collection methods of conversations and notes assisted the development of conceptual understandings of nurses’ perceptions of quality of life.

**Grounded Theory: An Overview**

As with data collection, symbolic interaction has no fixed rules regarding data analysis. As a result, it is often unclear how researchers analysed their data, which, once again, leaves the beginning researcher floundering. Grounded theory, however, does offer a structured way of analysing data.

The aim of grounded theory is theory generation from the data: the researcher looks for the processes involved during interviews and observation from which theory emerges (Stern, 1985, 1994). The sequence of steps in grounded theory are different from those of other research approaches (Bowers, 1988) because the process is not linear and involves simultaneous literature review, hypothesis generation, data collection and
analysis. Moreover, ongoing analysis directs the researcher's questions and sample selection.

Grounded theory’s method of constant comparative analysis (Hutchinson, 1986) uses three levels of coding to develop theory: open, axial and selective coding (Strauss & Corbin, 1990). **Open coding** identifies and develops concepts by asking questions of the data and comparing instances of data, for example, “What is this?”, “Is it the same as or different from?”. Similar instances are grouped into categories. **Axial coding** uses the same processes to relate categories. This process is enhanced by the use of Glaser’s (1978) theoretical codes, often referred to as "the six c’s" (Swanson, 1986) - causes, contexts, contingencies, consequences, covariances and conditions - or by what Strauss and Corbin (1990) call the paradigm model. Thus, each instance is examined, using the six c’s, to find the relationships of categories to each other. **Selective coding** involves selection of a core category, or basic social process (Fagerhaugh, 1986), which integrates all the categories and conceptualises the story.

Sampling in grounded theory is theoretical because, rather than sampling people, sampling occurs on the basis of concepts. Strauss and Corbin (1990) describe three levels of sampling which align with the three levels of coding: open, relational and variational, and discriminate sampling. The aim of **open sampling** is to discover as many categories as possible. **Relational and variational sampling** aims to validate relationships between categories. **Discriminate sampling** is directed and deliberate sampling which will maximise opportunities to verify the story line. Sampling continues until theoretical saturation of each category is reached (Strauss & Corbin, 1990), that is, until there is no new conceptual information which indicates new codes (at any level) or expands existing codes (Hutchinson, 1986).
Grounded theory was a method of data analysis which was pertinent to the theoretical perspective and the research question of this study. It required the selection of situations where the concepts associated with nurses’ perceptions of quality of life for people with severe multiple impairments would most likely be found. It also provided a clear way of analysing data which, in turn, was easily audited, one of the criteria for rigour in qualitative studies, which is taken up later in this chapter.
Data Collection and Analysis: Procedures for this Study

Indepth interviewing was the data collection method used in Stage One of the study and participant observation was the data collection method used in Stage Two of the study. The grounded theory method of analysis was used throughout the study.

Development of an Interview Schedule for Stage One

The interviewing approach I used relies on the social interaction between the interviewer and the interviewee to elicit information, by means of semi-structured interviews which focus on specific content but use the interviewing approach of unstructured interviews. To achieve this end, "an interview guide or schedule is developed around a list of topics without fixed wording or fixed ordering of questions" (Minichiello et al., 1990, p. 92). As a result, the initial broad interview schedule, reflecting the analytical elements of Blumer’s (1969) method of inspection, was developed from the quality of life literature.

While reviewing the literature for issues in quality of life (Chapter Three), I identified twenty-eight characteristics of quality of life for people with disabilities (Appendix III) which were content analysed into five categories:

1. Physical well being
2. Emotional well being
3. Freedom and ability to choose and act
4. Relationships with others
5. Resources to facilitate each of the above categories.
Probes, rather than specific questions, which were developed for each category based on the twenty-eight characteristics are listed in Table 5.1.

Table 5.1

Probes for Interview Schedule: Version One

<table>
<thead>
<tr>
<th>1. Physical well being:</th>
<th>How does</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) age,</td>
<td></td>
</tr>
<tr>
<td>(ii) health,</td>
<td></td>
</tr>
<tr>
<td>(iii) number of disabilities</td>
<td>relate to quality of life?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Emotional well being:</th>
<th>How does</th>
</tr>
</thead>
<tbody>
<tr>
<td>(iv) satisfaction with life,</td>
<td></td>
</tr>
<tr>
<td>(v) privacy,</td>
<td></td>
</tr>
<tr>
<td>(vi) interests</td>
<td></td>
</tr>
<tr>
<td>relate to quality of life?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Freedom and ability to choose and act:</th>
<th>How does</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) Freedom to choose,</td>
<td></td>
</tr>
<tr>
<td>(ii) Ability to choose,</td>
<td></td>
</tr>
<tr>
<td>(iii) Freedom to act,</td>
<td></td>
</tr>
<tr>
<td>(iv) Ability to act</td>
<td></td>
</tr>
<tr>
<td>relate to quality of life?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Relationships with others:</th>
<th>How do</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) other residents,</td>
<td></td>
</tr>
<tr>
<td>(ii) family,</td>
<td></td>
</tr>
<tr>
<td>(iii) staff,</td>
<td></td>
</tr>
<tr>
<td>(iv) community</td>
<td></td>
</tr>
<tr>
<td>relate to quality of life?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Resources:</th>
<th>How do</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i) residence,</td>
<td></td>
</tr>
<tr>
<td>(ii) income,</td>
<td></td>
</tr>
<tr>
<td>(iii) leisure/ recreation</td>
<td>relate to quality of life?</td>
</tr>
</tbody>
</table>
In an attempt to ensure that the participants and I shared similar meanings about people with severe multiple impairments, the interview schedule also included a question which asked participants to describe these people. In addition, demographic data, as well as educational background and professional experience of the participants, was sought.

The initial interview schedule was used to guide the first interview. Emergent interviewing, however, uses, as a starting point, concepts derived from the literature, which are considered provisional. As interviews progress, new concepts emerging from preceding interviews are added, and the interview schedule is altered to incorporate such concepts for later interviews. In turn, this allows sufficient space for other potentially relevant concepts to emerge (Strauss & Corbin, 1990).

In this way, data from the first interview resulted in the addition of two further topics. Firstly, participants were asked to compare their own quality of life with the quality of life of people with severe multiple impairments. They were asked about, for example, differences and similarities in the constituents and/or the degree of quality of life attainable. Secondly, they were asked to discriminate among the types of impairments, that is, the effect on quality of life of individual impairments such as cerebral palsy, epilepsy, hearing and visual impairments. This second interview schedule was then used to guide the next three interviews.

In turn, data emerging from these interviews resulted in a third version of the interview schedule (Appendix IV) which incorporated ideas emerging from the first four interviews. These ideas concerned such
themes as ability versus disability, labelling, institutionalisation, past and present quality of life, the relationship of nursing work to quality of life, and gender issues. It also included phrases frequently used by the participants such as "I know them", "they are individuals" and "it's just little things". Added to the demographic data which accompanied the third version of the interview schedule were three further questions concerning how participants may have developed quality of life definitions in relation to: (1) previous discussions in their work and/or education, (2) parenting, and/or (3) personal experience of disability (Appendix V).

The third version of the schedule was then used to guide the remaining interviews, and, while the interview schedule could have potentially continued to vary as long as new themes emerged, there were no new themes emerging from the fifth to the ninth interviews.

**How the interview schedule meets theoretical goals.**

Methodology represents the principal ways the [researcher] acts on his [or her] environment; his [or her] methods ... lead to different features of this reality, and it is through his [or her] methods that he [or she] makes his [or her] research public and reproducible by others. As the [researcher] moves from his [or her] theories to the selection of methods, the emergence of that vague process called research activity can be seen (Denzin, 1972, p. 76).

The development of this interview schedule reflected the theoretical perspective of symbolic interaction in a number of ways. The literature review guided topic selection in the initial schedule, for example, but only broadly and very tentatively, because the methodology aims to attend to every idea of participants, and to allow those ideas (data) to direct the
research activity and tell their own story. Further, each interview was treated as an informative conversation because symbolic interaction calls for "as much as possible, a concept-free mode of discourse and expression [and] assumes that the streams of situations that make up the life world do not conform to prior conceptualisations" (Denzin cited in Morgan, 1983, p. 132). The participants, then, gave meaning to the concepts as the emergent technique lifted my experience to the level of their shared meaning.

**Conduct of Interviews during Stage One**

Between March and July, 1991, individual interviews were conducted in a manner which involved participants in a collaborative approach to the research. One interview was held in the home of a participant; the remaining interviews were held in a private, quiet place at the residential centre in which the participant worked. Interviews ranged in length from ninety minutes to three hours depending on the amount of information participants gave. All but the shortest individual interview were conducted over two or more sessions. All interviews were audiotaped. Demographic data were collected separately in written form to protect the identity of the participant, after which the demographic data and audiotapes were coded to match.

In an attempt to elicit the largest number of potential categories, interviews were conducted in an open-ended way. No fixed order of questioning and no fixed way of asking a question was used. Interviews, guided by the interview schedule, were an interaction between the researcher and the participants, with participants directing the flow of the interviews. My questions depended on their responses. If they mentioned relationships, for example, in their initial response to the broad question on quality of life, I pursued an elaboration of that, rather than interrupt to
follow the sequence on the written schedule. This required my attending to particular aspects of what they were saying, and some note-taking to remind myself to return to instances of what had been said. The broad question: "What do you mean by quality of life for people with severe multiple impairments?" was asked once it was established that the participant and I were discussing the same group of people. When that question was exhausted, open questions were asked about the five categories, for example: "How does physical well being relate to quality of life for people with severe multiple impairments?" before the somewhat more guiding probes were used.

Analysis of the Interviews during Stage One

The audiotape was transcribed as soon as possible after each interview, attending to both words and non-verbal messages, for example, pauses, emphasis, irony, humour. Analysis was guided by the grounded theory method as described by Swanson (1986): the transcripts were analysed for recurrent phrases and themes, which were listed and coded; the codes were grouped into clusters by difference and similarity; each cluster was then labelled, each labelled cluster being a category; and the categories were then fully described, including the range and variation in each category.

My analysis was completed in collaboration with my associate supervisor, who checked codes, clusters and categories at intervals throughout the study by seeking justification from the data and by challenging inadequacies. When memory or memos failed me, I listened to the audiotapes again to avoid the "potential recessive style of research where the interpretive process occurs during the editing and selection of
Reasons for additional data collection

Because data analysis occurred concurrently with data collection, I knew by the end of Stage One of this study that the interview technique had helped to produce a descriptive model of quality of life for people with severe multiple impairments but had not elicited the processes within that model. There are a number of likely explanations for this. Firstly, because of the broad nature of the questions, participants were asked to generalise from their experience of many situations with many different people rather than focus on any one particular interaction. Secondly, Field & Morse (1985) say that interviews may not always expose what participants take for granted and nurses whom I interviewed may have taken for granted the processes in their actions and therefore failed to state them. Thirdly, and perhaps most importantly, I was unable to rid myself of my preconceptions of quality of life which were similar to the list of topics in the interview schedule.

Use of grounded theory had brought the “story” to the level of description. The analysis had successfully employed open and axial coding but the data were insufficient for selective coding. In order to move beyond description to conceptualisation, the story had to be told analytically (Strauss & Corbin, 1990). Most important was identification of the processes which involves an indepth examination of, and incorporation of, changed action/interaction into analysis. In this regard, the processes must be accounted for to a degree sufficient to give the reader a sense of the flow of events that occur with the passage of time (Strauss & Corbin, 1990).
To get at the processes in quality of life seemed to require discriminate sampling, that is, observation of the interactions between nurses and people with severe multiple impairments and further subsequent conversations with participants concerning their meanings in each situation. The most logical way to proceed, therefore, seemed to be observation of nurse-resident dyads followed by questions about what had happened, as a second stage. This is the method of participant observation. Rather than pursue more interviews in a fourth residential centre, therefore, I returned to one of the previous settings which was closer to my home and thus more convenient for spending long periods of observation.

**Participant Observation during Stage Two**

From April to August, 1994 I was a participant observer for a total of 120 hours in one residential unit where three expert nurses agreed firstly, to their interactions with people with severe multiple impairments being observed and secondly, to my asking them questions about those observations. I ascertained when the nurses would be working and, at first, arrived in the unit at the commencement of their shifts, and usually stayed for the duration of each shift; as the nature of the observation changed, I altered my times of observation to selected activities throughout the shift. As a participant observer, I spent most of the time observing, some time participating in the same activities in which the nurses were involved, while simultaneously interacting closely enough with the participants, both during their work and in their breaks, to expand what was already perceived as an insider’s identity.

Initially, this observational task was overwhelming since every interaction of the participants was something to be observed. Periods of observation varied with the interaction from ten to ninety minutes. As time
went on, and I was finding some patterns in my field notes, the
observations became more focused. At first, interaction between the
participants and myself was minimal:  I asked few questions. Then, as
patterns emerged, I asked many, many questions. Questions usually took
the form of:  "Why are you doing that?"  How do you know (what s/ he
likes)?"  "How do you know (what his/ her communication means)?"
Another general question was:  "What does this work (particular incident,
generally) mean to you?"  These changes in the focus of observation and
interaction reflect the stages of observation recognised by Adler and Adler
(1994).

While I had thought of audiotaping my observations and the
interviews, it was not practical, mostly because of noise levels.  I made
observational notes during the periods of observation and analytic notes
immediately after each period of observation. Methodological notes and
further analytic notes were usually made after I left the field and reflected
on the happenings of the day. These notes usually raised questions which I
pursued during the next encounter. One methodological note, for example,
followed my observation early in the project of how distraught one nurse
was when she missed her timing while feeding someone because I was
asking her a question.  I noted that it was important to check from then on
when it was alright to ask questions.  Similarly, an analytic note about a
month into the project followed my proposition that nurses responded to
the facial expressions and gestures of people with severe multiple
impairments. In a session with my supervisor, I noted to check during
subsequent interactions what it was that the nurse participants ignored.

Initially, questions were put to the participants after I had perused my
notes of a particular observation and when the participant had some quiet
time. As we all became better at doing and talking at the same time, and I
became more focused, questions were put immediately after an interaction
while the participant continued with the next task at hand. This was variously successful, dependent on the participant, the concentration required for the task, and whether I was participating, for example: if we were involved in some automatic task, such as folding laundry, the conversation proceeded smoothly; if the participant was doing something with a resident, such as postural drainage, the conversation was often distracted; if I was participating in a task, such as assisting someone to a position to eat, I usually needed to concentrate on the task, even if the participant did not.

On several occasions, participants gave me tacit consent to continue asking questions in the presence of others who were not consenting participants. This always gave rise to a discussion among all present. Members of staff who were not consenting participants (because they did not fit the criteria) often approached me to discuss their views on interaction. My participation, and these discussions, often occurred naturally during informal occasions such as lunch, consisted of assisting with tasks such as feeding, lifting and bed making, but most importantly, I was seen as someone to talk with about ideas and problems with work and study. I was also invited to participate in informal staff activities, and usually did. Towards the end of my visits, I was informally consulted on a number of issues in the unit.

Analysis of the Observations during Stage Two

Data analysis during the observational period occurred concurrently with data collection. The grounded theory method of analysis as described by Strauss and Corbin (1990) was utilised, with particular attention to discriminate sampling and selective coding.
In order to maximise opportunities for theoretical saturation, sampling was directed and deliberate. Because I wanted to know what was happening in the interactions between nurses and people with severe multiple impairments, I chose informed registered nurses familiar with individuals and observed them in interaction. While not actually using their method of sequential analysis, ideas from Babeman & Gottman (1986) helped me to assemble the observational notes under headings of what is interpreted, how it is interpreted and response.

The aim of selective coding is to integrate the categories along the dimensional level to form a theory, validate the integrative statements of relationship, and fill in any categories that need further development: theoretical saturation. I therefore asked the participants questions about their interactions. As themes emerged, I focused more closely on them. Hypotheses were constantly compared with the observational data, modifications made, and the emergent hypothesis tested again. I also began to sample the literature and pursue negative cases, the aim being to sample representativeness of concepts (Strauss & Corbin, 1990). These research activities are taken up in more detail as the chapter now turns to the question of rigour.

**Rigour**

The question of rigour constantly arises in relation to qualitative work, with a number of authors (e.g., Appleton, 1995; Becker, 1993; Burns & Grove, 1993; Glaser & Strauss, 1966; Guba & Lincoln, 1981; Koch, 1994; Sandelowski, 1986; Stern, 1985; Strauss & Corbin, 1994) addressing the question. Drawing on Guba and Lincoln's (1981) criteria, Sandelowski (1986) proposes a number of strategies to achieve rigour in qualitative research. These criteria and strategies have been considered in the writing
of this report. Particular strategies which are not addressed elsewhere in this report are considered here in relation to three criteria: auditability, creditability and fittingness.

Auditability

The challenge by Guba and Lincoln (1981) to leave an audit trail is addressed here with an example from the data analysis. Figure 5.1 shows the relationships of codes, clusters and sub-categories for the category: well being.
Figure 5.1. Relationships of codes, clusters and categories for well being.

I began analysis after the first interview, and analysed each interview thereafter as soon as possible after that interview. Each transcript was coded line by line, by asking of the data "What is this?". Sometimes the answer to that was checked by listening again to the audiotape. Laundry lists of substantive codes were made, memos were kept on each code, and clusters were formed when the memos showed the relationships among the codes. The analysis proceeded similarly with clusters, sub-categories and categories, which were all labelled. Each category was then fully described with attention to range and variation. The range of a category such as “well being”, for example, was from its absence to its fulfilment, while the variation in this category was represented by its dependence on and among its codes.

Theoretical sampling involved testing hypotheses derived from the data in other situations. For example, participants frequently said in the
interviews that “it depends”. “Depends on what?” I asked myself. From the data, I hypothesised that physical well being depends on emotional well being, and vice-versa. I then sampled friends and colleagues, as well as the participants, to test this hypothesis. I asked them what they meant by quality of life (for themselves). The answers always contained aspects of physical well being and emotional well being, but rather than one leading to the other, they existed simultaneously. This expansion of the categories led to a higher-order category of “well being”, which, in turn, was linked to another category.

The process of relating categories was completed using the six c’s. Commencing with well being as the consequence, I asked “what causes well being?”. Finding an answer to that, I then asked “under what conditions does this cause lead to well being?” Context, contingencies and co-variance were then each examined.

From the observational notes I was able to identify the acts and responses of nurses and people with severe multiple impairments. These acts and responses were labelled as actions, verbals, expressions and other (no response, or physiological occurrences). The response to each type of act was of any type, and in any combination. Questions were asked of participants to get at the meanings of the acts and responses. Typically, the answer to “why did you do that?” was the interpretation by participants of the acts of people with severe multiple impairments, which, in turn, led to the response by the nurse. Some examples may help here.

Why did you give her that bubble bath? (Action)
Because she likes it. (Interpretation)
How do you know?
Because she kicks and swims. (Response)
Why did you fuss over her clothes? (Action)
Because she likes the attention. (Interpretation)
How do you know?
Because she smiles and looks in the mirror. (Response)

Not all answers were so simple. The range and variation were extremely diverse. This led me to a number of hypotheses, such as:

- nurses behave in response to individuals' preferences;
- some interactions are initiated by residents and others are responses to nurses' interactions;
- nurses "read" residents' interactions as expressions of emotion;
- residents' interactions consist of eye contact, facial expressions, vocalisations, and movements;
- nurses' interactions consist of eye contact, facial expressions, talking, touching and action;
- interpretations of the reason for residents' emotions differ among residents and among nurses;
- interpretations occur against "background expectancies" (Garfinkel, 1967);
- nurses' behaviour enhances/ alleviates their positive/ negative feelings;
- nurses' behaviour changes over time; and
- time with residents alters nurses' perception of residents.

Such hypotheses were tested not only with participants in Stage Two of the study, but also with some of the nurses who were participants in Stage One of the study, as well as with mothers, using their infants as examples, and employing the same questions: "Why did you do that?" and "How do you know?" It would have been interesting to sample nurses who work with people who are non-verbal for reasons other than severe multiple impairments, for example, coma, but I was running out of time.
Creditability

The criterion of creditability was used to evaluate the truth value of my interpretation of the data.

The final test of accuracy comes from the subject group. If a theory fits, mouths drop open, eyes light up, and the audience, grasping the idea, fairly shouts its acceptance. "That's it", they say, "that's just the way it is!" Or they may say, "Oh of course" as in, "Of course, who doesn't know that" (Stern, Allen & Moxley, 1984, p. 376).

Towards the end of Stage One of the study, two focal group interviews were held with the participants. The purpose of these interviews was to ensure that my interpretation had not been overly objectivised and to check that my analysis reflected what the participants had said. The interviews offered an opportunity for participants to refute any part, or the whole, of the analysis and provided me with an opportunity to review the model. The first interview was conducted with nurses from Residential Centre One and the second with nurses from Residential Centre Two. All four nurses previously interviewed from Residential Centre One participated, but only three of the five nurses previously interviewed from Residential Centre Two were available for the group interview. The proposed model (Appendix VI), and a list of the elements (Appendix VII) of each of the components of the proposed model, were presented to each of the nurses at the commencement of the interview. The model and the list of elements were explained in a fifteen minute presentation. Each interview continued for approximately ninety minutes seeking clarification and adding examples.

Throughout my explanation of the proposed model in the first interview, nurses in Group One nodded their agreement. To the question:
"What do you think of it?" at the conclusion of the explanation, there was general validation that the model represented what they had said in the original interviews: "you've covered everything"; "it's fairly accurate"; "the circles are pretty good". Probably the most outstanding acclamation was that a number of the group wished to keep the printed model at the conclusion of the interview to "show others what we do". Most of the discussion about the model was simply to reinforce the importance of particular aspects. The group's general comments, and the majority of the content of the discussion, indicated that the model made sense to the participants. There were, however, three areas which prompted me to further contemplate the fit of the model. These areas were: some differentiation between the influence of society and of the disability lobby on departmental policies for people with severe multiple impairments; the respective importance of quality of care and of quality of life; and the impact of nurses' values versus the preferences of people with severe multiple impairments on the care given. The three areas which raised the possibility of changes to the proposed model were held in abeyance until after the second interview.

Once again, throughout the explanation of the model in the second focus group interview, nurses in Group Two nodded affirmatively. To the question: "What do you think of it?", they said: "it's summarised properly"; "it makes sense"; "you're on the right track". This discussion, like most of the discussion with Group One, also reinforced the importance of these areas with elaboration by the use of more examples. The second group's general comments and the majority of the content of the discussion indicated that the model also made sense to these participants. Two of the three areas raised by Group One were chosen for discussion by this group, and the third area was raised by the researcher when it had not been forthcoming towards the conclusion of the interview. The discussion of the three areas raised by Group One led me to conclude that there was need to make some changes to the model. Firstly, the influence of society and of the disability
lobby on quality of life for people with severe multiple impairments was more complex than originally depicted in the model and the model needed to reflect this. Secondly, there was not strong enough evidence to alter the respective importance of quality of care in relation to quality of life, and therefore the concepts were left in the model with the same significance. Thirdly, a note was included in the explanation of “individual preferences” to indicate the instances in which they might be of secondary concern to nurses’ values. These changes were reflected in a revised version of the model (Appendix VIII).

During the observation period, early analysis (Appendix IX) yielded some themes (Appendix X), which were given to the participants. I asked them separately what they thought of it. Their reactions were less than enthusiastic. It was not that there was anything wrong, but there was something missing. Towards the end of the observation period, after further data collection and analysis, I posted to the participants a further draft of the analysis of the fieldwork with an attached letter (Appendix XI) asking for their comments. This was more acceptable: “it seems a good observation about what does actually happen”; “I felt after reading it that you are fairly accurate in your observations”; “this draft makes sense”. Other comments were incorporated into the final draft. The major concern expressed was whether readers would understand the themes without a picture of the lives of people with severe multiple impairments. This concern, and my own preoccupation with the matter, shaped this thesis by including, at the outset of the findings, a story as it might have been written by a person with severe multiple impairments (Patrick’s day, Chapter Six).
Fittingness

Fittingness was the criterion against which the applicability of this research was evaluated.

In terms of making generalisations to a larger population, we are not attempting to generalise as such but to specify. We specify the conditions under which our phenomena exist, the action/interaction that pertains to them, and the associated outcomes or consequences. This means that our theoretical formulation applies to these situations or circumstances but to no others (Strauss & Corbin, 1990, p. 191).

In quantitative research, representative sampling is the means of achieving generalisation to the population, while the concern of qualitative research is with "representativeness of concepts" (Strauss & Corbin, 1990, p. 190). Evidence of the presence of the concepts in new situations achieves greater density and wider applicability of the analysis. The purpose of the following procedure was to further demonstrate the fittingness of the revised model (Appendix VIII) in specific situations.

Towards the end of Stage One of the study, using the same approach as for the previous group interviews, an additional focal group interview was conducted with four nurses from a third Residential Centre. These nurses had not previously been interviewed nor had they been in contact with any of the nurses who had been interviewed. At the commencement of the interview I asked the participants to make personal notes about what they meant by quality of life for people with severe multiple impairments. This took about fifteen minutes. The notes were for the purpose of discussion once I outlined the revised model. There were affirmative nods throughout the explanation of the revised model. In response to the question: "What do you think of it?", they said: “it makes sense to me”; “I
agree with all that”; “I believe it, so I'd be proud of it [if it were published]”; “it's
good to know that someone else is thinking about the things you're thinking
about”; “it's good to have [a model] to focus on”. There were no new ideas
emerging about quality of life for people with severe multiple impairments
from the notes that the nurses were requested to compile at the beginning
of the interview. Thus discussion of each of the elements of the revised
model, and of the relationships among the components of this model,
validated their presence in this new context.

Leaving the Field

At some point in the fieldwork process, the wise researcher attends to
closure and to leaving the field (Wilson, 1989). Following the group
interviews at the end of Stage One of the study, I wrote to each of the
participants thanking them and enclosing copies of a conference paper
based on analysis of the interviews. After an intense initial period of
observation in Stage Two of the study, visits became more irregular and
were usually the result of having found an hypothesis to be tested. I
attended a farewell party for one of the participants and gradually
decreased my contact with the others. The participants from Stage Two
have each read and commented on the themes in Chapter Nine, an exercise
which we did by correspondence. I have formally written to thank each of
them for their participation.

SUMMARY

The data collection techniques used in the two stages of this study,
that is, indepth interviewing and participant observation, provided me with
information about the nurse participants' perspectives of quality of life for
people with severe multiple impairments. Concurrent data analysis, using the grounded theory method, incorporated literature with the participants' views to provide further explanations of how nurses define quality of life for people with severe multiple impairments.

The presence of the researcher in the data means that my interpretation may well be different from that of another investigator. Grounded theory, along with ethnography and phenomenology, depends heavily on the researcher's use of self: "researchers use themselves as both data elicitors and processors" (Lipson, 1991, p. 74). This area of research is about people with whom I am familiar and about whom I have a passion. Thus, it is important to separate what is me and what is not me, by differentiating what I and others say, but that does not mean that I leave "me" out. "Strauss said something like: 'Everything is data, including everything that's happened in your life' " (Stern, 1991, p. 202). My involvement with the people and the context, therefore, is exploited in the research (Oiler, 1982). In this regard, I found it useful that Ellis (1991) argues for an emotional sociology, which includes focusing on how we feel as researchers in research situations as a way to understand what is going on emotionally in these studies. Further, my interpretation is not mine alone but one in interaction with the participants. "And Glaser said: 'the best way to approach a subject is to say to the person "teach me" ' - so they're co-investigators as well" (Stern, 1991, p. 202). The interpretation has been highly dependent on the participants, particularly throughout the observation period and during analysis of the observational data.

Most previous quality of life research uses a positivist epistemology wherein quality of life is predefined. While much valuable work has ensued from this approach, it avoids contextualisation. Different contexts give rise to different interpretations of quality of life and to different ways of managing quality of life. This has been hinted at by Borthwick-Duffy
(1992) and others. While some of the findings of this study reflect previous quality of life research, there are many expansions of that research and some quite novel connections with other areas of study. The next chapter outlines the findings of this study and is followed by four chapters which explain each theme in more detail.
Oh, there are lots of things ... just all these little things which are really so important to quality of life ... they’re basic things but they come into the nice category ... just little niceties ... it’s these little things

[Interview 1].

The participants defined quality of life for people with severe multiple impairments as "just little things". This central concept of "just little things" was made up of four themes: humans being, supporting, becoming intimate, and situated belonging. This chapter presents a model and an overview of those little things and is followed by four chapters examining each of the themes in "just little things".

The chapter begins with a story which was prompted by the participants' comments during the study about prospective readers not understanding about people with severe multiple impairments. As the researcher, I shared the participants' feelings about this lack of understanding. Therefore, I have constructed a story of a typical day as it might have been experienced by Patrick, a young man with severe multiple impairments. The story is based on the interviews and observations in the research, as well as my previous experience. This story provides some context for the reader about the social life of people with severe multiple impairments and nurses that may make explanation of the concept of "just little things" easier to understand.
PATRICK'S DAY

I am woken by the curtains being drawn. A muted light filters through the eucalypts outside my bedroom window. It’s autumn and the sun has not yet warmed the day but I am warm in my bed. My bed is a waterbed with a brightly coloured quilt which matches the quilts on the other beds in the room. They're getting the others up first - there are three other men sleeping in my room, men I have known since we were all children. We must have all wet the bed - the smell is putrid this morning. Kay says "Come on, Patrick" and she and Sue change my wet nappy and lift me out of my bed onto my waterbed chair. The sheets are cool but they put my blanket on. Kay wheels me down the corridor past the other bedrooms and the covered courtyard to a dayroom, chattering all the way. Kay and I have known each other for years and I’m always happy to see her.

From my position in the day room I can see the familiar shapes of the people with whom I've shared this room for ten years. I cannot always see clearly - some problem with focusing - but I also know them by their sounds. During my first fifteen years here, I used to spend the morning in other areas of the unit but this is my group now. There are ten of us in this group and ten others who spend the morning in the covered courtyard. We are all in our chairs waiting for breakfast. While each of us is being positioned near our friends, I can hear the food being dished out in the unit's kitchen. We used to sit in the dining room while the toast was cooking in the adjacent kitchen but all the food comes in dixies from the central kitchen now. And our elaborate chairs wont all fit in the dining room any more, even without the tables.
Suddenly Kay is hovering over me with a bib and asking someone to help her sit me back up. I have slipped down in my chair and am mesmerised by the mobiles on the ceiling. They pull me up and Kay puts my bib on. She goes to the trolley with the food on it and comes back with a dish and spoon. "Here's your breakfast", she says. The smell of Weetbix with warm milk and sugar wafts under my nose and the food enters my mouth. I can swallow pretty well in the morning while I'm still relaxed. I used to feed myself a long time ago, with lots of help, but that was before my body became so twisted that I could no longer sit and my arms so stiff that it is almost impossible to steer them from the plate to my face and my hands so frozen that I cannot manage the spoon. During my next course - mashed something - and my drink - warm milo - Kay tells us about her adventures on her days off. She has been to a concert - some band I've never heard of - and there is a funny story about some mix-up with the tickets. I haven't done too badly with my breakfast - only a few spills on the bib Kay takes off.

For the next hour, others are fed and some taken off to the bathroom. People are busy coming and going. There are more stories of the staff's adventures but I miss a lot because I keep drifting off. The breakfast trolley is taken out by one of the domestic staff and the medication trolley is pushed in by a nurse whom I've never seen before. She has to keep checking our names with Kay or Sue. She brings me my pills in jam on a spoon - someone must have told her that I like it that way. I have slipped down again but she doesn't seem to notice. "Open up, Patrick", she says and puts the spoon in my mouth. I have become used to swallowing while I'm lying down, so I don't choke on the pills, but I don't like it.
"Time for your bath", says Kay, as she pushes my chair towards the bathroom. The radio is on the local station and the tune is familiar. Kay strips me and Sue helps her lift me into the bath - well, onto the bath. This bath is like a table with a very shallow lip. Water comes from a shower rose attached to a long hose, washes over me and then down the drain at the end of the bath. The other two baths in this bathroom - there are two other bathrooms - are deep tubs. Every so often I soak in one of those but I don't really fit into them properly. Neither do the two guys who are in them now. The deep tubs are here from when we were all smaller. Kay wets my body - the water is always warm, soaps me up with a sponge and then washes it off, telling me what she is about to do as we go. She dries me off and then she and Sue lift me onto a bench. Kay dresses me in my usual attire - T-shirt, nappy, track suit and socks. Today my T-shirt is red, and my track suit and socks are dark blue. The clothes are warm and comfortable and everyone says the blue highlights my blue eyes and blond hair. Kay and Sue lift me back to my chair, and Kay brushes my teeth, shaves my face and combs my hair. I can't spit so I swallow the toothpaste - it's not much. The comb is communal but the toothbrush and the electric razor have my name on them. My name is in a number of places throughout the unit: on my bed, on my locker in the corridor where my "good" clothes are kept, on the fireboard at the front door which monitors our comings and goings, and on my file which is kept in the cabinet in the Nursing Unit Manager's office. It used to be on my old chair but it's not on this one.

Kay pushes my chair out to the back verandah. From here I can vaguely see the outlines of other buildings. There are a number of buildings at our centre. Several other units house about two hundred people in all. I attended the school in the grounds until I was twenty
one years old and then I spent some years sporadically at the activities centre where we listened to music, played instruments, prepared and ate food like chocolate crackles, watched movies and went on bus trips and picnics. I never went to the workshops - no one in our unit did. I also never went to the gym, but I did go to the swimming pool. It was always cold and I used to shiver and stiffen up. Now there's a hydrotherapy pool in our unit. It's warm and very relaxing but it does not work more often than it does. From the back verandah, which is draped with hanging plants, I can also see the edge of the adventure playground. Sometimes we go there in our chairs and, while it's fun watching the antics of others, it's a long time since anyone tried to put me on the slippery dip or push me through the tunnel. I can hear some traffic noise from here. We are near a very busy centre. I can also hear the birds in the trees and occasionally see the ducks wandering on the grounds. We come out here when the weather is mild.

Sue brings me a drink of orange juice which mostly goes down the right way. She tells me that Kay has gone to have her morning tea and, when I am finished the juice, says "Well done!" All twenty of us are on the verandah now. It's better than in the dayrooms because lots of people have had suppositories and the results are beginning to be overwhelming. People are coming and going, as they need to be cleaned up. I haven't had a suppository today - things are working on their own for a change. I drift off again.

An hour later I hear the sounds of lunch. I can't see anything but the overhanging plants - I've slipped down again. Someone pulls me back up and Jenny brings me lunch. The afternoon shift has arrived. I cough and splutter my way through the pureed meat and vegetables, and the custard. I refuse the banana and the drink. My muscles have
tightened, my spasms have increased, and my breathing is uneven. Jenny says "It's OK - we'll try again at dinner". By the time I calm down, I've missed most of what is going on around me and find myself in the bathroom having my nappy and my food-splattered top changed and my face washed.

Jenny pushes my chair into the covered courtyard where the big-screen television is on the afternoon soaps. I don't watch it but notice that one of the women has a visitor. They are lying on a mat on the floor playing with a toy. The staff used to put me on the floor to roll around and to do some exercises. Sometimes there were a lot of us on the floor and we would all roll into one another. I don't go on the floor since I got my waterbed and special chair. The staff say that the chair is more comfortable than a mat on the floor and that my skin is more protected on water. I used to have visitors. I lived at home with my mother and brother until I was seven years old. When I first came to live here, they used to visit me, and sometimes take me out or home for the weekend. I haven't seen my brother for twenty years. My mother brought me a cake on my twenty first birthday, eleven years ago. The staff here give me a party with a cake every year since then, but my mother has never come. The volunteers came for a while to help with physiotherapy or have some fun with us, but they are few and far between these days.

I must have drifted off again. It is two hours since lunchtime. The morning staff are folding nappies and bibs and sorting socks while the afternoon staff are on a break. The soaps are still on the television. The afternoon staff bring us drinks and the morning staff leave. After Peter pulls me up, I manage to get about half of my drink down, the other half on the bib. Sometime during the next hour, Peter changes my
nappy, replaces my track suit with my pyjamas and sits me back up. The few people who go to activity centres or school return and join us in the courtyard. The staff ask them how their day was and they smile or groan in reply. I used to spend an hour in callipers in a standing frame when I came home from school. The frame had a tabletop attached to the front where I used to paint or play with water. When I was older and unable to stand any more, I used to sit in my chair to paint. The staff used to guide my hand to the tabletop, dip it in paint and let me move it across the paper.

About 5.00 p.m., dinner is served. Most of mine ends up outside rather than inside me. Swallowing is very difficult at the end of the day, despite Peter’s encouragement. I watch while the others have dinner.

Jenny takes me to the bathroom to clean me up and change my clothes again, and then she and Peter put me to bed. My body only allows me to lie in one position, but Jenny wedges some pillows under one side of me to tip me slightly off my back. She asks me if I’m comfortable. I have never spoken, but after a moment, she says "good". She puts the music box I got for Christmas where I can see it and turns it on. The horses revolve around a light as the music plays.

It is a moonlit night. The trees outside my window glitter. A slight breeze stirs their leaves. I doze on and off until I feel someone checking my bed for wetness and tipping me in the other direction with the pillows. She says "Go to sleep now, Patrick". I see the torches of the night staff as they check us. Someone closes the curtains. I watch the torchlight bounce along the corridor walls and listen to the retreating footsteps.
This story does not reflect all the possible permutations of a day for Patrick but is meant to give a feel for what people with severe multiple impairments might experience. Patrick, of course, cannot tell his story and I have little idea of how his sensorimotor impairments and his life experiences affect his view of the world. This story, however, may illustrate what the participants meant by saying that quality of life was “just little things”.

“JUST LITTLE THINGS”

When I first asked participants what they meant by quality of life for people with severe multiple impairments, they said that it is “just little things”. On further exploration, the little things in this study referred to a complex view of quality of life for people with severe multiple impairments. This is not the first time that research has found nurses referring to their practice in this way. MacLeod (1994) found that nurses in a surgical setting in two teaching hospitals in Scotland referred to their practice as just little things, and that this practice is imbued with complex nursing knowledge and skill.

The data analysis uncovered some of the meaning in “just little things” and these meanings can be found in the following four themes: (1) humans being: the life in quality of life; (2) supporting: the quality in quality of life; (3) becoming intimate: mediating the quality of life; and (4) situated belonging: making a place for quality of life. These themes, however, represent an artificial separation of the components of quality of life as perceived by the participants; they occur simultaneously and are only separated to provide clarity for the reader. These four themes and their relationships are depicted in a model of quality of life for people with severe multiple impairments (Figure 6.1).
For the participants, quality of life for people with severe multiple impairments means, firstly, **humans being**, a concept which refers to the life in quality of life. It means that people with severe multiple impairments are humans, not only with the right to life itself but also to the right to live their own lives. Secondly, it means **supporting**, which refers to the quality in quality of life. Supporting is acting on behalf of people with severe multiple impairments so that they can have a life and live the lives they want. Thirdly, supporting humans being is mediated by **becoming intimate**, which is the process of knowing the lives people with severe multiple impairments want to live. Fourthly, because there is tension between the views of the participants and of society about the lives of people with severe multiple impairments.
impairments, quality of life also means making a place for people with severe multiple impairments, which is called situated belonging. These themes emerged from the data in both stages of the study, and the codes and categories which helped formulate the concepts are outlined in Appendix XII. Chapters Seven to Ten are dedicated to a detailed discussion of these four themes but, for now, the following is provided as an overview of those themes.

Humans Being: The Life in Quality of Life

The participants described one aspect of quality of life in a number of ways which together I have called, with debt to Draper (1992), humans being. The life in quality of life is located in the concept of humans being. When I was able to put aside my preconceptions regarding quality of life, I found that the participants had been saying that quality of life is related, not to well being, but to humans being. They repeatedly asserted that people with severe multiple impairments are human beings and that this humanness is defined, not by the productivity demanded by society and by many quality of life models, but by their very being, hence the concept of humans being. The participants insisted that this humanness gives people with severe multiple impairments the right to life and the right to live the life one wants.

For people with severe multiple impairments, the right to have a life means abolition of abortion and euthanasia, when they are implemented on the grounds of impairments. It also means the right to treatment when warranted, without consideration of impairments. The right to live the life one wants incorporates a number of ideas about life. Firstly, there is a recognition by the participants that life cannot be lived in isolation: individuals and society are inseparable units (Meltzer et al, 1975). Thus,
individuals live in the everyday social life. Secondly, everyday life is experienced through the body which strives for health, comfort and development. Thirdly, engagement with everyday life is expressed through the emotions. Finally, identities of individuals emerge in their everyday life, and these identities are defined by individual preferences for how each wants to live their life. These preferences make a singular definition of (quality of) life difficult, in that (quality of) life is different in the doing for each individual.

Supporting: The Quality in Quality of Life

While there may be differences in the lives of people with severe multiple impairments from the lives of others, the participants insisted that people with severe multiple impairments, as humans being, have the same right to quality as others. These differences, or difabilities (O’Halloran, 1993), relate mostly to the humanness and strengths, as well as the dependence and vulnerability, of people with severe multiple impairments. Their humanness and strengths give lessons in life to others, and their dependence and vulnerability means that they require support to live the lives they wish; a reciprocal arrangement. The everyday quality of their lives, therefore, is related to support from others: the quality in quality of life for them is located in the concept of supporting.

The participants in this study conceptualised what I have called supporting in a manner reminiscent of Henderson’s (1978) definition of the unique function of the nurse: they were and did whatever the person with severe multiple impairments wanted to be or do if only they could. According to Mead (1938), life proceeds on the basis of people anticipating what others are about to do, by observing the incipient acts in the gestures (or attitudes) of others. The data suggest that nurses not only observe the
incipient act but complete it on behalf of people who are unable to do so for themselves. This means that supporting consists of completing acts: body acts, emotion acts, and identity acts. Body acts are those which support the everyday health, comfort and development of the body; emotion acts promote opportunities for engagement with life; identity acts support positive images of people with severe multiple impairments as well as particular identities of individuals. The extent to which these acts can be performed determines the quality in quality of life for people with severe multiple impairments.

Reviewing these first two themes, quality of life for people with severe multiple impairments is defined by the participants as living the life one wants and being supported in that. Given, however, that people with severe multiple impairments cannot speak and have no other formal systems of communication, how do nurses know how people with severe multiple impairments want to live their lives and how supporting is to be done? The next section focuses on this question and outlines the third theme in "just little things".

**Becoming Intimate: Mediating the Quality of Life**

Intimacy is thrust on nurses and people with severe multiple impairments by the nature of the dependence of people with severe multiple impairments and the supporting role of nurses. Becoming intimate is the name I have given to the four processes described by the participants as being the ways in which they know how people with severe multiple impairments want to live their lives and how to support them. These processes are knowing, interpreting, feeling, and empathising; together they mediate the concepts of humans being and supporting. Knowing means knowing the individual in the situation through time and experience. A
critical element of knowing the situation is knowing the body, particularly the impaired body of the individual. Knowing the patient is a recurrent theme in the nursing literature (for example, Benner, 1984; Moch, 1990; Radwin, 1996) and has again occurred in this study. The description of knowing in this study, however, still did not get at how nurses know. This was better explicated in the other processes of becoming intimate: interpreting, feeling, and empathising.

According to the participants, how they know is through interpretation of the impaired body in context, against a background of knowing. They explained that they become familiar with the routine symbols of individuals with severe multiple impairments and constantly monitor their presence, absence or alteration. They further indicated that all symbolic communications from people with severe multiple impairments are interpreted as some type of emotion. The body is checked for the source of the emotion and action is taken to maintain or restore routine communication. This action is prompted by the feeling nurses have in response to the interpretation of communications from people with severe multiple impairments: the gestures (attitudes, feelings) of people with severe multiple impairments are felt in the bodies of nurses. Nurses want to maintain their own comfortable feelings and alleviate their uncomfortable feelings. The way that they do this is in maintaining or restoring the comfortable feelings of people with severe multiple impairments. According to Blumer (1969), the process of interpretation includes designating objects (in this case, the communications of people with severe multiple impairments, as well as the aspects of the situation) and giving them meaning (in this study, different emotions). This empathising process occurs when one places oneself in the attitude of the other (Mead, 1938), or, in Goffman’s (1969) terms, takes the role of the other. The data in this study suggests that repetitive (over time and with experience) role-taking, or placing oneself in the attitude of the other, enhances knowing. Placing
oneself in the attitude of the other occurs at an emotional level, with nurses interpreting the communications of people with severe multiple impairments as emotions, and feeling those emotions in their own bodies. This is the process Stone and Farberman (1986) called physiological empathy. Much of this emotion work is hidden, as is much of women’s work, and is exhausting. This exhaustion can partly explain the emotional distancing sometimes observed in nurses who work with people with severe multiple impairments. The participants further explained that such distancing is also used when there is conflict between cognition and emotion in the performance of their work, for example, when nurses have to complete a task which they know the recipient will find unpleasant.

The findings have so far demonstrated that nurses define quality of life for people with severe multiple impairments in terms of supporting the lives people with severe multiple impairments want to live. Nurses ascertain the wishes of individuals in everyday situations through four processes of becoming intimate: knowing, interpreting, feeling, and empathising. It is this intimacy which explains how nurses know how people with severe multiple impairments want to live their lives, indeed, whether they want to live at all. This intimacy also provides some understandings of the different views of quality of life for people with severe multiple impairments held by nurses, the disability lobby and society, because it seems that views of quality of life (for others) is related to degrees of intimacy.

**Situated Belonging: Making a Place for Quality of Life**

This study commenced with a recognition of three views of quality of life for people with severe multiple impairments: the view of society, the view of the disability lobby, and the view of nurses. I noted that nurses disagree with the other two views but have not articulated their own view,
except in terms of their disagreements with the other two views. The previous three related themes: humans being, supporting, and becoming intimate, now articulate the view of nurses and, further, provide the background for the fourth theme: situated belonging. Situated belonging is meant to reflect both the importance to individuals in society of belonging, and the only place where people with severe multiple impairments can belong - in a particular situation. To further explain situated belonging, this theme examines the context, the situation, and the tensions.

The context refers to the attitudes of society and of the disability lobby towards people with severe multiple impairments, and the consequences of these attitudes. These attitudes have been discussed earlier in this thesis in terms of exclusion and inclusion. The consequences of exclusionary attitudes include limited resources for life and ways of causing death, while the consequences of inclusionary practices comprise integration into a society in which people who are different are not welcome.

A situation is constituted by those aspects which are important to the actor (Halas, 1985). Participants have a view of the situation of people with severe multiple impairments which stresses the importance that others recognise: the humanness and the dependence of people with severe multiple impairments; the attitudes, knowledge and experience of nurses who work with people with severe multiple impairments; and the everyday nature of quality of life. Clearly, this view of the situation is in tension with societal and disability contexts in a number of ways.

Nurses find it difficult to visualise a society which values people with severe multiple impairments and are sceptical, therefore, of the illusion of integration advocated by the disability lobby. They sometimes postulate that people with severe multiple impairments would perhaps be better off dead than having to live in a society to which they do not belong. They long for a
society, however, which values these people, and therefore sometimes find themselves caught up in the rhetoric of integration. Further, nurses who work with people with severe multiple impairments are devalued by society, by their employers, and by other nurses, but feel valued by people with severe multiple impairments.

Faced with these tensions every day, it is not surprising that nurses are driven to make a place where people with severe multiple impairments can belong. Such a place is a metaphorical one: a situation which incorporates all the themes of nurses’ perceptions of quality of life for people with severe multiple impairments - a place of situated belonging.

**PROPOSITIONS LINKING THE CONCEPTS**

Having outlined the four concepts which together provide some understandings of the meanings in “just little things”, there follow four theoretical propositions which represent the relationships among the four concepts in the model of quality of life for people with severe multiple impairments.

**Proposition 1:** Nurses’ meanings of quality of life for people with severe multiple impairments are to be found in interaction. Quality of life is conceptualised as humans being, dependent on supporting, and mediated through intimate interaction. In interaction, through empathising, nurses get to know the body, interpret the body’s expression of emotion and have a feeling response to that interpretation. This feeling response moves nurses to support people with severe multiple impairments in ways nurses have interpreted as being the wishes of these people.
Proposition 2: Nurses’ meanings of quality of life for people with severe multiple impairments are situated.

The intimate support for humans being is related to aspects of the situation, aspects related to the actors and the context. The vulnerability and dependence of people with severe multiple impairments makes the concept of humans being meaningless without the concept of supporting. Aspects of the nurse, such as attitudes, knowledge and experience are connected to supporting and intimacy. The attention to the individual in the everyday guides the purpose of supporting, and reflects the purpose of humans being.

Proposition 3: The situated and contextual definitions of quality of life for people with severe multiple impairments are in tension.

The contextual definition of exclusion is predicated on the belief that no potential for quality of life for people with severe multiple impairments exists. The contextual definition of inclusion assumes quality of life exists for all people with disabilities. The situated definition establishes the potential for quality of life and is sceptical of inclusion for people with severe multiple impairments. The contextual definitions devalue people with severe multiple impairments and nurses who work with them, and create tension between the situated meanings and other meanings. The situated meaning is perpetuated by nurses feeling valued by people with severe multiple impairments.

Proposition 4: The tensions between situated and other meanings of quality of life for people with severe multiple impairments create a response of situated belonging.

Society denies the humanness of people with severe multiple impairments and rejects their being. The disability lobby argues that people with severe multiple impairments should join this society. Nurses cannot envision a situation in society where people with severe multiple impairments have
intimate support to just be. Therefore, nurses question the validity of exposing vulnerable people to such extreme rejection and prefer to make a place where people with severe multiple impairments can belong.
Quality of life for people with severe multiple impairments is defined by the participants as “just little things”. The symbolic interaction perspective and the grounded theory method of analysis have uncovered four themes and the relationships among them, which together provide some explanations of what the participants mean by “just little things”. A model depicting these themes and relationships has been constructed. The significance of the model lies in both the recognition of the possibility of quality of life for people with severe multiple impairments and its ability to explain the reasons nurses reject other views of quality of life for people with severe multiple impairments. The following four chapters discuss in detail the data from which the four themes and their relationships emerged.
We have worked to undo that which society stresses and conditions us to believe - that bigger, stronger, and brighter is best. And so we accept Casey for who he is: a wonderful, worthwhile, important, integral part of our family. We respect his individuality and uniqueness. We are in awe of his tenacity and determination ... it's easy to assume what's best for Casey. But we try to give him opportunities to show us what he can do and where he needs help (O'Halloran, 1993, pp. 21-23).

This chapter focuses on the first theme in nurses' perceptions of quality of life for people with severe multiple impairments as “just little things”: humans being. Humans being refers to the life in quality of life. The chapter discusses, firstly, how I moved from the concept of well being to the concept of humans being, as a consequence of my interpretation of the participants’ words. Secondly, the chapter examines the participants' view of quality of life for people with severe multiple impairments in terms of the right to have a life and the right to live their own lives. Finally, there is a discussion of the everyday life of people with severe multiple impairments as experienced through the body, the emotions and identity. Each of these aspects of humans being is shown in the shaded area in the model in Figure 7.1 and the emergence of these concepts can be found in Appendix XII.
As was mentioned in Chapter Five, an interview schedule reflecting the literature was developed for this study. One of the themes in the literature, and therefore one of the topics in the interview schedule, was well being. I asked the participants questions about well being and they gave me answers. Whenever I tried to incorporate their words into my analysis, however, there was a jarring note. It was not until I was able to give up my preconceptions of the concept of well being that I was able to “hear” the words of the participants. The following discussion outlines, then, how I was able to move from the concept of well being to the concept of humans being.
Well being is often associated with quality of life. Indeed, well being is frequently used interchangeably with quality of life, even though an analysis of the literature shows that there is no common meaning for the term, quality of life. Given the relationship between quality of life and well being, I sought a definition of the term, well being. Dictionary definitions include “happy or healthy or prosperous condition, moral or physical welfare” (Onions, 1973), “good or satisfactory condition of existence” (Delbridge et al., 1990). So, while quality of life is often defined as well being, well being has no more meaning than quality of life.

It may be useful, therefore, to turn the words around and examine well being as being well, since one can then draw on the phenomenological literature of being, and the health literature where well means healthy, to enhance understanding. Being, in the phenomenological sense, is a simple concept: it refers to what it means to be a human being. Looking for a meaning for well - as healthy, however, becomes circular in that healthy is often defined in terms of well being. So being well, in this sense, becomes being being, or more simply, being. Being well, therefore, is just another way of describing what it means to be a human being.

Draper (1992) arrived at the same conclusion, albeit by another route, when he said “in order to understand the nature of quality of life, we need to understand what it means to be a human being” (p. 968). Similarly, Heal and Sigelman (1990), and Taylor and Bogdan (1990) suggest that quality of life is related to an understanding of how people view and experience their lives.
Humans Being

For people with severe multiple impairments, this discussion of well being is more than a semantic exercise because it opens the way to the notion of humanness. While most people take for granted that they are being discussed when talk turns to humans, the humanness of people with severe multiple impairments is often denied (for example, Kuhse and Singer, 1985). If such a view is held, it may account for why the concept of quality of life has been denied to people with severe multiple impairments. If your humanness is denied, how can there be any discussion of what it means to be a human being?

At the outset of each individual interview, I asked the participant to describe people with severe multiple impairments so that I knew we were talking about the same group. I expected them to answer in terms of the impairments of this group but they never did. Rather they replied in terms of individuals and their personal characteristics, in short, in terms of their humanness. The different views of people with severe multiple impairments in the literature, as described in Chapter Two, may be explained in terms of whether they are viewed as human or not. In a study of relationships with people with severe disabilities, Bogdan and Taylor (1989) found that participants took for granted that people with severe disabilities are human. In this study, participants, weary of the view of society, explicitly stated that people with severe multiple impairments “are human beings, equal with all human beings”. They feel inadequate in trying to convey that humanness: “They’re people and they just respond ... maybe a little bit differently to how we would respond” ... “Human, in the sense that they’re just like me and you ... I mean they might not be so-called normal, able to hold a job, have perfect legs and perfect hands, able to drive a car ... but they’re human, they’re human, to me they’re still human”. Participants located the humanness of people with severe multiple impairments in what Wolfensberger (1988a) described as the heart qualities.
“When they say to you what’s it like working there, I think of Anna, because she’s got these bright sparkling eyes, this great big wide grin ... the little twisted body and the kicking when she talks to you” ... “I remember when I was a student, I remember that I slipped over on the floor and somebody laughing, I turned around and it was one of the girls laughing and I thought, you’ve got a pretty good sense of humour”.

The humanness of people with severe multiple impairments is not defined by their productivity, that is, their worth is not valued in terms of what they can do, but rather in their very being. In a discussion of skills development, one of the participants said: “... if that person can achieve, can learn how to feed himself or drink from a cup, there’s an achievement, his personal self esteem has improved ... What if we fail? Maybe there’s something he likes, he likes to listen to music ... maybe he likes swimming ... its something they’re enjoying doing”. Similar discussions reflecting the worthwhileness of the person regardless of their abilities were summarised in these words: “I just like people to be people and to be given the opportunity of being the person that they are”. From the participants’ perspective, therefore, the being of people with severe multiple impairments defines their humanness - they are simply humans being.

THE RIGHT TO LIFE

As humans being, people with severe multiple impairments have the same rights as other humans. Such rights include the rights to have a life and to live a life. “I just feel that these people have got a right to life ... an existence where they have a right to some form of life regardless of whether it may be minute or not, I think they have a right to actually see life or feel life in whatever possible way that they can ...” The following section focuses on the participants’ disagreement with society regarding the right to have a life, and on the
participants' disagreement with the disability lobby regarding how that life should be lived.

**The Right to Have a Life**

While the participants were not specifically asked about the right of people with severe multiple impairments to live, comments about their right to life often emerged during interviews, for example, “You’re born and, if you’re born like this, well, you’re like it”. Nurses who work with people with severe multiple impairments often discuss them in this way because of the potential threat to this group’s lives, usually through the withholding or withdrawal of treatment which would be routinely given to a person without severe multiple impairments. One participant put it this way: “They [the general hospital] send them back before they’re physically well enough to return and they come back with things written in their notes, like why bother operating on them, they’re only mentally retarded anyway. And that’s such a negative thing, and they’ve been coming back for years ....” A number of authors (for example, Bailey, 1986; Gordon, 1984; Luckasson, 1990; Ralph, 1995) note that people with severe multiple impairments are the first to be deprived of health care services in a time of finite resources. Moreover, Wolfensberger (1994) warns of the growing threat to the lives of all people with disabilities through a process he calls societal deathmaking which is widely disguised and denied. Societal deathmaking refers to “all actions by humans that directly or indirectly, overtly or subtly, quickly or slowly, abbreviate the lives of humans (Wolfensberger, 1994, p.395). Further, as the leading proponents of active euthanasia, Kuhse and Singer (1985) argue, people with severe multiple impairments would be better off dead because they have no potential for quality of life. Kuhse and Singer have their opponents, however, including nurses who work with people with severe multiple
impairments and whose sentiments in this study are reflected in the words of Birch:

That living organisms have an urge to live means that life has value for them. And that value is presumably greatest when life is full and happy rather than when they are sick and miserable. An ethical principle follows. We should respect their experience of life and seek to enhance it (1990, p. 19).

The Right to Live their Own Lives

As has been mentioned earlier in this report, people with severe multiple impairments are caught up in the philosophies and policies which guide services for all people with disabilities. While there is no doubting the good intentions of the policy makers, the effect of such policies for people with severe multiple impairments is often bizarre. As part of the implementation of transition plans referred to in Chapter One, for example, meetings were held at large residential centres, with the purpose of enhancing choice and decision making for the residents involved. In 1994, during the observation period of this study, I attended one such meeting initiated by the government department responsible for people with severe multiple impairments and convened by consultants to the department. Staff were asked by the consultants to advise all residents of the centre, as well as interested relatives, of one large meeting which was attended by approximately three hundred people. The consultants asked the meeting to identify concerns and issues regarding the movement of residents from their present abode to group homes accommodating four to six people. As staff and relatives began to answer, the consultants directed them to allow the residents to put their views to the meeting. Whether the residents understood the questions, given the probable level of their receptive language abilities and their undeniable lack of experience, is a
moot point. This aside, no resident present could speak, nor did any resident attempt in any way to communicate with the consultants. From there, the meeting deteriorated and the people dispersed.

When I followed up on the meeting with the participants in this study later, one said: “As if they’re going to answer! They’re so realistic!! Who makes this stuff up, anyway? Someone who’s never been here”. As a result of such examples of rigidly applying disability policies to people with severe multiple impairments, which illustrate a lack of understanding of this group, nurses are bemused and cynical. Shortly after this meeting, when a young man with severe multiple impairments was throwing his vegemite sandwiches on the floor, one of the participants drew the action to my attention in this way: “Chris, look at this. You can tell them he wants lobster ... he’s exercising his rights”. And when one of the nurses brought a copy of the residential centre’s transition plan into the room, the response was: “Oh good, we need some toilet paper”, a comment reflecting the participant’s views about both the policy of transition and the lack of needed resources. It is clear, then, that nurses disagree with the proposal by people who are unfamiliar with people with severe multiple impairments outlining how they should live. What has not been clear is how nurses perceive how people with severe multiple impairments should live. This study uncovered those perceptions and found that it is the everyday where life occurs, the life whose quality is at issue.

THE EVERYDAY LIFE OF PEOPLE WITH SEVERE MULTIPLE IMPAIRMENTS

The participants perceive quality of life for people with severe multiple impairments, not in discrete categories which when added together equal quality, but in the interaction of everyday life. Quality of life is to be found
in “just little things” and some of these little things are the everyday life of the body, the emotions and the identity.
The Everyday

“Well, my interpretation of quality of life - maybe I’m wrong, I don’t know - but my quality of life is your actual everyday living, what you get out of life and what life gives you and what have you - every day.” The study data suggest that quality of life is found in the everyday, a sociological concept which is reflected in both Nirje’s (1969) explanation of the principle of normalization and nursing’s notion of activities of daily living (Roper, Logan & Tierney, 1990), both of which influence nurses’ thinking in this area of practice. There is, therefore, an element of time in quality of life. I was alerted to this during the early stages of the first interview when I asked the general question: what do you mean by quality of life for people with severe multiple impairments? The response was: “What it is at the moment, or, I’m not quite sure what you’re asking, what their quality of life should be like ...”. The remainder of the interviews indicated quite clearly that participants thought that the quality of life of people with severe multiple impairments had changed over time, for example, “Do you want to talk about now or what happened before?” and that it could change in the future, for example, “There’s room for improvement”. There is also some suggestion that participants perceive it is what is in the everyday which makes quality of life different, but probably not comparable, for different people, for instance, “Well, I suppose, because they’re not going to have the experience that other people have and that’s all to do with the quality of life. I mean their quality of life - you can’t compare it in that sense with others - oh no, that doesn’t sound right, does it? I don’t know how ... I can’t tell you what I mean about that.” This confusion also spoke to me of the intrinsic value, or the non-evaluative quality, of the life of the individual.

In describing the “little things” which make up quality of life, the participants spoke of the everyday life of the body, the emotions and identity. It was only towards the end of this study that the now obvious
connections between quality of life, and the body, emotions and identity became apparent. From the literature it can be seen that well being is typically divided into physical and emotional well being in most models of quality of life. However, use of the terms, physical well being and emotional well being, seems to overlook the significance of this division, since physical well being is clearly related to the body and emotional well being to the emotions. The concept of identity is meant to reflect the individual who emerges as a consequence of the everyday life of the body and emotions of people with severe multiple impairments.

The Everyday Life of the Body

The body is central to quality of life because the body is how we experience life. The bodies of people with severe multiple impairments, in particular, figure significantly in nurses’ perceptions of quality of life, firstly because of the time focused on bodies which take most of the day to complete bodily tasks, and secondly, because nurses relate to the bodies of people with severe multiple impairments. The everyday life of the body is highly valued by participants and consists of three tasks: (1) being healthy, (2) being comfortable, and (3) developing.

Being Healthy: The First Task in the Everyday Life of the Body

“Quality of life is maintaining their physical health to the optimum level.” It is clear that nurses find physical health so intrinsic to quality of life that they wonder why the question is even put. “I don’t quite understand that because that just seems such a common sense thing. Obviously if you’re not physically well it’s going to affect your quality of life. Is there something hidden in that?” The task of being healthy emerged from discussion with the participants about the
bodies of people with severe multiple impairments. It can be described by eight elements: (1) being adequately nourished, (2) eliminating waste appropriately, (3) breathing freely, (4) accessing fresh air and sunshine, (5) having sufficient rest and sleep, (6) having a sexual life, (7) being sick, and (8) dying peacefully. Some discussion of these elements follows.

Eating and drinking are taken for granted by most people but for people with severe multiple impairments, oromuscular dysfunction means that they are often underweight and undernourished. "I mean, quality of life, you're talking about the best food ... I mean presentable food, tasty food" ... "variety of their food ... getting enough and of the right things ... ". Adequate nutrition means being able to consume a sufficient quantity and variety of food and fluids of suitable texture to maintain weight and hydration.

Nutrition is also related to the quantity and type of food and fluids which would enhance appropriate function of the bowel and kidneys because inconsistency of fluid and roughage and lack of movement leads to rectal distension, constipation and urinary tract disorders. "Some of them do have quite a chronic problem with their bowel elimination ... that does impair their quality of life a little bit." Waste is usually eliminated in nappies but some people can sit on toilets. "The majority of them have to wear nappies all the time because they're doubly incontinent. Some of them will go to the toilet if they're put on."

Most of us do not notice that we are breathing easily until an interruption such as a cold or inhalation of food brings our breathing to our attention. People with severe multiple impairments often have irregular and laboured breathing throughout their lives. Limited control of breathing, as a consequence of dysfunctional oropharangeal musculature and extensive orthopaedic deformities, also has several potential complications. It is particularly dangerous when people with severe multiple impairments are
eating and drinking: “they are very prone to chest infections. Many of them have breathing difficulties which have led to choking and aspiration pneumonia.”

Getting out in the fresh air and sunshine makes “you feel better yourself”. For people with severe multiple impairments, fresh air may assist with breathing, and a degree of sunshine, necessary for the production of Vitamin D, prevents further bone disorders. The sun is also “useful for healing nappy rash and pressure sores”.

People with severe multiple impairments tire easily and “they need a little bit of rest”. Rest is important as a balance to activity during the day, “people who are elderly needing more rest”. Uninterrupted sleep at night is important to physical health and “if more than one person sleeps in a room, one can disturb another”.

On the whole, people with severe multiple impairments, like most people with disabilities, are viewed as asexual. Nurses, however, are constantly confronted by the sexuality of people with severe multiple impairments. Finding adult male and female bodies under the nappies and tracksuits of people with severe multiple impairments is often a shock to the beginning practitioner. Hair on the body, menstruation, penile erections and masturbation are part of the everyday. Far less common are sexual abuse and fear of pregnancy or sexually transmitted diseases. Sensuality, on the other hand, is recognised as a window to the world for people with severe multiple impairments. Experiencing pleasure through the senses is closely linked with quality of life: “A bit of variety ... spaghetti bol ... that’ll slide down just as well as the bowl of pureed brown stuff”. “He’s usually on the floor on a mattress, so he sees everything from ground level ... so this day I sat in the swing, had him up over my shoulder and he could see the trucks. Well you should have heard him. Now he can’t talk and he’s going ‘oh! oh!’ He really enjoyed it.” “...
different sounds ... music ... not the clang, clang, clang of the noise around here ... the smell of the sea ... the grass, flowers ... just a gentle touch.”

It may seem strange to the reader that sickness and dying are included in a model of quality of life. They are included, however, because the participants talked about them. This is one example of how the participants’ words helped me shift from the concept of well being to that of humans being. Sickness and dying are not usually associated with well being, and they were not for the participants. They were, however, aspects of the everyday life of the body and, hence, associated with humans being. Just like all people, people with severe multiple impairments sometimes get sick. “Colds and influenza are common”, and some have surgery as a result of impairments. People with severe multiple impairments do not live long lives, although a combination of technology, when granted, and attentive care has extended their lives. Their body organs, nevertheless, are highly prone to repeated stresses and early failure. While the participants argue for the right of people with severe multiple impairments to live, they recognise that there is a time for individuals to die, even though this may be difficult to determine. “... he used to get so sick. I’d go home not expecting to see him again but so many times he was O.K. again ... this went on for years ... then he died.”

**Being Comfortable: The Second Task in the Everyday Life of the Body**

“Quality of life is when they’re not suffering, they’re not rolling around in pain or discomfort.” Comfort is viewed as a buffer against the physical impairments and chronic health problems of people with severe multiple impairments. Three elements of comfort emerged from the data: having clean, dry, intact skin; having appropriate body temperature; and being physically safe. Because of uncontrolled bodily excretions and immobility, the skin of people with severe multiple impairments is constantly at risk.
“Quality of life occurs when they’re comfortable, they’re clean, things like pressure area care...they’re changed.” Both immobility and impaired circulation contribute to lowered body temperature. In addition, inability to alter clothing, or to adjust heating or cooling results in fluctuating body temperatures. Thus, participants saw that “quality of life is access to warmth and shelter every day”. People with severe multiple impairments are at risk for choking during eating, injury during seizures and accidents at any time. Some developmental behaviours, for example, eye-poking, may cause injury to self and others. Their vulnerability also puts them at risk for physical abuse and physical neglect. Therefore, participants identified safety as part of quality of life: “They've got a right to safety, as we all have ... safety's a big issue.”

**Developing: The Third Task in the Everyday Life of the Body**

“Quality of life is development, knowing that the person has the ability to increase their development, perhaps from holding a spoon to holding a knife and fork. Instead of using a walker, being able to walk on their own.” Developing physically means having correct body alignment and posture, exercising muscles and joints, and developing fine and gross motor skills. People with severe multiple impairments have very limited cephalo-caudal development and rarely achieve proximal-distal control. Their impairments, as described in Chapter Two, work against physical development. People with severe multiple impairments have limited ability to align or posture their bodies, to exercise, or to develop fine and gross motor skills.

In summary, the three tasks of being healthy, being comfortable and developing make up the everyday life of the body. These three tasks are onerous ones for people with severe multiple impairments, consuming hours a day and requiring an enormous expenditure of energy. The everyday life
of people with severe multiple impairments, however, consists of more than the everyday life of the body. It also includes the everyday life of the emotions.

**The Everyday Life of the Emotions**

If the body is how we experience life, the emotions are how we express our experience of life. “Emotional well being’s got a lot to do with these people’s quality of life.” The data suggest that the body and the emotions are interdependent. The separation of the body and emotions is an artificial separation: the body and emotions are interactional. In a review of the participants' interviews, this separation may have been a consequence of my reliance on the literature, rather than the participants’ words, to make sense of, to provide a schema for, the data. In turn, this influenced both the questions I asked and my interpretation of what the participants were saying, one of the traps into which beginning grounded theorists fall (Strauss & Corbin, 1990).

Certainly the nurses in this study attempted to communicate the gestalt of the body and emotions with their implicit and explicit comments on the relatedness of what I initially labelled physical well being and emotional well being. For example, one young man’s tactile defensiveness and his unhappiness are associated: “he doesn't like eating, doesn't like drinking, he's unhappy, I think ... he doesn't like being touched, he cringes when you touch him, doesn't like being lifted”; relaxation is related to adequate nutrition: “I mean if they’re sort of happy and relaxed, they enjoy their dinner more.”

The emotions, therefore, are expressions of the body’s experience of life. The everyday life of the emotions is as highly valued by participants as the everyday life of the body. Participants spoke of a range of emotions
expressed by people with severe multiple impairments and these emotions are represented in the data regarding engaging with life. Engaging with life speaks of a sense of belonging (Hagerty, Lynch-Sauer, Patusky, Bouwsema, & Collier, 1992) and means: (1) being involved in interests, (2) striving for independence, (3) being in relationships, (4) being free from emotional abuse, and (5) reciprocating.

Engaging with Life through Interests

Being involved in interests may have different meanings for people with severe multiple impairments. Many models of quality of life would include occupation or productivity as interests. In our society, occupation or productivity most often refers to some kind of work - a job. The participants, however, take for granted that people with severe multiple impairments will not work in that sense, but will, nevertheless, engage in some activity other than the everyday care of the body. “They like going, they seem to like it because they smile and they laugh, going out - just seeing different things, other people, food - they have an interest in food, different food - and being in different places.” “The experiences a family would have“ are generally of interest to people with severe physical impairments. Outings and performances are also popular, as are some types of music and television programmes. Different individuals have a variety of particular interests.

It should be noted here that Halpern et al. (1986), in a study of quality of life for people with disabilities, found a strong relationship between occupation and community integration. The lack of a job would therefore decrease opportunities for community integration for people with severe multiple impairments. On the other hand, Borthwick-Duffy (1987) found that residential environments determine the degree of community
involvement and the above data suggest that this is the case for people with severe multiple impairments.

Engaging with Life through Independence

Striving for independence, no matter how limited, adds to engagement with life. While people with severe multiple impairments clearly cannot perform the usual activities most people take for granted, the participants noted their abilities and their persistence at a task. “He’s trying to scratch his nose and, to me, I think it is a voluntary action and it takes him so long to do it yet he’s so determined to do it. I mean we’re probably talking about three minutes, three or four minutes to lift his hand up.” Gleason (1993), too, noted such ability and persistence in his observation of two young men with severe multiple impairments at play.

Engaging with Life through Relationships

Being in relationships is limited by opportunities for people with severe multiple impairments. Relationships figure significantly in most quality of life models, particularly in those models developed for people with disabilities. While people with disabilities are often excluded from relationships, Wolfensberger (1988a) highlights their capacity to relate to others. Turnbull and Brunk (1990) go so far as to state that quality of life is measured by relationships. Certainly, in this study, participants noted a strong link between relationships and the everyday life of the emotions. It is to be remembered, however, that relationships for people with disabilities are often limited to family, peers who share accommodation and staff who work with them. People without disabilities still have more opportunities to meet other people through their interests than do people with disabilities.
The range of emotions experienced in relationships are depicted in the following examples. Participants spoke of the importance of relationships between people who have been residing together for as long as twenty years. “Well, they don't communicate in terms of words or any type of speech, and I suppose it's mainly done with touching and looking and they watch each other, one more so than the other, and they know, well they just feel comfortable having each other around, [so] that when one isn't there the other one looks around to see what happened to that person.” Not all residents have visits from their families, and it may be that not all residents whose family visit are aware of the fact. However, where family relationships exist, these relationships contribute to the everyday life of the emotions. “Yes, those ones that do [have contact], yes. Yeah, it is [important]. They can identify them, they come running and know when they’re going out. As soon as you start changing them, no matter what hour, or tidying them up, they know they’re going home, they know that someone's coming, their relatives are coming, yeah. That's pretty important to those ones.” Not all people with severe multiple impairments like interaction with staff but for those who do, it is perceived to add to their emotional life. “I park my car under his bedroom window every morning and I see him actually looking for that car.”

The excitement and anticipation experienced in relationships is balanced by the sadness upon the loss of relationships through death or separation from family, other residents, or staff. “One of the guys who had a sibling here as well, his brother passed away and the surviving brother was quite distraught ... Loneliness is a pretty horrible thing. I'm quite sure they miss people when they're gone and gone away on holidays and things like that ... I don’t know how deep those feelings are but you can see the anger and the sadness ... you’d absolutely cut your throat if you had nobody to talk to, or even though they don't talk, but just had nobody, nobody to even smile at.”
There are some people with severe multiple impairments who do not appear to participate in any relationship. They are perceived to be unresponsive to any attempt at interaction. "There's probably one or two that I can think of who are extremely miserable and I can't really give them, or add [anything] to make their life better." This observation on the part of participants represents the negative case in grounded theory which strengthens the association of relationship and quality of life.

Engaging with Life through Freedom from Emotional Abuse

People with severe multiple impairments are vulnerable to emotional abuse and/ or neglect. Instances of emotional abuse/ neglect are interpreted as not contributing to their quality of life. Emotional abuse and neglect may occur as a result of institutionalisation. "There's so much that's taken away from them in an institution - self respect, individuality, their personality in some of them, just their freedom to express themselves ... their own space, their parents, any other relatives, friends." While the participants recognise the potential abuse of institutionalisation, they are also concerned about emotional abuse in community living. "They may be more restricted in the community. Their eccentric behaviours won't be accepted. They'll have to conform, that is if they're not locked up inside all the time. They've either got to reduce that behaviour or be locked in a smaller environment where they can do it."

Engaging with Life through Reciprocating

Reciprocating is inherent in engagement with life. This is not a novel idea: Hellner and Norberg (1994) found reciprocity the principal ingredient in the relationship between nurses and severely demented patients. The nurses in their study attributed worth and dignity to the individual and took
for granted that the individual had something to give. Geanellos (1997), in her themes of mutuality, attachment and self knowledge, also found that nurses recognise the nature of their relationship with their clients and how they receive from them. What is interesting in the present study is how this reciprocity occurs between nurses and people with severe multiple impairments.

According to Bogdan and Taylor (1989), one of the ways that nondisabled partners maintain the humanness of people with disabilities is by viewing the other as reciprocating: reciprocating is defined as giving back something important in the relationship - companionship and social relations, and as having a sense of accomplishment in contributing to the other's well being and personal growth. These ideas are also reflected in this study, for example, participants often referred to that which people with severe multiple impairments give them. One participant said: “It’s nice when you come in and they’ll recognise you. It isn’t all give, it’s giving and taking”.

Most participants are satisfied with such social relationship, but many stress a more important aspect of their relationships with people with severe multiple impairments: learning and growing. “I think I've learnt with them, the way they are, the life that they have to live, I have learnt different things from them, for example, the way they endure pain.” The participants' sense of accomplishment in contributing to the life of people with severe multiple impairments is also evident in the data. Doing something which a person with severe multiple impairments wants “reaffirms my role. It makes me feel good.” “I know I can make a difference.”

The Everyday Life of the Identity
For the participants, there is a connection between the everyday life of the body, the emotions, and the person (or identity). “I could keep going about those sort of differences, they all sort of intertwine and, because they’re profoundly disabled, people tend to treat them, I think, like they’re just this body with a whole lot of things that are wrong with it, without thinking that there’s a person in there that might have feelings and emotions [emphases mine].” When speaking of the everyday life of the body and emotions, I have been referring usually to people with severe multiple impairments collectively. The participants made it abundantly clear, however, that they relate to people with severe multiple impairments individually. It is this emphasis on individuality which led me to use the term “identity”. The participants often used the words “individual” and “personality”, for example, “I mean they all are individuals. They might all have epilepsy and all have spasticity but they've all come from different families, different countries, so they’re very different. They have different personalities. They’re all very, very different.” Stone and Farberman (1986, p. 155) say that, in psychology, personality refers to “persistent and characteristic patterns of individual behaviour” and prefer the sociological term, “self”. A definition of “self”, however, remains problematic, as was briefly discussed in Chapter Three. Moreover, “self” implies an “I” and a “me”, and it is particularly difficult to get at the “I” of people with severe multiple impairments. As a result, I leaned towards use of “identity” because, as both Perinbanayagam (1985a) and Stone (1986a) state, the term “identity” better reflects the various roles and situations in which a person exists, and refers to the “me”, a concept which is more available in this research. This use was further reinforced by the presence in the data of (1) varieties of identity, (2) how identity is defined by preferences, and (3) how preferences and values relate to quality of life.

Varieties of Identity
“Almost all writers using the term imply that identity establishes **what** and **where** the person is in social terms ... One's identity is established when others **place** him [or her] as a social object ...” (Stone, 1986a, p. 188). Given the variety of placements, it is not unexpected that there will be a variety of identities (Perinbanayagam, 1985a). Stone (1986a) lists four vocabularies which demonstrate the varieties of identity: (1) universal words designating one's humanity; (2) names and nicknames; (3) titles, usually referring to occupation; and (4) relational categories such as customer. In an earlier typology, Gross and Stone (1964) talked of human, structural (or occupational), interpersonal (indicated by nicknames) and existential identities. All of these varieties of identity were represented in the data of this study.

The allocation of a human identity has already been discussed in this chapter. Use of nicknames by nurses is common and interpersonal identities strong: my brother, for example, is known by many as “Mr Cool”, a nickname which conveys considerable information about him. While the existential identity has been dropped from Stone’s later typology, people with severe multiple impairments are still identified by some as “holy innocents” or “God’s punishment” (Wolfensberger, 1969). Interestingly, even when asked about existential identities, nurses in this study denied any attribution of them, the most common reason being “I’m not a spiritual type of person”, although I think this needs further investigation.

People with severe multiple impairments do not have an occupational identity and are rarely given titles. This is also the case with children. It should not be surprising, then, that participants often refer to people with severe multiple impairments as “kids”, reflecting both their structural and their relational identities (although they may use the word “resident” in reference to the latter identity). The use of the word, “kids”, is ambiguous and worthy of further study. I found two references to such usage. The first
was in Bogdan’s (1992) work regarding community acceptance of people with developmental disabilities. In his inimitable style, Bogdan tells of “simple” dairy-farming brothers living in a small community who were referred to as “the boys”. Aware that demeaning child-like imagery of adults with developmental disabilities is an important target of concern for people in this field, Bogdan was surprised to find that the use of “boys” in this context did not have a negative connotation but rather, the word was endearing and constituted a designation for those who belong. The second reference was in Anne Deveson’s (1991) book about her son with schizophrenia. She did not try to explain why staff involved in an alternative treatment programme called people with schizophrenia “kids”; she simply reported it. The situation, however, was similar to that of people with severe multiple impairments, reflecting the inadequate living skills and the vulnerability of people referred to as kids, and conveying a sense of family where staff “mother” the “kids.” “I mean you don’t look on any of them as an adult, you look on the lot of them as kids because you’re always doing things for them ... they are helpless and they are dependent on you ...”

It can be seen, therefore, that varieties of identity differ markedly between nurses who are familiar with people with severe multiple impairments and people who are not familiar with them. Nurses place people with severe multiple impairments socially as humans, with names, who, in terms of their dependence, are like children. A xenophobic society places them as not human, with no names, as a burden on society, and occasionally, as holy innocents and/ or punishments from God.

Stone (1986a) has also explored the relationship between identity and appearance. He says that identity is established, maintained and altered as much by appearance as by other forms of communication such as speech. The appearance of people with severe multiple impairments does much towards establishing their identities. Goode’s (1984, p. 231) first encounter
with people with severe multiple impairments led to a response of "profane object, monster or object of disgust". He was initially unable to relate to them as human. Appearance, therefore, has a significant impact on interaction with others. Goffman (1969) says that information about the individual helps to define the situation and that information is conveyed through various means, including appearance. The participants' awareness of the effect of appearance is found in the following quote: “A lot of these kids haven’t got a lot going for them. So I figure it's really important that, when they're dressed, they have matching gear and their hair's combed and they're shaved and their finger nails are clean and cut.”

How Identity is Defined by Preferences

Participants also identify individuals in another way: by the preferences of individuals. There were many examples in the interviews of how preferences differ among individuals and how this is important to the identities of individuals.

Participants noted, for example, that individuals have food preferences. “They know what they like to eat. I know they like some foods and they dislike other foods.” Some individuals show indifference to being comfortable but the majority demand particular mechanisms for achieving comfort. “They prefer a bath or a shower.” “They come back really distressed [after a trip in a hot car].” Most have preferences for body alignment and passive movement. “They know what positions they like being in. They indicate how they like to be lifted.” Some individuals demonstrate no preference for environment, “they don’t appear to know where they are”, while others prefer particular environments, “he always goes down the back [of the unit]. He loves the trees, he loves the grass.” Some show no interest in anything, “they don’t appear to enjoy anything”, but others have specific interests: “Now, with one boy, I come on at 3 o’clock and the
TV's on football and I hate football. I tell him how much I hate football and I stand in front of the TV and he's going like this [waving her aside]. I know when it's winter. But you've got no idea how important watching football is to that kid. It's just his whole life. Winter, he just comes to life because there's the football.” Some people with severe multiple impairments prefer interaction and others require a lot of personal space. “I mean we have some, not very many, that really don't like being touched ... I mean one boy absolutely loves you just going like that [tousling his hair], and another girl just likes doing that [hand games] - she'll come up to you and she'll get your hand and she'll do like that, so I mean that's an indication that she wants it - but then if you did it to somebody else who really didn't like it they'd go ‘aaagh’ and pull himself away, so I mean that's his indication that he doesn't like it.” Preferences for other people's company can be quite clear. “John likes to sit with Paul- then they'll eat their food and behave ... Now if certain ones aren't sitting in certain positions, they won't do what you want. They'll make life difficult in terms of - I won't feed. I won't eat this food, I'll spit it out. And that happens. And I suppose it's their way of being angry.”

In each of these examples, participants identify particular individuals by their preferences. Participants also think that individual preferences are probably much broader than this but that institutionalisation limits the opportunity to express those preferences: “They do not get to make any important decisions - things about what you're going to wear today, how you want to spend that money, handling their own affairs - they don't even get consulted.”

How Preferences and Values Relate to Quality of Life

A number of quality of life models include the concept of choice, some suggesting that choice is central to quality of life. The model which emerged from this study includes the notion of preferring. "Preference", however, implies a more limited range of alternatives than "choice" and is probably grounded in the limited ability and limited experience of people with severe
multiple impairments. The link between preference and quality of life is found in the work of Fretwell (1990) who states that personal preferences are intrinsic to quality of life and quality of care for the frail elderly.

Overall, individual preference is a pivotal concept within this study’s concept of quality of life since it is these preferences which make the difference in individual quality of life and explain how one person's quality of life is different from that of another. The inclusion of the concept of preferring in a concept of quality of life implies that quality of life means having some control over that life and supports Lachs’ (1986) notion that we make quality of life decisions in miniature every day. It also acknowledges that people with severe multiple impairments each have an identity, defined by their particular likes and dislikes and that they can affect, at least to some degree, their own quality of life.

It is interesting to note that, despite the acknowledged centrality of preferences, nurses' values often override preferences. Some activities of daily living are so valued by the participants that the preferences of people with severe multiple impairments are put aside. Nurses may attempt to achieve the activity in a different way or at a different time but the activity will occur. Eating, for example, is so crucial to a person's survival that persistent food refusal is not acceptable to the nurses in this study. The following quote about hygiene highlights this point but also provides some explanation of the relationships among valued activities. “One little boy, the minute you bathe him or go to undress him, he screams. To me, he is indicating he doesn't want a bath but we know damn well that he's got to have a bath because if he doesn't have his bath he's going to get stinky and horrible and get sick so we just ignore the screams and laugh it off and bathe him. I mean, we don't hold him down to bathe him but we just sort of bathe him.” It can be interpreted that this nurse’s values include the relationships between the person's hygiene and health, as
well as between his hygiene and appearance and hence his longer term quality of life in contrast to the unhappiness associated with bathing.

In summary, the everyday life of the identity of each person with severe multiple impairments emerges from the everyday life of each person’s body and their emotions, and nurses define their identities by their preferences for the lived experience of their bodies and emotions. The body, emotions and identity occur simultaneously and have only been separated in this chapter to add to understandings of the everyday lives of people with severe multiple impairments. The everyday lives of people with severe multiple impairments include: the tasks of health, comfort and development of the body; the expression of emotion through engagement with life; and the emergence of an identity defined by preferences.

**SUMMARY**

As identified in the review of the literature, all models of quality of life have underlying assumptions. Nurses take for granted so much about people with severe multiple impairments, and their work with them, that it has been a particularly difficult task to uncover their assumptions. Nevertheless, the preceding data has begun to make explicit some of the participants’ assumptions about the quality of life of people with severe multiple impairments. To recap, the nurses in this study assume that people with severe multiple impairments are human, that society generally views people with severe multiple impairments as less than human, and that the humanness of people with severe multiple impairments entitles them to all the same rights and privileges as other humans.

With these assumptions in mind, quality of life is meaningless without, firstly, having a life, and secondly, living the life one prefers. Therefore,
quality of life is somehow diminished when people with severe multiple impairments have to contend, in the first place, with unnecessary threats to their very existence and then, have to argue about the lives they want to live. The antithesis of such threats and arguments is the concept of humans being. Humans being refers to the humanness of people with severe multiple impairments, and therefore their right to have a life, and also to their everyday lives, and their right to live it as they wish. This concept slightly shifts the meaning of quality of life because it means more than what is usually meant by well being, a term often used interchangeably with quality of life. Everyday lives are not just healthy and happy lives, but are lives which capture all the human experiences, including sickness and sadness. This is not to say that the participants think that sickness and sadness contribute to well being, but rather, that their concept of quality of life moves beyond well being to encompass the whole of life in quality of life.

In summary, the first theme of “just little things” is humans being, the everyday life of people with severe multiple impairments. Everyday life is experienced by the body and expressed through the emotions. People with severe multiple impairments have attributed to them a variety of identities in their everyday lives; for participants in this study, the identities of individuals with severe multiple impairments are defined by each individual’s preferences. Nurses’ perceptions of quality of life for people with severe multiple impairments, therefore, includes their everyday lives from which their identities emerge.

It has been suggested by a number of authors (for example, Heal and Sigelman, 1990; Taylor and Bogdan, 1990) that in order to understand quality of life, we need to understand the lives of people with disabilities. The participants in this study have demonstrated such understandings of the life in quality of life. It would be a mistake, however, to conclude that nurses’ perceptions of quality of life consist only of the concept of humans
being. The complexity of the everyday life of people with severe multiple impairments is simply one aspect of “just little things”. Based on the understandings of the everyday life of people with severe multiple impairments the participants described a second theme of “just little things”: supporting. Supporting is where the quality in the everyday lives of people with severe multiple impairments resides and is taken up in the next chapter.
Chapter Eight

SUPPORTING: THE QUALITY IN QUALITY OF LIFE

The nurse is temporarily the consciousness of the unconscious, the love of life of the suicidal, the leg of the amputee, the eyes of the newly blind, a means of locomotion for the newborn, knowledge and confidence for the young mother, a voice for those too weak to speak, and so on

(Henderson, 1978, p. 121).

This chapter focuses on the second theme in nurses’ perceptions of quality of life for people with severe multiple impairments as “just little things”: supporting. Supporting refers to the quality in quality of life. The chapter discusses, firstly, how the everyday life of people with severe multiple impairments is different from that of others. Secondly, it examines how I came to see that quality resides in the concept of supporting. Thirdly, it describes how the participants complete acts to support the lives of people with severe multiple impairments. These aspects are depicted in the shaded area of Figure 8.1 and the emergence of the concepts can be found in Appendix XII.
DIFFERENCES IN THE LIVES OF PEOPLE WITH SEVERE MULTIPLE IMPAIRMENTS

It is quite clear, even to the casual observer, that people with severe multiple impairments would literally die, just as infants would, if no one attended to them. People with severe multiple impairments are unable to produce any effective movement to sustain life and they are also unable to communicate in the usual way their needs and desires. They are unable to seek meaning in isolation; they are dependent on other people to make their lives meaningful. “I think the quality of their life here obviously depends on the staff that are working here. They’re totally dependent on the staff in the ward. Totally. For everything. Absolutely everything.”
While the previous chapter depicted the dependence and vulnerability of people with severe multiple impairments in their everyday lives, it also showed their humanness and strengths - what O'Halloran (1993) called “difability”. Unable to achieve alone the tasks for health, comfort and development of the body, people with severe multiple impairments nevertheless engage in these tasks. Limited as they are in the expression of their experiences, they convey a range of emotions, and engage in an emotional life reflected in their interests, their attempts at independence, and their relationships. Crucial to quality of life is the emergence of an identity, and while the identities of people with severe multiple impairments are usually described in terms of others' experience with them, identities defined by preferences nevertheless emerge.

So, while this chapter focuses on the dependence and vulnerability which makes the lives of people with severe multiple impairments different from those of others, this dependence and vulnerability must be seen within a context of reciprocity. It cannot be ignored that all of us are dependent on others in some way, and it is this interdependence which defines our humanness.

**QUALITY RESIDES IN SUPPORTING**

The participants' assumption of the humanness of people with severe multiple impairments is associated with the right to life, as discussed in the previous chapter, as well as the right to quality of life. “They have a right to the same things as you and me ... good things, enough things”. “I mean, I'm a believer that everybody deserves what I deserve in life.” The concept of quality in quality of life, however, remained elusive for some time. Difficulties were encountered in interpreting the participants' words because the lives of people with severe multiple impairments were so closely interwoven with
the care given. During the interviews, participants tended to use the phrases "quality of life" and "quality of care" interchangeably. I could artificially separate quality of life and quality of care for discussion, but the participants soon lapsed back into the interactive nature of their meanings of quality of life and quality of care. Thus, quality of life, for people with severe multiple impairments, was only meaningful to the participants in the context of quality of care.

This lack of differentiation of the two concepts on the part of the participants was my introduction to the frustration of the grounded theorist having to move away from their usual way of thinking. It was an excellent lesson in letting go of the usual schemata and trying to make sense of what the participants were saying. The breakthrough came when I found the concept of well being described by Shibutani (cited in Meltzer et al., 1975, p. 33) as a dynamic-tension state which is restored to equilibrium by the strategies employed. This reminded me of the words of a participant during one of the focal group interviews. She insisted that "quality of care was more important than quality of life", in this situation with people with severe multiple impairments, because it was the strategies employed to restore equilibrium which made the difference. From there, I decided that the quality in quality of life resides in supporting.

The concept of supporting is reflected in Henderson's (1978) definition of the unique function of the nurse as found in the epigraph of this chapter. My interpretation of the participants' descriptions of quality of life was influenced both by Henderson and Shibutani: nurses supporting the lives which people with severe multiple impairments want to live. Such supporting occurs via a number of everyday acts. People usually perform suitable acts for themselves, but given the extreme dependence of people with severe multiple impairments, nurses act on their behalf.
COMPLETING ACTS

The name of this process was inspired by three different sources: symbolic interaction theory, and the nursing theories of Virginia Henderson and Dorothea Orem. When applied to nursing, Mead’s (1938) theory of the act proposes that nurses can anticipate how people with severe multiple impairments are going to behave, if only they could, by observing the incipient act in the gesture of these people. Completing acts, therefore, refers to nurses completing, for people with severe multiple impairments, the incipient act they saw in the gesture. Henderson (1978) defines nursing as helping people in the performance of activities that they would perform unaided if only they had the necessary strength, will, or knowledge. With regard to people with severe multiple impairments, nurses complete acts on behalf of, indeed, instead of, the person, because this is what they mean by quality of life. “I mean, quality of life, it’s very difficult to actually explain, because what we have as quality of life and what they have as quality of life are two totally different things, because we know what we can get for ourselves whereas they can’t get it for themselves ... and I think I, as a nurse, have to give them in whatever way possible I can give.”

Nurses complete acts, however, in relation to the level of ability of the individual with severe multiple impairments. Orem’s (1985) self-care deficit theory of nursing, therefore, is useful in that it includes a theory of nursing systems which elaborates on Henderson’s concept of nursing as helping, by describing three ways of helping: wholly compensatory, partially compensatory, and supportive-educative. These three ways of providing self-care describe the levels at which nurses complete acts which the person cannot. It is also interesting to note that acting, as one of the processes of nursing practice, is not unfamiliar to nursing and was found in MacLeod’s (1994) study of expert nurses in a surgical setting. The acts which nurses complete for people with severe multiple impairments are those which
support the everyday life of the body, emotions and identity. I have therefore called them: (1) body acts, (2) emotion acts, and (3) identity acts.

**Body Acts**

The nurses provided an enormous amount of data to support the concept of body acts and it has been condensed with regard to space. The amount of the data suggests a number of ideas about body acts, including: the focus on the body; the ease with vocabulary related to the body, as opposed to the difficulties with vocabulary associated with emotions and identity; the emphasis in nursing on doing; and the inference that body acts are vital to the quality of life of people with severe multiple impairments. Body acts reflect the everyday life of the body described in the previous chapter as participants described body acts in terms of supporting the health, comfort and development of the body.

**Supporting the Health of the Body**

The body acts which support the health of the body include: (1) providing adequate nutrition; (2) assisting with appropriate elimination of waste; (3) monitoring respiration; (4) providing access to fresh air and sunshine; (5) ensuring adequate rest and sleep; (6) promoting the sexual being; (7) supporting in sickness; and (8) enhancing a peaceful death.

The participants describe providing adequate nutrition to people with severe multiple impairments as "just basic care". It is seen as simply part of the everyday, taken for granted. On closer observation, however, it has many elements. Food refusal among people with severe multiple impairments is common. The task of assisting someone with eating takes half an hour on average
(Ohwaki & Zingarelli, 1988). One nurse would help approximately six people to eat at any one meal. Adequate nutrition is maintained by: the presentation of several meals a day, promotion of independent eating, use of neurodevelopmental techniques (Bobath & Bobath, 1967) to reduce abnormal reflex patterns, methods to overcome food refusal, communication about intake and weight, and patience during mealtimes. “When it comes to eating they either push your hand away or just clamp their mouth shut. I give them two or three chances. I'll put the food down and go and feed somebody else and come back to them. If they continue doing that after the third time I'll say, okay, this person just doesn't want to eat this. That's fine. I wouldn't eat it myself. So we'll go and I'll try the dessert.” Fluid intake is a problem too. It is usually much more difficult for people with severe multiple impairments to swallow liquid than to swallow food, because it requires more oromuscular control than they usually have. They are forever running the risk of aspiration and are often quite frightened on presentation of a drink. Nurses ensure correct timing of breathing and swallowing.

As with eating, management of their bowels is considered to be everyday. There are two major concerns: avoidance of constipation, and toilet timing for those who can sit on a toilet. Therefore, strategies to avoid constant enemas and suppositories are used; for example, “massaging the abdomen”, “a high fibre diet is worth a try but it is probably too chronic a problem to make any difference after twenty years. [It is better to] sit on the toilet for ten minutes every morning rather than have an enema once a week.” It is also important to “record bowel motions properly to avoid unnecessary rectal examination with the risk of bowel perforation and invasion of the person's privacy.” For those who can sit on a toilet, “they can be toilet timed “ for the elimination of urine and faeces. Most people with severe multiple impairments wear nappies, and nurses, utilising universal precautions, change these when necessary to provide comfort.
Monitoring respiration is another body act performed by nurses to support the health of the body. To ensure adequate breathing, “chest physiotherapy is performed, medication is administered and monitored”, potential risks for pneumonia and asphyxia are monitored, and instances of choking, seizures and status epilepticus are managed. Pneumonia is treated very seriously because it is frequently the cause of death for people with severe multiple impairments. “Trained nurses will recognise that for a lot of them here, a cold, a sniffle, means pneumonia twelve hours later.” The risk of choking on food is high, so attention is paid to the consistency of food and there is close monitoring during eating. “Some of them are so fragile. When you see some of the older guys here, they've got lovely teeth. We have volunteers here that come in and [people with severe multiple impairments] can't chew. They give them that jube or whatever, I mean they just swallow it.” During grand mal seizures, the person usually stops breathing for about thirty seconds because the diaphragm is rigid. This is generally followed by a large inspiration of breath; if there is anything in the person's mouth at the time of this inspiration, it may be inhaled. During a discussion of eating and potential seizures, one participant said: “The staff are aware of people in here who have epilepsy. So if they do have a seizure, we can cope with it.”

Providing access to fresh air and sunshine is a body act which nurses employ to support the health of the body. The participants use “mild days” as opportunities for fresh air and sunshine because, as people with severe multiple impairments live in an environment with controlled temperature and are physical fragile, nurses are extremely wary of exposing them to very hot or very cold weather; the risks of “colds, and sunburn of sensitive skin” are too great. Apart from the health-giving properties of fresh air and sunshine, participants discuss it in the same breath as “a change of environment” and access to the “natural habitat”.

According to the participants, nurses provide a balance of activity and rest during the day for the people with whom they work. “After lunch, they lie down. They’re out of their chairs and they’re having a lie down.” They are sensitive to the need for rest of elderly people with severe multiple impairments. “I don’t push the older ones to do things that they don't want to do.” “Relaxation ... warm drinks ... special beds and bed making” help promote sleep. Nurses “do rounds to check that they’re asleep, that they’re comfortable in bed” and “move an unsettled person to another room”.

“It doesn’t make any difference (whether they are male or female) in how I relate to them.” This is essentially what the participants said about the sexuality of people with severe multiple impairments, but the body acts they completed were significantly different. Hairstyles and mode of dress, particularly colours, are typically gender specific. Choices are made about facial hair for men but, interestingly, female axillary and leg hair is unshaven. Females often wear face make up and nail polish. The management of menstruation is ethically complex. Penile erections and masturbation (male and female) are usually ignored. If acknowledged, it is usually with gentle humour. Overall, overt sexuality for people with severe multiple impairments is an undefined area and further study is required in order that greater understanding may occur. In relation to sensuality, the participants are extremely alert to a rich sensory environment. While they said that people with severe multiple impairments do not receive enough sensory input, there was evidence, during the observation period, of the provision of touch, massage, temperature, different postures and movements, water, mirrors, different music, colour, different textures to touch and eat, different aromas, indoor plants, and a pleasant leafy outlook.

Maintenance of health and special attention when people are sick are acts which support the everyday life of the body. Maintenance of health occurs through the completion of the body acts already mentioned and also through special procedures: “you get blood tests taken [to check] anticonvulsant
levels ... you see that they’re getting the right medication, that they have their physical checkups, that they’re up to date on all their tests ... one of the boys, we want to get a standing frame for him, so we sent him off to get x-rayed first to make sure that his legs and hips are not too weak to stand the way that he’d stand on his legs in a standing frame”. Participants are alert to early signs of illness or injury, for example, “After we’ve been with them so long we can sort of say, ‘look, so and so’s not very well today’ ... maybe the doctor should look at him”. If individuals are very sick, they might be hospitalised. Knowing the difficulties people with severe multiple impairments encounter in unfamiliar settings with unfamiliar people, nurses often send profiles with them to hospital to assist with the everyday life of the body: “The biggest problem is feeding ... we have a profile on every one of our residents ... so that profile could go up with the patient, it could be clipped on the base of their beds for all staff to read and know how to feed them.”

If individuals are sick but remain in the unit, it brings out special feelings in the participants, which might better fit under the heading of emotion acts but are left here for the sake of continuity. “If they’re physically unwell, they might get more attention ... sort of loving attention.” “It’s a combination of some sort of nursing care for them but also in [nurses’] hearts they care for them.” During the observation period, participants told me that they feel sorry for people with severe multiple impairments who are sick or injured. The tenderness I witnessed when one participant was bathing a girl with a fractured femur exemplifies the acts which are completed for people during illness.

So too for the acts completed when a person is dying. While I did not observe any participant interacting with a person who was dying, there were glimmers in their words of how it might be, for example, “He knew the staff that he loved or that liked him. Any sound whatsoever, you could have him in fits of laughter, he would really cackle. I mean, the day he died, I was just sort of going like
this [blowing] on his belly and he was cracking up, he thought it was wonderful. I came in the next morning and he'd died.” During the observation period, one participant told me of the relief she felt when one of the young men died because the period of dying had been such an emotional time, and of the grief she, and others, experienced when he died: “I cried and cried ... all the nurses were crying”. The final act is attending the funeral. “I mean, he had a fantastic funeral because there were just so many staff that really thought he was lovely ... it’s hard coming to terms with it, but to me it seems a good indication of how staff feel that, even staff on their off duty time, would take time to go to that kid’s funeral.”

Supporting the Comfort of the Body

As well as completing body acts which support health, nurses complete body acts which support the comfort of the body. These acts include: attending to the skin, monitoring body temperature, and ensuring the safety of the body.

Clean, dry, intact skin is maintained by bathing and changing people with severe physical impairments and using positioning and waterbeds for pressure area care. These acts were again seen by the participants as everyday. “It's just basic: bathing, changing them, change of position.” Appropriate body temperature is maintained by the use of appropriate clothing, by moving people inside and outside the unit, by giving warm or cool drinks, by adjusting the environmental temperature and by attention to pyrexia. “Make sure that they're warm enough or cool enough. They might need a drink of cold water or something cool if they're hot.” To ensure safety of the body, a number of body acts occur: the environment is monitored for safety risks, environmental protection is provided, physical neglect is countered, people are handled gently and restrained when necessary.
There was concern on the part of the participants when referring to the use of restraint. They were reluctant to discuss the issue in the current atmosphere of interpretation and misinterpretation of normalisation and guardianship legislation. When pressed, they identified the problem of their duty of care versus the service policy of individual rights. A policy of individual rights does not allow restraint to be used without specific written permission from the Guardianship Board. While most nurses, therefore, are reticent about acts they use to ensure safety of the body, they believe that the issue has to be brought into the open, especially given the imminent move of people with severe multiple impairments to community living. “I mean a kid had his tooth out the other day and he’s always putting his hands in his mouth. So we couldn’t stop the mouth from bleeding. So I put splints on his arms for two hours. To me that was the right thing to do.” Nurses see such splinting as an example of their duty of care and fear that it would not occur in community living, with the person consequently suffering through continued bleeding and possible infection.

Supporting the Development of the Body

Finally, there are body acts which support the development of the body including: the promotion of correct body alignment and posture, exercise for muscles and joints, and fine and gross motor development. “You might need to spend an extra couple of minutes positioning them right. If you haven’t got them positioned properly or they slip down, then you sit them up again.” To promote correct body alignment and posture takes time and the use of aids to position people with severe multiple impairments correctly. Commonly used are beds, wedges, mats and standing frames, orthopaedic shoes and appropriately adjusted wheelchairs. Exercise for muscles and joints is provided through passive ranging, hydrotherapy as well as active movement. Passive ranging is
performed during the activities of daily living and when there is a break in 
activities. “I mean you do it when you’re bathing them. You get them to move 
their arms and their legs and you straighten them all out. I mean when you’re 
sitting there it’s no problem really to do some little passive range exercises with 
them.” Nurses also promote motor development during the various activities 
of daily living with attention to fine and gross motor skills. “You would 
encourage, really encourage them to help, to be able to lift the fork, to push their hand 
through the arm hole of a top. Then you would also have them using a spoon which 
is designed for them ... All types like finger painting, tactile stimulation, 
physiotherapy in the afternoon, all sorts of things.”

Body acts, then, are those acts which support the everyday life of the 
body; the body’s health, comfort and development. Participants perform 
these acts on behalf of people with severe multiple impairments who are 
unable to complete such acts for themselves. It was interesting to see, during 
the observation period, how nurses tailor their support by only completing 
acts which the individual intended but was unable to perform. Body acts, 
however, are only one way of completing acts. Participants also perform 
emotion acts to support the everyday life of the emotions.

**Emotion Acts**

Body acts and emotion acts occur with and through each other, one 
shaping the other. If, for example, the body is clean (a body act), it follows 
that the person is more likely to be the recipient of interactions (an emotion 
act). “He had a running nose dripping down his face - it made me feel ill. I had to 
wipe his nose so that people could find something nice about him.” Alternatively, if 
people with severe multiple impairments are relaxed (an emotion act), eating 
is much more effective (a body act). “… and when I put the dress on she just 
laughs and laughs and that has sort of heightened her mood and she’s in a better
mood and then she's easier to feed, easier to get on with.” In this way, emotion acts support engagement with life and include: (1) assisting with involvement in interests, (2) promoting independence in activities, (3) encouraging relationships, and (4) providing emotional security.

**Assisting with Involvement in Interests**

The participants assist people with severe multiple impairments with involvement in interests by identifying individual interests and maintaining them, by exposing them to potential interests, and by adapting the environment for better access to interests. “If someone sees a person who seems to be interested in something, in doing something, they will persist in doing that.” The array of potential interests include indoor and outdoor activities, organised and spontaneous activities, activities which are educational, which develop motor skills, which are relaxing, and which are just plain fun. They include school, activities groups, musical activities, water activities, food, outings and games.

**Promoting Independence in Activities**

The name of this emotion act was purposely chosen to differentiate independence in activities (a skills based process) from independence as a mark of individuality, as recognised by Corbett (1997). The concept of independence in activities is addressed here, while the latter concept is incorporated into identity acts later in this chapter.

Promoting independence in activities was expressed by one participant as: “You don't always do everything and you encourage that person to help you.” Promotion of independence in activities means having expectations about the potential ability of people with severe physical impairments, emphasising the
importance of practising skills at the appropriate time in the appropriate environment, giving consistent instructions and praise, and allowing time for individuals to develop independence.

Encouraging Relationships

Encouraging relationships means nurses being involved in relationships with individuals and their families, facilitating relationships between individual residents, encouraging contact with the world external to the large residential centre, and teaching the uninitiated how to relate with people with severe multiple impairments.

The primary relationships of people who live in large residential centres are with the staff, as they are with the residents more consistently than anyone else except other residents. Residents “relate better to staff because staff are able to talk to them, take them for walks, do activities with them”.

To promote relationships between people with severe multiple impairments and their families, it is necessary to get involved with the family to discover who and what to talk about and to encourage continuation of the relationship. The participants watch the responses of people with severe multiple impairments and their families to visits and observe the sadness of individuals who miss out on expected visits. They know that some people with severe multiple impairments recognise members of their families but are unsure whether others do. They encourage relatives to visit or take individuals out by having no restrictions on hours and try to maintain relationships between individuals and their families. “So, I mean, if mum arrives and these kids smile or sort of do something, who'd take that away from them? You just go along and you say, oh yes, she really does smile and she really appreciates you coming.”
Facilitation of relationships between people with severe multiple impairments is achieved through knowing who likes whom and bringing them together for meals, activities and outings. “[They think] I’ll probably be next. They’ll take me over and we’ll just sit together for tea, and they are sat together.”

Contact with the ‘outside world’ is encouraged through visits to the unit by students, volunteers, special friends and advocates, and occasional ventures into the community. Nurses attempt to put the uninitiated at ease in the presence of people with severe multiple impairments, by pointing out positive features of individuals and helping people to talk with them in an everyday way. “I think now, because I work in the field, I think I can see people’s apprehension before it actually gets, well [before] they actually express it. I mean sometimes I try to help them through the fact that this person is twisted up. The person’s in no way going to hurt you.”

**Providing Emotional Security**

Protecting against emotional abuse and/or neglect means having a consciousness of the everyday feelings of people with severe multiple impairments. “I’m sure they can appreciate. We make the choice on their behalf as a staff member, on the understanding that we take into consideration how the person feels.” It means engaging in an emotional life through intimacy, for example, making time in the day to sit with individuals, hold their hands, massage their foreheads. “Just to have someone put their arm around them. Just to feel the warmth of somebody else.” It is easier to do this with some individuals than others, but it seems that each individual receives time and intimacy from someone. Such intimacy may explain how negative attitudes expressed towards people with severe multiple impairments angers the participants, as can be seen in this
example. “The doctor came over one day with a couple of medical students and Matthew was sitting in his wheelchair. Now Matthew is such a little delight. He’s noisy and he loves attention and he leant over his wheelchair and touched one of the medical students and this fellow just about jumped out of his skin and he just looked down his nose at Matthew. Now Matthew did it again, touched him and the fellow moved. I just felt like getting, I did, I felt like getting this fellow’s head and hitting it on the wall and saying “for heaven’s sake, this is a kid, say hello to him.”

**Identity Acts**

As well as completing body acts and emotion acts, participants complete identity acts for people with severe multiple impairments. Identity acts are those acts which firstly, support the particular identities of individuals, and secondly, promote positive images of people with severe multiple impairments generally. Identities are supported through the acts of (1) impression management, (2) discerning preferences, (3) managing resources, and (4) advocating.

**Impression Management**

The concept of impression management draws on the work of Goffman (1969) who argued that the presentation of self, including the appearance of people, is instrumental in the way that others define or identify self. It is the connection between the impression that people make and how this affects their life chances (Goffman, 1983) which gave this category its name. Nurses endeavour to manage the impressions that others have of people with severe multiple impairments. They attempt to overcome the identities usually attributed to people with severe multiple impairments by carefully presenting the identities which they have come to know. Participants make
an effort to present positive images of people with severe multiple impairments generally through their appearance. “Caring that the kids have colour co-ordinated clothes on or the clothes fit properly and the hair looks nice or they’ve had their shave.” Grooming entails attention to hair, beards, eyes, nose, mouth, ears, nails, menstrual care and clothing. It was also noted, during the observation period, that participants support the particular identities of individuals through the use of names and nicknames, and through acts to enhance particular features of individuals, for example, the participant put away the communal clothes laid out the night before for Therese and chose other clothes about which she said “the colours suit her better”. I also noticed that Alan had grown a full beard since I last saw him. When I asked about it the nurse said that it had “started as a bit of a joke but it really suited him”. And it did.

**Discerning Preferences**

When I presented the second version of the model of quality of life for people with severe multiple impairments to a group of peers at a conference (Atkins, 1992), a member of the audience asked what it was that made this model different from a situation where nurses decide what is best for individuals and then go ahead and do that. The difference, as I said then, is in nurses discerning what it is that the individual, not the nurse, wants. The notion of discerning preferences is implicit in work on nurse patient relationships/interaction (for example, Kasch, 1986), in work on individualised interventions (for example, Horvath, Secatore, & Reiley, 1990) and in studies of knowing in nursing (for example, Swanson, 1993; Tanner, Benner, Chelsea, & Gordon, 1993). One aspect of building relationships, seeing the person as an individual (an identity), and getting to know patients is discovering what they like as a way of providing it. Radwin (1996) identified discerning preferences as an explicit strategy of the process of knowing the patient.
Discerning preferences, in this study, means spending time getting to know people with severe multiple impairments in order to identify their preferences and then manipulating situations wherever possible in an effort to suit those preferences. Discerning preferences is perceived by nurses as part of the everyday. “We’ve got to know what they like and what they don’t like. As far as possible we do cater to their preferences.” Discerning preferences requires spending time getting to know people with severe multiple impairments through observation and by asking relatives in order to identify their preferences. “You get to know what they like, what they don’t like, what makes them happy, what makes them sad. You find things from their family about likes and dislikes.”

There are some relationships among discerning preferences (an identity act) and the everyday life of the body and emotions. Nutrition, for example, is enhanced when the individual is presented with preferred foods. “Let’s say one person prefers a milk drink, and if you don’t know him well, you give him an orange drink and he’d throw it away. But being with him for so long, we know this person prefers milk to cordial. So you give him milk by knowing him.” Also, the life of the emotions is enhanced when the individual is involved in preferred interests. “We’ve decided that he doesn’t like it because he screams. We moved him out of the area yesterday and he settled down. So I mean that was his, obviously his way of telling us that he didn’t like it.”

Managing Resources

According to the participants, nurses manipulate available resources to support the identities of individuals. The data in this section reflects one of Benner’s (1984) domains of nursing care: organisational and work-role competencies. There is evidence of setting priorities, team building and
coping with staff shortages, all elements in this domain. As in this study, Benner's participants were uncomfortable working in restricted circumstances and “extremely dissatisfied with the fact that they often could do only too little and too late” (pp. 145-146).

The participants in this study often expressed frustration with working in a system which they perceive does not support the lives of people with severe multiple impairments. “Well, at this present time, [the residential centre] cannot provide the facilities to improve their quality of life.” They see attitudes, policies and a lack of resources at all levels as working against nurses' efforts to contribute to the quality of life of people with severe multiple impairments. The policy of community integration, for example, means that funding is split between two systems so that neither community living projects nor institutions are adequately funded (Directors of Nursing, personal communications, 1990). The consequence of inadequate funding is poor resources which, in turn, makes the support which participants perceive contribute to quality of life difficult to achieve, for example: “She's so fragile because of her position and she is getting quite circular. Years ago we did the therapy constantly. Apparently before I came they used to have a lot of bus trips. We don't do many of those at all because we haven't got the numbers [of staff required]. These kids are getting bigger so therefore you need more staff to look after them properly and to handle them and to carry them and put them in the bus and do all sorts of things with them.” Another effect of poor funding is the availability of appropriately qualified staff. Participants express frustration with the extra work they have to do towards quality of life for people with severe multiple impairments as a result of inconsistent, inappropriate staffing. “That makes it really difficult, because you're basically working the group on your own and giving every bit of direction.”

The participants, therefore, attempt to manage available resources in terms of time, staff and materials in order to complete acts and take into
account the preferences of people with severe multiple impairments. The more effective this resource management, the more likely it is that support will proceed based on preferences, enhancing the particular identities of individuals. The following paragraph provides examples of the management of time, the management of staff, and the management of materials, in relation to supporting preferences.

An example of the management of time is taken from my observation in the field. Because Patrick enjoys Weet-bix and is more relaxed during the morning than later in the day, nurses utilise breakfast time to give him the bulk of his diet. This is rapidly achieved compared to later in the day when he often does not like the food and his anxiety increases his spasm, making eating a time-consuming task. This example of time management, then, adds to Patrick's nutritional intake, suits his preferences for type of food and time of eating, and adds to the time that can be spent on either his or others' preferences. An example of the management of staff relates to Sophie, who prefers a particular nurse to provide her care. Because all the staff appreciate this, and because the nurse likes to do it, nurses rearrange activities among themselves when that nurse is working in order that she can provide Sophie's care. An example of the management of materials came from a tea-room discussion. Nurses were talking about the ways in which they order and manage unit supplies from the general store. In relation to food, they order foodstuffs which the central kitchen does not usually provide and which the residents like. Stores are kept in a locked area so that they can be monitored and be available to residents as they want them.

**Advocating**

The final identity act is advocating. Through advocating, nurses support individual identities and promote positive images of people with severe multiple impairments. Advocacy, for people with disabilities, is
formalised in legislation and through citizen advocacy programs (Cocks & Stehlik, 1996). Few nurses, however, including nurses who work with people with severe multiple impairments, are represented in such programs. Advocacy, however, is an element of nursing practice. Chinn & Jacobs (1987), for example, state that advocating is one of the dimensions of ethical knowing in nursing, and Gadow’s (1989) paper on advocating with silent patients reflects many of the findings of this study.

In this study, I found that the focus of the participants’ advocating for people with severe multiple impairments is at the personal level, as they do not usually involve themselves with advocacy groups but advocate for people with severe multiple impairments in their immediate context. Most examples of advocating, in the data, relate to staff involved with people with severe multiple impairments, some to visitors to the residential unit, and a surprising number to relatives of the participants, and through this, to the wider community.

With regard to staff, for example, one participant said, very angrily: “I saw the most bizarre things when they were redecorating. It was a young lady who slept in a bed with no sides ... they’d moved her into a cot, with cotsides. I couldn’t believe it. They said, ‘oh, there’s no room to put her anywhere else’ and I said, ‘garbage’! I said ‘let’s open the day room ... a corner in the day room’. I said, ‘do you realise what you’ve taken away from this girl?’ ... they’d taken away her dignity, a part of her person because she was good enough to sleep in a bed and they shoved her back in a cot. This nurse’s words reflect the importance of independence as a mark of individuality (Corbett, 1997), of particular identity.

Visitors are prepared, if possible, by participants to see the person (or identity) that nurses know, rather than initially encountering something horrific. “I tell them something about the ones they’ll be with ... something that might appeal to them, something about their personality.” It is interesting to note
Goode's (1984, p. 230) record of his experience in this situation: he had seen a person with severe multiple impairments prior to a nurse introducing him and goes on to say:

I immediately became nauseous and broke out in a cold sweat and light headedness. I grabbed the bed board for support, felt faint and tried to keep myself upright without ‘letting go of the cookies’. A nurse must have seen me. She miraculously appeared, grabbed my arm and talked in a calm and reassuring manner. Although at the time, due to the degree of physical distress, I did not hear a word she said, without her reassuring tone and physical support I probably could not have collected myself and left that room as quickly or as inconsequentially as I did.

Participants also introduce their own parents, partners and children to people with severe multiple impairments. There were a number of examples of this behaviour but the following quote perhaps reflects the intention behind such introductions. “I tried to explain to my mother the type of people I take care of and she just had no concept ... until I took her and showed her where I worked. It was really distressing for her, but, well, it educated her too and then she educated her friends.”

SUMMARY

This chapter surfaces the participants’ implicit assumption that the everyday lives of people with severe multiple impairments, which may be different from other lives, have an impact on quality of life. It also points to how the supporting strategies of nurses have an impact on quality of life. This assumption is reflected in the quality of life literature which notes the relationship between quality of life and quality of care (for example,
Borthwick-Duffy, 1992). The data in this study suggest that this relationship is one of interdependence, where nurses support people with severe multiple impairments in their everyday lives when required, while always promoting independent activity. In turn, they receive from people with severe multiple impairments lessons about life and affirmation of their supporting role. Corbett (1997) describes such a relationship in her discussion of independence, interdependence, and individual differences of people with disabilities by saying that “to be fully alive as humans being requires a complicated inter-dependency upon networks of people and systems” (p. 90).

Another point of interest is that, while Edgerton (1990) found, in his longitudinal research, that quality of life is more dependent on the personal attributes of people with disabilities than on environment, the case for people with severe multiple impairments may be different. The findings of this study link changing quality of life to support rather than to the personal attributes of people with severe multiple impairments. Edgerton (1990) goes on to propose that researchers return to individual choice when exploring the concept of quality of life. It is noted that, in this study, the participants support a move to individual choice (or preferences), but insist that individual choice is meaningless for people with severe multiple impairments unless there are resources - staff, time and materials - to support their ability to choose and to act on that choice. This insistence on the importance of resources to quality of life suggests that the quality in quality of life resides in supporting.

In summary, from the information provided by the participants, two themes have been identified so far in nurses' definitions of quality of life for people with severe multiple impairments as “just little things”: these themes are humans being and supporting. Quality of life occurs, therefore, when people with severe multiple impairments are supported in their everyday
lives. This supporting consists of completing acts which restore to equilibrium the dynamic-tension state that we call life. These acts, completed on behalf of people with severe multiple impairments, include body acts, emotion acts and identity acts. While the description of these acts tells us what nurses do, it remains unclear how they do it. If nurses support the way people with severe multiple impairments want to live, how do nurses know how people with severe multiple impairments want to live? It was this question which led to the second stage of this study and the observation of the participants which uncovered the third theme in “just little things”: becoming intimate.
Chapter Nine

BECOMING INTIMATE: MEDIATING THE QUALITY OF LIFE

Written on the body is a secret code only visible in certain lights; the accumulations of a lifetime gather there. In places the palimpsest is so heavily worked that the letters feel like braille. I like to keep my body rolled up away from prying eyes. Never unfold too much, tell the whole story. I didn't know that Louise would have reading hands. She has translated me into her own book

(Winterson, 1992, p. 89).

This chapter examines the third theme in the concept of “just little things”: becoming intimate. Becoming intimate refers to how nurses mediate quality of life, that is, how they know the way that people with severe multiple impairments want to live and how to support them. Becoming intimate mediates the concepts of humans being and supporting, and emerged from three processes in the data: knowing, interpreting, and feeling, which are related to each other through empathising. These relationships are depicted in the shaded area of Figure 9.1 and the emergence of these concepts can be found in Appendix XII.

I have interpreted the data in this study to mean that becoming intimate is the process by which humans being and supporting are mediated. This link between intimacy and quality of life is not evident in the research literature, but interacting has long been recognised as the core of all nursing practice and developmental disability nurse leaders in the United States and Britain have persistently asserted that human contact underpins quality:
Neither the size of a residential facility, nor its budget, nor the qualification of its staff, nor its programme objectives determine the institution's success in promoting health or human development. While these factors influence the likelihood of a healthy environment, the most significant factor is the quality of human contact received by residents (Blackwell, 1979, p. 250).

Nurse/resident interaction is a crucial issue which underpins all other aspects of working with mentally handicapped people. Poor quality or inadequate interaction will cause important opportunities for social contact and learning to be lost. At a more basic level, the lack of good quality interaction can condemn a profoundly multiply...
handicapped person to a life almost devoid of any human contact (Darbyshire, 1989, p. 50).

It is this human contact, which says more than interaction with regard to the relationship between nurses and people with severe multiple impairments, which, along with the categories of knowing, interpreting and feeling, led me to the concept of becoming intimate. It was noted during the observation period of this study that intimacy is a way of being when supporting people who are extremely dependent. The everyday consists of continual intimate moments when managing the usually concealed (Elias, 1978) support of the body, the emotions and identities. This necessary intimacy with people with severe multiple impairments then forms a backdrop for nurses to increase that intimacy. The purpose of increasing intimacy is for nurses to have a way of understanding the lives of people with severe multiple impairments in order to provide support. Nurses also are intimate with people with severe multiple impairments in order to get the best response from them, a process reminiscent of reciprocal trust (MacLeod, 1993) and through which nurses can discern individual preferences. It is these preferences which usually determine the support given, and such support is intended to enhance the lives of people with severe multiple impairments.

While the participants said that they know how people with severe multiple impairments want to live and how to support them, it was unclear how they know. How do people with severe multiple impairments indicate their preferences? How do nurses interpret those indications? How do nurses decide on their acts? The data suggest that nurses know by becoming intimate with people with severe multiple impairments. An analysis of interactions between nurses and people with severe multiple impairments suggests three processes in becoming intimate: (1) knowing, (2) interpreting,
and (3) feeling, the interrelationships of which can be explained by the empathetic processes of physiological empathy and role taking.

**KNOWING**

"Knowing the patient" is a recurring theme in the nursing literature (for example, Gadow, 1989; Kasch, 1986; May, 1993; MacLeod, 1993; Moch, 1990; Tanner et al., 1993) and its presence in the data of this study is central to nursing practice and to the quality of life of people with severe multiple impairments. In a recent review of the research on knowing in nursing, Radwin (1996) outlined three themes: knowing the patient actualises the value of people as unique individuals; understanding the patient and selecting individualised interventions are components of knowing; and related factors of knowing include experience, time and a sense of closeness between the patient and the nurse. While these three themes are reflected in the present study, the following discussion focuses on how interaction proceeds between nurses and people with severe multiple impairments on the basis of knowing.

A consistent phrase used by the participants is “knowing them”; they use it in the sense of both getting to know people with severe multiple impairments, and of knowing them as individuals. Nurses know people with severe multiple impairments through interaction with them, as well as through information from families and other staff and their own observations. Nurses obviously value this knowing, possibly because it allows them to answer questions about an individual's preferences: “They've got the staff that know them. Strangers who don't know these people are unable to understand their needs”. An analysis of interactions between nurses and people with severe multiple impairments resulted in an understanding of the processes through which knowing the person occurs: (1) knowing the
situation through time and experience and (2) knowing the body, particularly the impaired body of the individual.
Knowing the Situation

In Mead’s terms, there is no such thing as non-situated interaction (Morrione, 1985). Interaction is always situated. Situation refers to all aspects which actors attend to at a given time and place and situated interaction refers to the situation as an ongoing process, as defined by the actors (Morrione, 1985). Whenever they were asked what they did or why they did it, the participants replied: “It depends”. When asked to expand, their words clearly described interaction in a situation: “Well, take the other day, when Sue took Patrick to the dentist ...”. Benner (1984) states that the expert nurse operates from a deep understanding of the situation and, when asked about a hypothetical clinical decision, typically answers with “it all depends”. She further says that the context and meanings inherent in the situation influence the expert’s performance, and that it takes an interpretive approach to describing nursing practice to capture the knowledge embedded in that practice. I encountered difficulty in attempting to capture the knowledge in the practice of the participants, each of whom was an expert practitioner. I could not observe, and they could not tell me, how they knew. It was not until I observed other less experienced practitioners in the setting that the origins of the knowledge of practice became more evident.

Knowing through Time and Experience

Participants repeatedly said that “it takes time to get to know” people with severe multiple impairments. The data suggest that interaction changes between people with severe multiple impairments and nurses depending on the length of time that they have known each other and on the experience of the nurse. Schutz (cited in Altheide & Johnson, 1992) argues that people feel more intimate as relationships become tacit, taken-for-granted, non-
discursive. In the following examples, there appears to be increased intimacy with time and experience.
<table>
<thead>
<tr>
<th><strong>VERBAL</strong></th>
<th><strong>NON-VERBAL</strong></th>
<th><strong>ACTION</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse: OK, time to get dressed</td>
<td>Nurse: Picks up shirt</td>
<td></td>
</tr>
<tr>
<td>Tony: Noise (monotone)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse: (Imitates noise) to you too</td>
<td>Nurse: En face, smile</td>
<td></td>
</tr>
<tr>
<td>Nurse: Hand in</td>
<td>Nurse: Co-operate in putting arm in</td>
<td></td>
</tr>
<tr>
<td>Tony:</td>
<td>Nurse: Co-operate in putting arm in</td>
<td></td>
</tr>
<tr>
<td>Nurse: Other hand</td>
<td>Nurse: Co-operate in putting arm in</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nurse: Co-operate in putting arm in</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nurse: Lifts bottom</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nurse: Lifts arms</td>
</tr>
<tr>
<td>Nurse: Lift your bottom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse: Here we go, Tony</td>
<td>Nurse: Transfers Tony from bench to chair with Nurse 2.</td>
<td></td>
</tr>
<tr>
<td>Nurse: Arms up</td>
<td>Nurse: Finds toy</td>
<td></td>
</tr>
</tbody>
</table>

Table 9.1

Interaction: Experienced Nurse with Familiar Resident
The most common interaction observed was that between a person with severe multiple impairments and an experienced nurse who is familiar with the person, when the nurse initiates the interaction in anticipation of an everyday act, for example, getting dressed. A typical interaction as an experienced nurse is helping Tony to dress is demonstrated in Table 9.1.

This apparently simple interaction masks the complexity of the situation. The expert nurse is completing body, emotion and identity acts during this interaction. For example, being Tony’s hands can be interpreted as a body act; imitating and smiling can be interpreted as emotion acts; and allowing Tony’s input into acts, as well as offering Tony’s favourite toy, can be interpreted as identity acts. The nurse familiar with Tony makes these acts look easy because she has completed acts which call out a co-operative response in Tony. These responses are his input into getting dressed and his monotone which, according to the nurse, indicates that he is pleased. This ease only becomes obvious in comparison with other observations when the nurse is not familiar with the person.

When "new" nurses approach a person with severe multiple impairments, they usually have little knowledge of the aspects of the situation. They may have a general idea of the environment and the routine and may, or may not, be aware of the implications of severe multiple impairments. They have little information about an individual, even though information is usually available from other staff. An example of an
interaction when a new nurse (New) has been asked by an expert nurse (Expert) to bathe Michael is found in Table 9.2. The expert nurse is bathing another person in the same bathroom.
Table 9.2

Interaction: Inexperienced Nurse with Unfamiliar Resident

<table>
<thead>
<tr>
<th>VERBAL</th>
<th>NON-VERBAL</th>
<th>ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>New to Expert: This bath?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expert to New: Yes</td>
<td>New:</td>
<td>Starts to fill bath</td>
</tr>
<tr>
<td>Expert to New: He doesn't like water in the bath ... he gets frightened.</td>
<td>New: Quizzical facial expression</td>
<td>New: Pulls plug.</td>
</tr>
<tr>
<td>Michael: Noise</td>
<td>Michael: Frowning</td>
<td></td>
</tr>
<tr>
<td>New &amp; Expert: Lift Michael into bath.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: Removes sweater with difficulty.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Michael: Noise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New to Expert: He's very tight</td>
<td>Michael: Holding himself rigid.</td>
<td></td>
</tr>
<tr>
<td>Expert to New: Yes, he's frightened by new people. Talk to him.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New to Michael: Come on, we'll take your shirt off</td>
<td>Expert: Watching New</td>
<td>New: Removes shirt with difficulty.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>New: Red face</td>
<td>Michael:</td>
<td>Holding himself rigid</td>
</tr>
<tr>
<td>Michael: Noise</td>
<td>New: Removes socks, pants with difficulty</td>
<td></td>
</tr>
<tr>
<td>Expert: Eyes raised</td>
<td>Michael: Shivering</td>
<td></td>
</tr>
<tr>
<td>New: Removes nappy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New to Expert: Where does this go?</td>
<td>Expert: Eyes raised</td>
<td></td>
</tr>
<tr>
<td>Michael: Shivering</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: Leaves resident &amp; puts nappy in bag.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expert to New: In that bag</td>
<td>Expert: Eyes raised</td>
<td></td>
</tr>
<tr>
<td>Michael: Shivering</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New: Leaves resident &amp; puts nappy in bag.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Michael: Noise</td>
<td>Expert to Michael: Oh, you are a noisy boy today</td>
<td></td>
</tr>
<tr>
<td>New: Frowning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expert to New: Can I have a lift?</td>
<td>New &amp; Expert: Lift other resident to chair</td>
<td></td>
</tr>
<tr>
<td>Expert to New: Thanks</td>
<td>Michael: Shivering</td>
<td></td>
</tr>
<tr>
<td>New: Returns to Michael and turns tap on. Tests water and begins to wet Michael's hair.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Michael: Noise</td>
<td>Michael: Spasm</td>
<td></td>
</tr>
<tr>
<td>Expert to New: Don't shampoo it - he hates it.</td>
<td>New: Sigh</td>
<td></td>
</tr>
<tr>
<td>New: Wets rest of Michael</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Michael: Noise</td>
<td>Michael: Spasm</td>
<td></td>
</tr>
</tbody>
</table>

During the time of this observation, the expert nurse undressed, bathed and re-dressed the other person with severe multiple impairments. The
difficulties that the new nurse was having were probably going to escalate as Michael became colder and his spasm increased. Note that, apart from the initial explanation and when told to do so, the new nurse neither initiated nor responded to verbal interaction. The new nurse was focused on completing body acts. Completing other acts became difficult because of her lack of knowledge of the aspects of the situation. This example also highlights the interrelationships of body, emotion and identity acts because the new nurse was having difficulty with body acts in the absence of emotion and identity acts.

These two examples demonstrate instances at opposite ends of a continuum, of how interaction proceeds between nurses and people with severe multiple impairments. As can be seen, such interaction is related to the experience of the nurse and their familiarity with an individual. What happens when the nurse is experienced, but the resident is unfamiliar? When experienced nurses approach a “new” resident, they know many aspects of the situation. They know, for example, information about the environment, the routine and the implications of severe multiple impairments but there may, or may not, be specific information from relatives or other previous carers about the individual. Pauline, for example, is an experienced nurse who, returning from leave, finds a new resident called Louise. Pauline’s shift commences at lunch time so that there is no time to read Louise’s admission notes. She enquires of other staff as to who still has to have lunch and finds herself with Louise, a young girl of fourteen who is the size of a five year old and who is sitting in a posture chair. The interaction between Pauline and Louise is described in Table 9.3. Pauline used her knowledge of the situation to approach Louise and, within the interaction, commenced identity acts by relating to Louise in order to begin discovering the particulars about her.
Table 9.3

Interaction: Experienced Nurse with Unfamiliar Resident

<table>
<thead>
<tr>
<th>VERBAL</th>
<th>NON-VERBAL</th>
<th>ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pauline: Hello, Louise. Do you talk?</td>
<td>Pauline: Eye contact Louise: }</td>
<td></td>
</tr>
<tr>
<td>Pauline to other staff: Does she feed herself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff: No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pauline: What does she eat?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff: Pre-school</td>
<td>Pauline: Selects pre-school diet and a teaspoon and a bib.</td>
<td></td>
</tr>
<tr>
<td>Pauline: Does she like to eat quickly or slowly?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff: As fast as possible.</td>
<td>Pauline: Places bib on Louise.</td>
<td></td>
</tr>
<tr>
<td>Pauline to Louise: OK, let's eat</td>
<td>Pauline: Moves spoon to Louise's mouth</td>
<td></td>
</tr>
<tr>
<td>Pauline to Louise: There's mince, mashed potato, carrots, peas.</td>
<td>Louise: Swallows Pauline: Another spoonful</td>
<td></td>
</tr>
<tr>
<td>(Time passes) (Quarter of meal is consumed.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pauline to Staff: She's quite slow today</td>
<td>Louise: Swallows Staff: Puts pills in food Pauline: Spoonful with pills</td>
<td></td>
</tr>
</tbody>
</table>
These three examples with Tony, Michael and Louise demonstrate differences in practice with time and experience and further support the research on knowing in nursing. In the first example, the nurse with experience of people with severe multiple impairments and their situation, and with Tony in particular, so expertly completes acts that it is difficult to capture the knowledge embedded in the practice (Benner, 1984). On the other hand, the second example, with Michael, clearly reflects the characteristics of a novice (Benner, 1984) who, without the benefit of time and experience, has limited knowledge of the situation. The third example, with Louise, highlights a finding in the research on knowing in nursing: “an experienced nurse can more skilfully use her knowledge of a specific patient because she has more ability to both anticipate potential responses and evaluate actual patient responses” (Radwin, 1996, p. 1144). Thus, nurses know the person through knowing the situation, and they know the situation through time and experience. Nurses also know the person through knowing the body, particularly the impaired body of the individual.

Knowing the Body

While the study of the body is complex, Turner (1992) simplified the infinite number of approaches to the study of the body by encouraging
research which is open to both the body as an objective presence (Körper) and the body as lived experience (Leib). Lawler’s (1991) groundbreaking work on nursing and the body states that nursing is concerned with integrating the object body and the lived body. This study also found that nurses manage the bodies of people with severe multiple impairments not only as objects, but in a way which recognises the experience of the lived impaired body.

Knowing the Impaired Body

   In "primitive" society, people place themselves in the world with ease; there is a harmony among bodies, nature and society (Kupfermann, 1979). On the other hand, Cartesian dualism, prominent in Western philosophy, has alienated people from their bodies. As a result, body, mind, self, soul, feeling, society, culture are conceptualised separately. Moreover, the body has been conceptualised in various ways, Frank (1990) suggesting four conceptualisations: the medicalised body, sexual body, disciplined body, and talking body. While these concepts apply equally to people with impairments, for their particular issues to be addressed requires a discrete conceptualisation of the impaired body. Such a conceptualisation has been absent, even in the feminist literature (Morris (1993), despite the lives of people with impairments, like those of women, being defined by their bodies (Morgan & Scott, 1993) and their bodies becoming their destiny (Turner, 1991). More recently, Shakespeare (1994) has called for a return of the body to the sociology of disability because “it is not our disability, but our impairment which frightens people” (p. 297). Hughes and Paterson (1997) have responded with a beginning discussion of the sociology of impairment, employing “explicitly anti-Cartesian” (p. 331) theoretical perspectives of post-structuralism and phenomenology. The challenge to a sociology of impairment is to return the body to the social model of disability, which
“proposes an untenable separation between body and culture, impairment and disability” (Hughes and Paterson, 1997, p. 326) without going back to a biomedical model of disability where impairment means oppression and exclusion.

Because nurses are concerned with the everyday life of the impaired body which is dependent on others for the “details of ... corporeal existence” (Turner, 1984, p. 1), nurses attend to the details. They complete acts against a background of knowing the implications of severe multiple impairments for such activities as washing, grooming, dressing, eating and toileting. The participants know, for example, that people with severe multiple impairments generally cannot initiate and/or regulate movement. As a result, they move people with severe multiple impairments from one point to another. They know that people with severe multiple impairments cannot be left in places that put them at risk, so they place them on mats on the floor or use safety devices, such as bed rails or chair straps. The participants also know that contractures and spasms complicate any movement associated with undressing and dressing, bathing and grooming, or changing from one position to another. Thus, they use proximal-distal techniques and reflex-inhibiting positions to reduce spasms and ease contractures during these activities.

The participants know that eating and drinking are also complicated everyday acts for people with severe multiple impairments as they have little control of their oral musculature with the consequence of not being able, to a greater or lesser degree, to control food in their mouths with their tongue, to bring their lips together, or to chew, swallow or cough. Thus, the participants control mouth closure, tongue movements, chewing and swallowing on behalf of people with severe multiple impairments. They do this by using reflex-inhibiting postures with the aid of specially designed chairs, pre-feeding relaxation (or stimulation, for people with hypotonia), by using a spoon to control the tongue, and by manually manipulating the lips, jaw and pharynx. Participants also approach people with severe multiple impairments very calmly to reduce stimulation which might induce spasm and are
conscious of potential aspiration which may lead to asphyxiation or pneumonia. If individuals have sufficient movement in their arms and hands, they are encouraged to feed themselves, which is, of course, complicated by the problems previously discussed in relation to movement. Furthermore, the amount and consistency of food and the size of utensils reduce tongue thrust, the biting reflex and the gag reflex. Given the difficulty that eating and drinking present for people with severe multiple impairments and the poor range of food offered, they usually have very little appetite. As a result, these people are often underweight and participants spend a lot of time encouraging them to eat. Drinking is a high-risk activity which requires time and concentration while cups have to be specially shaped and fluid balance maintained.

Finally, in relation to knowing the impaired body, participants know that people with severe multiple impairments rarely have control over their bladder and bowel sphincters, so they protect them with nappies, monitor their output, and assist with bowel function when necessary. These examples, taken from the observation period of this study, demonstrate that nurses know the impaired body. The impaired body might be considered an aspect of the situation, for to know the person, the nurse has to know the individual impaired body.

**Knowing the Individual Impaired Body**

As nurses get to know a particular person with severe multiple impairments, they become aware of the idiosyncrasies of that person's body, for example, there may be a greater or lesser degree of spasticity, many or few spasms, tight contractures or none, more or less control over gross and fine movements, greater or lesser oromusculature control, differing sphincter control, or particular problems additional to motor control, such as sensory deficits, epilepsy and the adverse effects on the body of anticonvulsants. One person may be recognised as more at risk for pneumonia, or skin breakdown, or fractures, or seizures, or particular sensitivity to heat or cold while another person may have
health problems not necessarily related to their primary diagnosis, for example, diabetes, colostomy, or asthma. At any given time, a person may have had surgery, most likely orthopaedic, dental or ophthalmic. “Sometimes, like all of us, they may have a cold or flu, or just be very tired, or have a headache or body pain, for example, colic”.

Through their knowing of the individual impaired body, nurses relate to that body with familiarity and are alert to potential problems. Participants handle people’s bodies differently, more roughly with a healthy, robust body and more gently with a fragile body. They know the movements of a particular body: judging just the right amount and type of assistance to provide during acts, thereby skilfully complementing the body of the individual. They differentiate between active and reflex movement and are aware of the tiniest change in the body - a little tighter, a little floppier, more or less head control, mouth control, tense abdomen, increased spasm. In all these ways, participants demonstrate an intimate awareness of the individual impaired body.

The data from this study suggest that nurses, on behalf of people with severe multiple impairments, “take individual responsibility for ... bodies by engaging in strict self-care regimes” (Shilling, 1993, p. 5) which entail preventing disease, presenting the self, constructing identity, and finding meaning in life (Lupton, 1994). The support nurses give, as a result of knowing the individual impaired body, is reflected in Henderson’s (1978) nursing theory which conceptualises nursing as doing whatever the person would be doing for themselves, if only they had the ability/will. It is also reflected in Orem’s (1985) nursing model of self care where nursing activities are described in a hierarchy from doing for to doing with to advocating. Zola (1991) condemns medicine for “doing to” rather than “doing with”, but as noted in the data, nurse participants in this study were well aware of the balance required between the two. Fieldwork observations certainly point to
an acute consciousness of the subtle differences between “doing to” and “doing with”.

In this regard, the complementary assistance provided by the participants for people with severe multiple impairments and seen during observations is akin to dance. Ferris (1992) talks about two aspects of movement in contact dance: the contact, and the movement developed from one's feelings or physical relation to a partner. Nurses make physical contact with people with severe multiple impairments in order to perform the daily rituals of body care. When they touch them they “sense through the skin” (Ferris, 1992, p. 165) the body of the person as “conversation” (Ferris, 1992, p. 165) and develop movement to participate in the conversation. This interaction is also reminiscent of Goode's (1980a) "behavioural sculpting", and of Blumer's (1969) “joint action”. Goode coined the phrase "behavioural sculpting" to describe the actions of a mother caring for her child with severe multiple impairments, and in joint action, we are constantly aligning our actions to the actions of the other. The interactions I saw, therefore, where both parties are developing movement in response to the other’s movement, are better described as reciprocal sculpting. Participating in the conversation, however, requires an examination of interpreting, the second process in becoming intimate.

**INTERPRETING**

Blumer (1972) says that group life or group action occurs when individuals, in trying to meet their life situations, fit their line of action to one another through a process of interpretation. In this way, interaction proceeds between nurses and people with severe multiple impairments on the basis of interpretation. According to Blumer (1972), interpretation, or acting on the basis of symbols, involves designating different objects, giving them
meaning, judging their suitability to an action, and making decisions on the basis of the judgement. Symbols may take many different forms: for example, linguistics, bodily postures or movements, flags, works of art (Hewitt, 1979), “a change in ‘gaze-line’, a change in breathing tempo, a blush, a posturing of the body, clothing, makeup, hair sculpture or disarray ... The list is almost endless” (Stone & Farberman, 1986, p. 3). While symbolic interactionists typically privilege language in this process (Farberman, 1985), of particular interest to this work are symbols related to the body, for example, movement, facial expression and sounds. The different objects designated in the process of interpretation comprise the situation (Halas, 1985) and most situations encountered are defined through previous interaction which has developed common understandings or definitions of how to act in the situation. This does not mean that no interpretation is occurring, but rather that the process of interpretation places little strain on the actors.

The following example from the data demonstrates a common interpretation made by a participant. Nicole was lying in bed in the morning sobbing, with tears running down her face. The participant, concerned, wondered why she was upset. She checked her body and found that she had wet the bed and her clothing. She undressed her and gave her a warm bath. Nicole smiled and kicked, her usual response to a warm bath, which the participant interpreted as Nicole feeling content. Other situations, however, may be undefined: there may be no common understandings of how to act. In such instances, nurses discuss the situation with each other and relay their understandings of it to each other by referring to their previous experiences with the particular individual and with similar situations. Such discussion lends support to MacLeod’s (1993) argument that knowing in nursing is not idiosyncratic, personal knowledge but knowledge shared in language and practices. Interpretations are developed, therefore, and effective accommodation of
participants in group life is established (Blumer, 1972) when common understandings evolve through previous and shared interaction.

Blumer’s (1972) definition of interpretation is represented in the data in a number of ways. In the process of becoming intimate, participants demonstrated that they: (1) designate objects related to the impaired body and the situation, (2) give meaning to these objects in the form of emotions, and (3) act on the basis of these meanings.
Designating Aspects of the Body and the Situation

Nurses designate the body's "virtual forest of symbols" (Turner, 1991, p. 268) and read them through interpretative schemes (Bordo, 1992). They resist the person as body only and seek other explanations (Benoist & Cathebras, 1993), such as using aspects of the body as indicators of the person's ontological state (Saltonstall, 1993). While the participants indicated that they interpret the communications of people with severe multiple impairments as they would for "any kid on the street", this was sometimes difficult to see. When Sophie has a red face, is stiff and tight, and makes a particular sound, this is interpreted as feeling "humiliated". When her arms flail, she is "angry". When Nicole blows a raspberry, she is "frustrated and bored", but "sometimes it is a happy raspberry". When Tony tracks with his eyes something in the nurse's hand, "he hopes it is for him". When Louise pushes food out of her mouth with her tongue, "she has had enough" but she will eat more if encouraged, and when she puts her hand up to her face and pulls away, "she has really had enough". Participants explain that these interpretations commence in a sensitivity to facial expression and body language, as with "babies, toddlers and strangers", which according to Bruner (1975), is the beginning of joint action, the context for communicative intent which precedes speech, and which "become easier when you have known them for quite a while". In this way, knowing enhances interpreting.

Because people with severe multiple impairments have no verbal language, nurses exploit their intimate knowledge of the body as an avenue of communication. Goode (1990b) found this in his study of communication between a child who was deaf and blind (and without a formal language) and her parents, noting that it took time to develop intimacy which provided access to the intentional communications of the child. It is this intimate context which allows nurses to recognise the patterns in situations which are never alike because they appear in different temporal and spatial locations.
Returning to the analogy of dance, Hanna (1979) notes that the same symbol may have different meanings at different phases in a performance or in different performances. She demonstrates that dance is a system of signs, symbolic action, and shared reality, the significance of which resides in the whole. Dance, she says, is often referred to as 'speaking' to the human being in special ways and its meaning occurs in three domains which have relevance for this study: pragmatics, semantics and syntax.

Pragmatics is used here in the same sense in which Goode (1990b) uses it: the knowledge of doing (different from the knowledge available for the saying). Like the communication in his family study, nurses "do" communication with people with severe multiple impairments, for the most part, in an unproblematic way. When the usual interpretive routines do not work, they too converse about communication as a problematic and conduct pragmatic, naturally occurring, tests of sense-making. Tim made an unusual noise while he was sitting in the dayroom before lunch. The nurse thought he was unhappy about something. Lunch was late so she thought he might be hungry. She offered him some food from the kitchen but he refused. She thought another nurse might be sitting too close to him because he likes his personal space. The nurse moved and Tim became quiet, his usual verbal state.

Semantics, the relation of a body movement to what it signifies, includes learnt tacit knowledge, "the assumptions which are not explicitly stated but within which symbols are embedded" (Hanna, 1979, p. 90). The body movement is part of a larger whole, that is, understanding the movement requires a contextual knowledge, knowledge of the situation. Within this study, nurses have "background expectancies" (Garfinkel, 1967) of a person's body movement and tone (developed over time in intimacy) and this expected movement and tone, or alterations to movement and tone, has meaning. Nicole was sitting in her posture chair, all set up for lunch, which was late. She began making an unusual noise, frowning and hitting the side of her
body. The nurse knew she was not happy because she was hungry and does not like extended time in her chair. The nurse explained that lunch was late, that if Nicole ate sandwiches she could be finished lunch by now, but as she didn’t eat sandwiches she would have to wait. The nurse tried to distract Nicole by playing a game where she imitated a "thumb up" action initiated by Nicole. Goode (1980b) found similarly in his study of Chris who could walk, but was unable to see or hear, that “Chris did not seem to share any awareness of what a linguistic symbol was. However, this is not to say that she did not regularly communicate with me and with staff. To communicate her wishes, she used gross physical actions which relied heavily on ‘background expectancies’ (Garfinkel, 1967, p. 191).

Syntactics is often included in semantics. It denotes the rules dictating how symbols may be combined (Hanna, 1979). Perinbanayagam (1985b) states that in order for gestures to be successful in eliciting the required interpretation, they have to be connected by any respondent to certain universal experiences of the members of a community. As members of a community which includes people with severe multiple impairments, nurses in this study expertly interpret the body symbols of people with severe multiple impairments. These symbols, however, cannot lead to any clarity of interpretation without syntactical connections somewhere in the presented gesture. Perinbanayagam suggests that syntactical capacities function to construct and participate in acts which convey messages to each other, with each act an individual creation. The symbols which Tony combines in the following example construct the nurse’s acts, a process reminiscent of reciprocal sculpting. Tony actively participates in dressing by not resisting his position being changed and by moving his limbs through clothing. His facial expression is usually neutral and he vocalises in a monotone most of the time.

Nurses become intimate with people with severe multiple impairments, therefore, through three domains of interpretation: pragmatics, semantics and syntactics. They usually communicate in an unproblematic way by
understanding gestures in the context of the situation and by participating in acts which are the basis for communication to proceed. Problematic communications are managed by pragmatic tests of sense making which, in turn, increase knowing and, thus, intimacy.

Important to interpreting the impaired body in the situation is differentiating symbols and non-symbols. The participants demonstrated that nurses, who are intimate with individuals, differentiate between the intentional communication and the involuntary movement of the impaired body. Nurses become familiar with the actions, facial expressions and vocalisations of an individual. Once familiar with the individual, the nurse expects particular actions, facial expressions and vocalisations - “We very much depend on this type of communication from the resident for what we do.”

The following examples from the observational data are the usual expectations of particular individuals: John splashes in a deep bath, smiles and is quiet. He cries if he is touched; Patrick opens his mouth, does not cough or spit, has a less anxious expression and is quiet when eating weet-bix in the morning; Sophie looks in the mirror, smiles and laughs, while she is dressed and groomed. She laughs and giggles when particular staff attend to her. MacLeod (1993) also found that nurses in her study were similarly attuned to the usual symbols of people who are unable to speak.

The absence of these usual symbols is interpreted as problematic, for example, when someone who is usually active is listless, when someone who often smiles does not, when someone who usually makes a lot of noise is quiet. Also interpreted as problematic are those symbols which are different from those expected and which have negative connotations, for instance the individual may pull away, turn their head from side to side, clamp their mouth shut, throw food, bang their head on the chair, pout, cry, hit themselves, make sounds, or bite their clothes. There are also unusual symbols with positive connotations, for
example, laughter from the person who usually does not laugh, or interest from the person who usually appears not to notice the surroundings. In each of these examples, nurses interpret the symbols as intentional communication.

There are, however, a number of actions which are sometimes interpreted as involuntary, or non-symbolic, for example, dribbling, spitting, slipping, grimacing, turning away, pulling away, and holding rigidly. While I observed that these same actions, or what appeared to me to be the same actions, were sometimes interpreted by the participants as intentional, these interpretations varied with the individual and the situation, for example, I wrote in my fieldnotes: On Tuesday, Jenny interpreted Tom’s grimace as indicating that his back was painful. On Thursday, she ignored the grimace. When I asked her about this, she said: “His back was hurting on Tuesday but he’s OK today”. When I persisted, Jenny eventually explained that Tom’s grimace is involuntary, and therefore non-symbolic, it is “the look in his eyes” and “his overall mood” which are the symbols she interprets.

Nurses, therefore, interpret the impaired body in the situation by designating different objects. These objects include body symbols such as the actions, facial expressions and vocalisations of people with severe multiple impairments. These body symbols, however, are interpreted as intentional, symbolic communication or involuntary movement, which is not symbolic, and occur within situations. Other objects which are designated, therefore, include aspects of the situation. The meaning of all these objects occurs in the domains of pragmatics, semantics and syntax. It is interesting to note that the meaning given to these symbols usually resides in the language of emotions.

**Giving Meaning to the Body in the Situation**
Nurses become intimate with people with severe multiple impairments by giving meaning to the body in the situation. In the above examples from the data, the participants interpreted symbols as emotions. In other words, the objects which nurses designate, that is, the symbols of the body and the aspects of the situation, are given meaning, and these meanings are described in the language of emotions. Symbols are usually interpreted as liking or not liking what is happening, feeling happy or unhappy, wanting or not wanting something. Less often, symbols are interpreted in a more complex way, for example, feeling humiliated, angry, or bored.

At the simple level of emotions, there is general consensus among the participants on the interpretation, although, like the nurses in MacLeod’s (1993) study, the participants keep their interpretations in question. “... I think I’m right but I mightn’t be”. At a more complex level, there may be disagreement among participants. Apart from an acknowledgment by the participants that more complex emotions are difficult to interpret, there appear to be two processes operating in problematic communications. Firstly, there is, in any situation, the emotion felt by the participant. “It may depend on mood” or on “whether [the participant] likes the individual”. Ben, for example, among a group of people who are immobile, moves his own chair and others’ chairs and is variously interpreted as “curious” and “trouble-making”. Secondly, the participants observe and discuss a symbol which is unfamiliar, a situation which has not been previously defined. Like Goode’s (1980a) study of a mother and child with cerebral palsy, the participants test their interpretations in a number of situations, as well as with others.
Acting on the Basis of Interpretation of the Body in the Situation

Nurses become intimate with people with severe multiple impairments by acting on the basis of interpretation of the body in the situation. These acts are created in the domain of syntactics in response to the meaning given to the gesture in the situation. When a symbol is interpreted as happy, as liking what is happening, participants continue what they are doing. An action, facial expression or vocalisation interpreted as happy is often met with a comment about that emotion, perhaps with an accompanying smile or laugh, and no further/different action on the part of the participant. Any deviation from these usual “happy” symbols elicits a different response from participants. In most cases, participants alter the situation by stopping what is happening and finding alternatives, for example, changing the food presented, bathing differently. The aim of these acts is to restore happy symbols, for example, Patrick was spitting out his food. The nurse interpreted this spitting as Patrick not liking the food. “O.K., you don’t like the cereal - let’s try some banana.” The nurse offered the mashed banana which Patrick ate without spitting. She interpreted his not spitting as liking the banana. “That’s better, isn’t it?” In some instances, the participant continues the activity but talks to the person, for example, when Tom does not like his contracted hand dried, the participant continues to dry it but explains why; when Jim does not like being changed, she tells him to “settle down”, that “it’s all right”; when Louise was “whinging” during her bath, the nurse made soothing noises, was gentle with her, performed the bath as quickly as possible, told her that they were “nearly there”.

Absences of usual symbols are interpreted as unhappy and, if they persist, action is taken to restore usual symbols. “Well, for instance, one of the kids, she feeds herself with assistance ... she kept dropping the spoon and being really stupid and I thought, well now, something’s wrong with this because she doesn’t usually do it. I looked at her, she’d caught her finger somewhere and she had this great ginormous finger. Now nobody had noticed that, but because I knew that that behaviour wasn’t normal behaviour for her, I sort of looked for obvious reasons ... so
you get the doctor to look at them.” Non-symbolic interaction, such as involuntary movement, are not interpreted as emotions. They often elicit a comment and a pragmatic act from the participant, for example, when an individual slipped down in the bath, the participant said: “whoops, you're going down the plughole” while she manoeuvred the individual back to where she could bathe him.

Nurses, then, interpret the impaired body in the situation. They treat the bodies of people with severe multiple impairments as a “field of expression” (Scheler, 1986, p. 132). Meaning is constructed, not in verbal language, but in the language of the body. The body is highlighted, in the absence of verbal language, as a way of making meaning (Travisano, 1993). The symbols of the body are interpreted by nurses as emotions, and they act to maintain and restore “happy” symbols. When the participants were talking about interpreting symbols as emotions, they hinted that nurses, too, have feelings. This is now taken up in the third process of becoming intimate: feeling.

**FEELING**

There is an expanding body of literature on the sociology of the emotions (for example, Denzin, 1984, 1985; Farberman, 1989; Franks, 1985a, 1987; Freund, 1990; Kemper, 1978; Mazis, 1993; Perinbanayagam, 1989; Scheff, 1985), much of which links the body and emotions. This literature suggests that the body and emotions occur simultaneously (Franks, 1987), since physiological response and emotional experience are parts of the same process (Kemper, 1978; Scheff, 1985); life is lived in one inseparable piece - “the lived body” (Denzin, 1985). In Saltonstall’s (1993) work on men and women's perception of health, witness one of the participant's words: It's really a **body feeling**, but it's also in my head [emphasis mine].
From the very beginning of this study, in our discussion of physical and emotional well being, the participants were trying to articulate the gestalt of the body and emotions. Towards the end of the study, when one participant had a sad expression on her face, I asked the reason. She said that she was upset about a young man who was dying and in pain and described her feeling thus: “it’s a heart pain ... I know it’s in the mind”. Further investigation showed that, when nurses interpret the body symbols of people with severe multiple impairments as emotions, they have a feeling response which is experienced by their bodies - They feel happy if the individual is interpreted as happy, they feel sad if the individual is interpreted as sad, they feel sorry if the individual is ill or in pain, they feel angry if someone is embarrassed by another. These feelings are experienced in their bodies. Interaction, then, between nurses and people with severe multiple impairments proceeds on the basis of feeling. This feeling enhances intimacy and is represented in the data by emotion work.

**Emotion Work**

Emotion work is described by Hochschild (1979, p. 561) as “the act of trying to change in degree or quality an emotion or feeling [through]...evoking or shaping as well as suppressing” a feeling. The emotion work which nurses do with people with severe multiple impairments and observed during this study includes: enhancing positive feelings, alleviating negative feelings, hidden work, and avoiding exhaustion.

The data suggests that nurses enhance positive feelings in both themselves and people with severe multiple impairments. When nurses interpret the gestures of an individual as being happy, they continue whatever is seen to be contributing to that happiness. If they interpret that
an individual wants to do something and they assist them to do it, this “re-affirms their role as caregiver”. If a person appears contented or happy with an outcome, the participants “feel good “ about the roles they play. They continue acting/interacting because they think they “can make a difference” in the lives of people with severe multiple impairments.

The participants also engage in emotion work by alleviating negative feelings. When nurses interpret the gestures of people with severe multiple impairments as being unhappy, they attempt to alleviate this unhappiness. A sad feeling directs them to find the cause and change whatever is happening or to explain why it has to happen. A sorry feeling directs them to do something about the pain or the illness. Angry feelings direct them to lessen the individual’s embarrassment and, very rarely, to berate the person who caused the embarrassment. More often, the angry feeling is dissipated by sharing the story with other nurses. When all efforts fail to alter the situation, they are “philosophical about it. We try our best! Sometimes there is not much else one can humanly do”.

Emotion work is, of course, hidden, just like most women’s work. A case in point is Beail’s (1988) analysis of interactions between people with disabilities and nurses. He indicates that only seventeen percent of nurses’ time is spent in interaction with people with disabilities. This figure, incidentally, far exceeds May’s (1993) analysis in other settings where nurses spent five percent of their time in interaction with patients. Nevertheless, if Beail’s categories are more closely examined, the emotion work can be found.

Beail’s (1988) first category, physical care, is, according to this study’s findings, not only a time of immense physical strain but also the most likely time for emotion work. Supervision is a time of observation when nurses gather data for their intimate picture of people with severe multiple impairments. Both Gleason (1993) and Sacks (1985) argue, in this regard, that observing a person in their natural state is an important way of getting to
know them. Beail’s category of staff-staff interaction is a time when nurses support each other by sharing emotions and by discussing problematic communications. May (1993) asserts that one of the most stressful factors in nursing is ambiguity in patients’ needs and that peer support is essential. According to Beail, off-ward time is supposedly a time when nurses perform activities unrelated to people with severe multiple impairments, for example, pay, leave, or buying lunch, although it is quite unusual, in my observations, for a nurse to leave the unit without one of its residents. It has been built into their routine to take someone for "the walk", regardless of where they are going. From my own experience, I am aware that this can be one of the most private and intense times for emotion work, for, without the distraction and invasion of others, this is often a highly intimate time between a person with severe multiple impairments and a nurse.

The emotional component of nurses’ work with people with severe multiple impairments is huge, given that for every emotion they perceive in an individual they experience a feeling response in their own body; their work day is an emotional roller coaster. Nurses, then, perform a high level of emotion work and find that they have to step back on occasions to avoid the exhaustion of this work, claiming that they “would be emotional and physical wrecks” if they did not. The participants said that they use a number of strategies to avoid exhaustion - no one nurse becomes too emotionally involved with a large number of people with severe multiple impairments, focusing instead on one or two people who appeal to the particular nurse. Nurses also seek a space where they can think, rather than feel. As participants said: “feeling may impair their judgement in clinical decisions” and “they put aside feeling when they have to perform unpleasant activities” such as taking blood.

The third process of becoming intimate, therefore, is feeling. Nurses enhance the positive feelings of people with severe multiple impairments and thus their own positive feelings, and alleviate the negative feelings of
people with severe multiple impairments and hence of themselves. Much of this emotion work is hidden, and, as it is experienced in the body, nurses use strategies to avoid exhaustion. The process of feeling is interrelated with the processes of knowing and interpreting, and these interrelationships can be explained by examining empathising.

**EMPATHISING**

Empathising is the process which ties together the processes of knowing, interpreting and feeling, and begins to explain their interrelationships. Stone and Farberman’s (1986) empathetic processes are particularly useful in this regard, while Shott’s (1979) explanation of empathy adds to the discussion.

**Empathetic Processes**

According to symbolic interaction theory (at least that evident in early theorising), symbols require interpretation of the other’s act through role-taking. In symbolic interaction terms, role taking is placing oneself in the attitude, or incipient act of the other. Stone and Farberman (1986), however, believe that placing oneself in the attitude of the other has an affective component, and the phrase, role taking, is unnecessarily restrictive. They therefore prefer the term, empathetic processes, which include physiological empathy and role taking.

The theory of physiological empathy is similar to other psychophysiological theories (Plutchik and Kellerman, 1980) which state that emotion represents the emergence of feeling from the body. In other words, what is observed in the incipient act is the expression of what is felt in the
body, or more simply, the incipient act has an affective component. By observing the incipient act, therefore, we can anticipate both the act (what the actor is about to do), as well as the feeling in the act (what the actor feels). Further, according to symbolic interaction, the incipient act calls out a response in the other. This response then would have to include an act and a feeling.

Extending this notion, Shott (1979) suggests that empathy is one important motivator of altruistic behaviour. In this regard, she says, “Perhaps more than any other sentiment, empathy connects us intimately with others, sharing their distress or pleasure. By relieving the unhappiness of those with whom we empathise, or increasing their happiness, we relieve or increase our own corresponding feelings” (p. 1329). Empathising, therefore, includes observing the incipient act and feeling, anticipating the act and feeling, and responding with an act and feeling.

**Relationships among Empathising, Knowing, Interpreting and Feeling**

From their standpoint of empathetic processes, Stone and Farberman (1986) ask how it is possible to empathise with or take the role of the other, without knowing the other. Further how can one anticipate the other’s act, without knowing the situation. The earlier discussion in this chapter of knowing implies that the better nurses know the situation and the body of a person with severe multiple impairments, the better they can take the role of, or anticipate the act of, that person. How did they get to know? The data suggest that through repetitive empathising with the same individual in multiple situations, they develop common interpretive understandings through shared interaction. And, in this endeavour, interpreting is the process through which knowing is forwarded. Against this background of knowing, nurses designate the incipient acts of people with severe multiple
impairments, as well as the aspects of the situation, and give them meaning, by interpreting them as emotions. The incipient act and emotion call out a response in nurses who feel the emotion in their own bodies and complete acts to enhance the positive feelings and alleviate the negative feelings of both people with severe multiple impairments and themselves.

**SUMMARY**

The question this chapter sought to explore was how nurses know how people with severe multiple impairments want to live and how to support them. The process of becoming intimate with people with severe multiple impairments provides some understanding of this question. The data suggest that becoming intimate has three intertwined empathising processes: knowing, interpreting and feeling. Nurses know the situation and the impaired body of individuals through time and experience. They designate aspects of the situation and the body for interpretation, find meaning in the domains of pragmatics, semantics and syntax, and interpret symbols as emotions. Nurses respond to these interpretations with their own emotions, which are felt in their bodies, and which compel them to act to enhance positive feelings and alleviate negative feelings. These three processes of knowing, interpreting and feeling are linked by the empathetic processes of physiological empathy and role taking. These processes provide some explanation of how becoming intimate mediates the quality of life of people with severe multiple impairments.

The meanings which nurses give to quality of life for people with severe multiple impairments, then, include the concepts of humans being, supporting, and becoming intimate. These meanings, however, occur within a wider context of the philosophies and policies of society. These philosophies and policies impinge so harshly on people with severe multiple
impairments that the data is replete with examples of the problem of nurses’ meanings of quality of life. This problem helped to uncover the process in which nurses engage to ensure quality of life for people with severe multiple impairments: situated belonging. The following chapter focuses on this concept, the final theme in “just little things”.
Chapter Ten
SITUATED BELONGING: MAKING A PLACE FOR QUALITY OF LIFE

There's a place for us ...
There's a time for us ...
We'll find a new way of living ...
Some how ... somewhere
(Sondheim, 1959).

Findings presented in the previous three chapters describe three themes of quality of life for people with severe multiple impairments, as perceived by nurses who participated in the research: humans being, supporting and becoming intimate. Quality of life for people with severe multiple impairments, therefore, has become defined as intimate support to just be. In coming to this definition of quality of life, it became obvious how nurses disagree with other definitions of quality of life in relation to people with severe multiple impairments. Their definition occurs within the wider context of exclusionary and inclusionary definitions of quality of life, which are in tension with the situated definition of the participants. Such tensions lead nurses to make a place for people with severe multiple impairments - a place of situated belonging - which is safe from the wider definitions of quality of life. The following section discusses how the context, situation and tensions uncovered the theme of situated belonging. This discussion concerns the shaded area of the model in figure 10.1 and the emergence of these concepts can be found in Appendix XII.
The term “context” has been used differently by different researchers. In this study it is used to describe the metacontext which is “a socially constructed source of knowing that operates continuously and ... is a source of explanation for and an indirect influence on behaviors and events” (Hinds, Chaves, & Cypess, 1992, p. 67). The context for nurses’ definition of quality of life for people with severe multiple impairments is one of exclusion versus
inclusion. These two views of exclusion and inclusion which determine definitions of quality of life are reviewed here.

As has previously been discussed, a philosophy of exclusion is predicated on society’s assumption that people with severe multiple impairments have no potential for quality of life. Most members of society, not confronted by people with severe multiple impairments, ignore their presence in the world. When the presence of people with severe multiple impairments becomes obvious, the usual response of society is that they would be better off dead. This is evident in the acceptance by society of “solutions” such as pre-natal diagnosis, abortion, withholding and withdrawal of treatment, euthanasia, and segregation.

The consequences of society’s attitude for people with severe multiple impairments who reside in large residential centres include a shortage of resources, both in terms of the materials needed to assist people with severe multiple impairments to live their lives, and suitably qualified staff. Society avoids confrontation with this group by isolating them and is not prepared to pay for more than a basic existence. Budgets for care limit the number of carers, the time to care, and the equipment for that care. The consequences are high levels of burnout and staff turnover, and maintenance of the very conditions which make this group unacceptable to society.

More importantly, it means that people with severe multiple impairments are not welcome in their communities. This is evident in the absence of consideration of people with severe multiple impairments in their communities, for example, the absence of access for wheelchairs to shopping and entertainment venues, the absence of suitable transport, the absence of suitable housing. It is also evident in the protests in neighbourhoods when housing is sought for people with severe multiple impairments.
A philosophy of inclusion, on the other hand, is an assertion by the disability lobby that people with disabilities have the same rights as any human and are therefore entitled to belong in society. This philosophy specifically rejects the “solutions” of exclusion and firmly places the responsibility for inclusion on society.

Much of the implementation in Australia of such a philosophy draws on the principle of normalization as described by Wolfensberger (1972), despite the differences between his North American and the Australian cultures, and despite the fact that even Wolfensberger (1983; 1988a) has altered his position. Complicating the situation even further is the continuing misinterpretation of the principle of normalization (Perrin & Nirje, 1985) by service providers.

Implementation of inclusionary policies have seemingly ignored the problems of insisting that people with disabilities should belong in a society in which they are not welcome. They have focussed on integration in the form of group home living. There is an increasing effort in relation to inclusionary education, work and social activities but there are questions to be answered about these practices which are not in the scope of this thesis. They have no application to the people with severe multiple impairments in this study. What is important is that there is a plan to move people with severe multiple impairments into group home living.

**SITUATION: A PLACE OF INTIMACY**

Nurses’ definition of quality of life for people with severe multiple impairments emerges from their situated interaction with this group. The situation consists of those aspects which nurses consider important. In examining the themes which make up their definition of quality of life, three
of those aspects are: (1) the humanness and dependence of people with severe multiple impairments; (2) the attitudes, knowledge and experience of nurses who work with this group; and (3) the everyday nature of quality of life.

In the theme of humans being, the participants were clear about their assumption that people with severe multiple impairments are human, describing their qualities and abilities, as well as their individuality. They did not want to give the impression, however, that impairments are irrelevant or unimportant. To the contrary, they are integral to the experience of these people. Their impairments are highly visible and highly dysfunctional in a world which values beauty and strength, communication and productivity. The theme of supporting is based on the dependence of people with severe multiple impairments.

The attitudes of nurses are complemented by their body of knowledge gained from education, reading and experience regarding the impairments, and consequent disabilities of people with severe multiple impairments. Through experience, they also have a body of knowledge regarding the qualities and abilities of people with severe multiple impairments. It is their attitudes, knowledge and experience which makes interaction with people with severe multiple impairments possible.

In relation to the everyday nature of quality of life, nurses focus on that one lives and how one lives rather than on where one lives. Nurses are fully cognisant of the principle of normalization but their idea of normalization is closer to that of Nirje (1969) than that of Wolfensberger (1972). Almost naturally, as a consequence of their nursing context, particularly the notion of activities of daily living, they practise with a view to the normal rhythms of the day, week and year. The preferred everyday life of the body, the
emotions and identity are at the core of their definition of quality of life for people with severe multiple impairments.

The data from which the theme of humans being emerged indicate that, in their everyday life, people with severe multiple impairments wish to belong, and the data from which the theme of supporting emerged is an acknowledgment by nurses of that wish to belong. In this way, the everyday life of the body, its health, comfort and development, is supported so that people with severe multiple impairments can exist in the first place. The everyday life of the emotions is also supported so that people with severe multiple impairments can belong through their engagement with life, and the everyday life of the identity is supported through the positive images of people with severe multiple impairments which nurses portray to others in order that they may more readily belong.

Nurses’ definition of quality of life for people with severe multiple impairments, however, is situated in their intimate interaction. Over time and with experience, nurses get to know people with severe multiple impairments through interpreting as emotions their impaired bodies in various situations. The meaning they give to these interpretations is that people with severe multiple impairments wish to live, wish to be healthy, be comfortable and develop, wish to engage in life in their own ways, and wish to be recognised as individuals who are part of society. These meanings are in tension with the views of the wider context in which people with severe multiple impairments exist.

Situated belonging, therefore, is a process which reflects this wider context. It occurs in relation to the rejection by society of people with severe multiple impairments and the misunderstandings about them by the disability lobby.
TENSIONS: CONTEXT VERSUS SITUATION

Tensions exist between the contextual and situational definitions of quality of life. Nurses who see the “solutions” of society for people with severe multiple impairments and who work in the under-resourced conditions of large residential centres soon realise the ramifications of a philosophy of exclusion. But they also witness the rejection of people with severe multiple impairments by their communities and, therefore, cannot agree with policies of inclusion. Nurses, however, are also members of society and for them, many of the tensions are internalised.

For people with severe multiple impairments, exclusion means several things. Currently it means that for the majority who still live in large residential settings there are few resources. Resources are focused on community projects, not on a mode of service that is no longer fashionable. One tension for nurses in this situation is that they find it difficult to support the wishes of people with severe multiple impairments when resources are so limited. Another tension is that which arises between their sense of adequate resources for people with severe multiple impairments and their internalised view of diminishing resources for all causes.

In the theme of humans being, the participants describe quality of life as people with severe multiple impairments just being (themselves) in a context of exclusion. This means that, generally speaking, nurses do not believe that people with severe multiple impairments are “better off” dead. In both the interviews and the observations, however, there is one negative case which requires some explanation.

This is the case of the resident for whom nurses feel they can do nothing towards quality of life. The resident is typically someone whom no nurse can get to respond; blindness and/or severe epilepsy further complicate the
picture of severe multiple impairments. This person's expression never seems to change, there is no alteration in body tone, and there is rarely any sound; if there is, it is a sound, usually interpreted as unhappy, which no nurse can find a way to change.

Nurses cannot identify this person's preferences because there is no sign from the body, no expression of emotion or no way known to change that expression. Because they cannot discern this person's preferences, they cannot use the other strategies. They feel that they do not contribute to this person's sense of identity and, of course, this person confounds their conception of self. They complete all the tasks that they do for others but they are adamant that they cannot affect this person's quality of life.

This negative case has some interesting implications. Firstly, it strongly supports the process identified in this research of nurses' perceptions of quality of life for people with severe multiple impairments. Quality of life for them is dependent on becoming intimate in order to complete acts which the person prefers. Secondly, in this situation, nurses say that this person would probably be better off dead. They perceive that this person's life is an awful thing, of no value. They believe that the person is unhappy and that death is the only way to end their suffering. This is not surprising thinking among nurses who often feel the same way about anyone in any situation whose suffering cannot be relieved. It does raise the question, however, of whether this is how society views all people with severe multiple impairments, and hence their attitudes regarding euthanasia.

While nurses reject a philosophy of exclusion, they are concerned about a number of issues related to a philosophy of inclusion. These tensions include: (1) the lack of recognition of the differences of people with severe multiple impairments; (2) the abundance of quality of life models which do
not support the wishes of this group; and (3) the lack of attention to issues associated with inclusionary policies in the context of current society.

While nurses believe that people with severe multiple impairments should belong in society, they are cautious of the misinterpretation of a philosophy which suggests that all people should be as like one another as possible. As they have expressed previously in this thesis, people with severe multiple impairments are different in many ways from other people. Until these differences are valued, people with severe multiple impairments cannot just be.

While nurses insist that the differences of people with severe multiple impairments are important, they also value these differences. Nurses modify their meanings about people with severe multiple impairments and their quality of life when they become intimate with them and recognise their communicative efforts and their productivity. This is, of course, not the productivity of the economic rationalists, but the productivity of giving to others in a way which reminds us of our common humanity.

A further reason for nurses’ disagreement with inclusionary policies, therefore, is related to the disability lobby’s lack of recognition of the dependence, individuality and vulnerability of people with severe multiple impairments. People with severe multiple impairments represent a minority within their own lobby group, and as such, are marginalised by that group. As one parent put it: “they are not talking about my child” (J. E. Moroney, personal communication, August 5, 1994).

In the theme of supporting, nurses have shown that there is potential for quality of life, as long as there is support to have a life and live that life in the way one wants. They therefore agree with a philosophy of inclusion by rejecting the “solutions” of a philosophy of exclusion and the ensuing lack of
resources. They disagree, however, with inclusionary practices which do not support the wishes of people with severe multiple impairments. This is the case with most quality of life models which have been based on the values of the authors of the models. Fortunately, there is movement towards developing models which respect the wishes of people with disabilities, such as in the work of Goode (1988) and Brown et al. (1989). The people with whom they are working, however, are able to talk about their wishes. Nurses disagree, in particular, with most models’ support of government policy which advocates community living, particularly in the form of group home living, as the implementation of the philosophy of inclusion.

The disability lobby promotes community integration as the way towards quality of life. Community integration has been shown to be a fallacy for people with significant disabilities, and has been misinterpreted as group home living. For the people with severe multiple impairments in this study, not even group home living has been an option; they continue to live in large residential centres. If integration, nevertheless, is essential for quality of life, it is not happening for people with severe multiple impairments.

One of the reasons nurses disagree with community living is that people with disabilities are still not welcome in their communities (Barlow & Kirby, 1991). Their presence confuses and discomforts people without disabilities (Keith, 1996).¹ Inclusion does not occur just because people live, or try to live, in houses in the community. Moreover, the practice of group home living, which permeates disability policy, is unlikely to achieve the goal of community integration on its own, and may even limit its future occurrence. Hence, nurses are sceptical of the motives of decision makers

¹ As I write, there is an ongoing feud in my local area (for example, Carney, 1998; "Mediation in limbo," 1998; "Row erupts," 1998; Webster-Hawes, 1998) between current residents and advocates for a group of people with disabilities for whom the government department
who maintain enthusiasm for a project which is not succeeding, and may even be harming the future success of inclusion.

In the theme of becoming intimate, nurses empathise with people with severe multiple impairments and come to believe that it is cruel to expose people as vulnerable as this to a society which rejects them. Mental health nurses have come to similar conclusions in relation to the mentally ill:

“Discharging the mentally disabled patient from the hospital ... without ... social or community support would be inhumane and contribute to the decline in the patient’s quality of life” (Niemi, 1987, p.60). People with severe multiple impairments are unable to actively alter the perceptions of society unless others make the effort to get to know them. Since this rarely happens, they continue to be subject to the oppressive attitudes of people in their communities. Sacks’ (1985) comments about pressing people with disabilities into a variety of workshops and classes apply equally to this situation:

It didn’t work with Rebecca, it didn’t work with most of them. It was not, I came to think, the right thing to do, because what we did was to drive them full-tilt upon their limitations, as had already been done, futilely, and often to the point of cruelty, throughout their lives (p. 174).

When talk turns to community integration as the key to quality of life, therefore, nurses are thinking of quality of life as intimate support to be. Community integration, in practice, however, has meant the removal of nurses who are familiar with people with disabilities from their lives, and there is no reason for nurses to believe that it would be any different for people with severe multiple impairments. Removal of nurses who have become intimate with people with severe multiple impairments means that

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wishes to purchase a house in the area. This feud reflects the limited success of community integration in the context of the entrenched attitudes of society.
their definition of quality of life collapses for, without intimate interaction, there cannot be individualised support for humans being. In addition, community integration, as we have seen, means that people with severe multiple impairments are subjected to rejection by their communities. The data in this study show that nurses have witnessed instances of rejection of people with severe multiple impairments by others and, as a consequence, have become angry on behalf of individuals whose identity they are trying to support. They fear, then, that people with severe multiple impairments, without nurses who know them, will not be known by others, and a further aspect of quality of life, the identities of people with severe multiple impairments, will not be supported. Without the support of their identities, and their individuality, people with severe multiple impairments are more likely to be subjected to the exclusion of anonymity and invisibility.

Not only do tensions exist between the views of nurses and of others, but also as a result of nurses’ membership of society and their desire for an integrated world. While, for instance, society continues to systematically exclude people with severe multiple impairments, nurses find it difficult to visualise a society which values people with severe multiple impairments, recognises their humanness and works to remove the barriers which prevent them living their lives. Consequently, nurses are sceptical of the illusion of integration advocated by the disability lobby. At the same time, nurses are members of society, and often find their internalised view of people with severe multiple impairments in tension with their intimate view. This means that they sometimes take the position of society regarding exclusion, albeit for different reasons, often postulating that people with severe multiple impairments would perhaps be better off dead than having to live in a society to which they do not belong. As well, nurses who work with people with severe multiple impairments long for a society which values these people, and therefore sometimes find themselves caught up in the rhetoric of integration. Further, nurses who work with people with severe multiple
impairments are devalued by society, by their employers, and by other nurses, but feel valued by people with severe multiple impairments.

These contradictions reflect both the external conflicts and the internalised tensions with which nurses live every day. It is not surprising, then, that the participants are driven to make a place where people with severe multiple impairments can belong. Such a place is a metaphorical one: a situation which incorporates all the themes of nurses' perceptions of quality of life for people with severe multiple impairments.

**SUMMARY**

In a world unwilling to accommodate impairment (Lupton, 1994), there is little hope of successful community integration for people with severe multiple impairments. Murcott (1993) recognises society's limited capacity to incorporate difference, in her research with infants, who are "out of place" in the adult world, and who are contained in a private place until they are socialised. Unlike infants, however, people with severe multiple impairments are unlikely to be socialised. Marginalised, as they are by society and the disability lobby, nurses and people with severe multiple impairments "are driven to affirm belonging at another level" (Kupfermann, 1979, p. 146). This other level is a metaphorical place, a situation which incorporates all the aspects of quality of life previously discussed: intimate support to just be.

Such a place is not new to society and has often been referred to as a safe place, "a physically protected place as well as an emotionally secure environment" ("There is a safe place," 1998, p. 38), or asylum. The meaning of asylum is reflected in the following excerpt from a conversation between a
woman who is recovering from an extended period of depression, as a consequence of bipolar disorder (or manic-depression), and her psychiatrist.

_ But tell me, why am I getting well now? ...
_ I don’t know: I think that’s what you needed more than anything else. Asylum. I like that word, don’t you? I can’t understand why people suddenly stopped using it. Asylum, a haven from the world, a secure refuge ...  
_ ... People in here can be real, we’re sort of allowed to be more real than in the outside world, in many ways. We can just be. No social niceties to keep up, no performances. Just be.  
_ It’s been good for you to just be, hasn’t it?  
_ Yes, said Clare, simply. It has (Rowe, 1997, p. 259).

Members of society will have incorporated difference when they can refer to individuals rather than people qualified by their difference (Ashman, 1989), and when they can recognise that how they treat others is more important than where they treat them (Deveson, 1991). The abode of people with severe multiple impairments, therefore, is inconsequential in nurses’ definition of quality of life but, until there is a time when their difference is valued and they are treated with respect, their quality of life consists of intimate support to just be, in a metaphorical place which is physically protected and emotionally secure, a place of situated belonging.
CHAPTER ELEVEN
WHERE HAVE WE BEEN?
WHERE ARE WE NOW?
WHERE ARE WE GOING?

The world is just made up of people; and they are entitled to go down any road
they choose. ... Meanwhile our true quality of life is to be gauged by factors much
more intimate, much closer to home. ... It is our perception of things, more than
anything else, that will determine what sort of future we experience
(Rodrique, 1997).

This chapter reviews the intention, the methodology, and the findings
of the study. Nurses' perceptions of quality of life for people with severe
multiple impairments are then discussed in relation to the current knowledge
about quality of life. This discussion is organised around the four themes
which together provide understandings of “just little things”. The chapter
then looks at methodological criticisms, as well as implications of the
findings. It concludes with a return to David and my story - the beginning of
this study.

INTENTION OF THE STUDY

At the beginning of this study there were two points of view about
quality of life for people with severe multiple impairments. Society generally
held the view that people with severe multiple impairments had no potential
for quality of life. The disability lobby insisted that the key to quality of life
was community integration. Nurses who work with people with severe
multiple impairments disagreed with both these views, but had not
articulated what they meant by quality of life for people with severe multiple
impairments. This study sought to uncover the view of these nurses by
ATTENDANT METHODOLOGY

The theory and methods of symbolic interaction were chosen to explore the view of nurses because the three basic premises of symbolic interaction suggest that meaning is found in interaction. In other words, the theory of symbolic interaction provided some explanation of how nurses’ meanings were different to other meanings and, more importantly, the methods suggested ways to get at these meanings. Semi-structured individual indepth interviews were held with four informed participants who worked with people with severe multiple impairments in a large residential setting, followed by a focal group interview with those same four participants. A further five individual interviews were held with informed participants from another residential setting, again followed by a focal group interview with three of those participants. The interviews were each analysed as soon as possible after the interview with any emerging concepts altering the interview schedule before the next interview. The group interviews focused on an emerging model of quality of life for people with severe multiple impairments which was revised after each group interview. This model then served as the focus of a third group interview with four informed participants from a third residential setting who had not been previously interviewed. The model was “validated” by this group and there were no new ideas emerging from this interview.

One vital aspect of the model was the interaction between nurses and people with severe multiple impairments. This aspect required further explanation because clarity was not emerging in the interviews. Here, I faced the same problem which other researchers have found when the participants asking them what they meant and thus, represents a third view of quality of life for people with severe multiple impairments.
take for granted the processes involved in some act - the tacit knowledge available for the doing but not for the saying. Investigating the interaction was extremely complex because people with severe multiple impairments cannot speak. The study therefore adopted a multi-method, multimodal approach using participant observation with a further three expert nurses as they worked with people with severe multiple impairments. The principal method was observation of dyads followed by questions about what had occurred in the interaction. This was supported by observation of, and informal discussion with, others in the setting. The outcomes of the observations were validated and refined individually with the three participants.

**REVIEW OF THE FINDINGS**

The themes which emerged from my analysis of the data have been outlined in Chapter Six and extensively discussed in the subsequent chapters. It is not, therefore, my intention to repeat those findings here except by way of a brief summary.

Quality of life for people with severe multiple impairments has been defined by the participants in this study as “just little things”. This way of describing the concept has, until now, concealed the meanings which nurses give to it. This study has uncovered those meanings and they are presented in the form of the four themes which emerged from the data: humans being, supporting, becoming intimate, and situated belonging. Humans being refers to the life in quality of life and supporting refers to the quality in quality of life. Becoming intimate is the way in which nurses mediate quality of life for people with severe multiple impairments. From the themes of humans being, supporting and becoming intimate, the theme of situated
belonging emerged. Situated belonging refers to how nurses make a place for quality of life to occur for people with severe multiple impairments.

The theme of humans being can be summarised as the right of people with severe multiple impairments to live the preferred everyday life of the body, emotions and identity. The theme of supporting means recognising the differences in the lives of people with severe multiple impairments which indicate that quality resides in completing preferred body, emotion and identity acts on their behalf. The theme of becoming intimate refers to a process of empathising with people with severe multiple impairments through knowing, interpreting and feeling. Knowing consists of knowing the individual impaired body in the situation. Interpreting means anticipating the communication of individuals by observing and giving meaning to the gestures of their impaired bodies. Feeling refers to the emotion work performed by nurses in response to the emotions felt in their bodies as a consequence of empathising with people with severe multiple impairments. The theme of situated belonging is the name given to the concept which rejects both exclusion and inclusion as options for people with severe multiple impairments. It replaces exclusion and inclusion with a safe environment where people with severe multiple impairments can experience quality of life.

The relationships of these themes can be described thus. Nurses define quality of life for people with severe multiple impairments as making a place where they can provide intimate support for these people to just be.

**DISCUSSION**

The concept of quality of life found in this study shares ideas with some concepts of quality of life in the literature and differs from others. This
study's conceptualisation also draws on literature not usually connected with quality of life, for example, sociological literature on the body, the emotions and identity, as well as the literature in nursing associated with knowing, and the symbolic interaction literature associated with interpreting. The measurement of quality of life in this study is different from the measurement in the literature, dispensing with the usual indicators and replacing them with the nature of the everyday. These similarities, differences and novel connections form the following discussion. It is organised around the four themes of humans being, supporting, becoming intimate, and situated belonging.

**Humans Being: The Life in Quality of Life**

Vital to the concept of quality of life in this study is the concept of humans being. This concept includes the assumption of the humanness of people with severe multiple impairments, the consequent rights shared by all people, and the individual identity in everyday life, which is experienced through the body and expressed through the emotions. Discussions of the concept of quality of life in the literature do not usually include discussion of humanness, although it would have to be said that humanness is implicit. There is, however, a move towards understanding the lives of people in order to understand quality of life (Heal & Sigelman, 1990; Taylor & Bogdan, 1990), alongside an explicit recognition of the humanness of people with disabilities (Bogdan & Taylor, 1989; Wolfensberger, 1988a). The link between humanness, life or being, and quality of life has been made explicit by Draper (1992) who says that in order to understand quality of life, we must recognise that the life in quality of life is the characteristic of human being and we therefore have to understand what it means to be a human being.
Where, then, do we begin to understand what it means to be a human being? We can turn to philosophy which, according to Russell (1961), reflects conflict between social cohesion and individual liberty throughout its history. From such conflict has arisen charters of individual human rights, and it is to such rights that nurses turn, as a result of their focus on the individual, to defend the lives of people with severe multiple impairments. So, first and foremost, being human means having a life. It then remains to consider that life. While a number of different perspectives of the life of human beings has been advanced in the literature review of this study, the study has been informed by the symbolic interaction perspective. According to Meltzer (1972), Mead’s theories explain that self and mind (or meaning), uniquely human attributes, emerge in the social processes in everyday life. In other words, at least part of what it means to be a human being is everyday life.

The everyday life of people with severe multiple impairments, according to the participants in this study, is experienced through the body and expressed through the emotions, and from this everyday life their identities emerge. It is surprising that the literature related to the body and the emotions has not previously been considered in the concept of quality of life given the close semantic relationship between well being and quality of life. Well being and quality of life are used synonymously, and well being is typically divided into physical and emotional well being. The sociology of the body and the emotions has added some understandings of what it means to be a human being with severe multiple impairments to this study, and may point to new directions for the study of the concept of quality of life. Moreover, for the people with whom this study was concerned, the emerging sociology of impairment (Hughes & Paterson, 1997) may have particular significance for their quality of life in that it may add to an understanding of their everyday lives from which their identities emerge.
The concept of identity (or self) is still poorly understood, the chief issue being lack of an explanation for other than a deterministic view of imputed identity. Schwalbe (1993), however, reads Goffman to mean that the self is evident in moments of decision, resistance and feeling in everyday life. In this study, identity was defined by the preferences of individuals, these preferences reflecting moments of decision, resistance and feeling. Quality of life, then, may also be considered in terms of affirming identity, another possible avenue of study. Preferences, however, might be thought of as limited choice, and choice is central to most of the literature on quality of life. As well, the choice described in the literature on quality of life is framed within expectations of changing to live as the majority of society does, while preferences in this study indicate how people wish to live their everyday lives. The concept of humans being, therefore, also emerged from the data which suggest that people with severe multiple impairments wish to engage in life, to belong in society, in the ways that their impaired bodies allow.

Supporting: The Quality in Quality of Life

According to the participants in this study, people with severe multiple impairments can only have a life, and live it in the ways that they wish, with support. Most models of quality of life include the notion of support, most often using the term resources. It is interesting to note that the latest definition of mental retardation (Luckasson, Coulter, Polloway, et al., 1992), in an endeavour to shift the emphasis from mental retardation as a trait of the individual to mental retardation as an interactive process between the individual and society, includes the concept of supports. There are some similarities between the resources in quality of life models, the systems of supports in the definition of mental retardation and the supporting which is described by the participants in this study. The resources, for example, to which Brown et al. (1989) and Goode (1990a) refer are those which are
necessary to meet the needs and expectations of individuals with disabilities. Similarly, Fredericks and Williams (1998) say, in regard to the systems of supports, that anything can be considered a support. It is only when they qualify this statement that the differences between supporting, in this study, and resources and support in other literature, becomes evident. Fredericks and Williams go on to say that the intention of support is the enhancement of adaptive skills and the maximisation of habilitation goals, as it is with most quality of life models. In other words, while the emphasis has moved away from mental retardation as a trait to that of an interaction, with the responsibility of support falling to a society which defines some of its members in this way, there is still a focus on changing people who are different so that they can better fit in society. On the other hand, the focus of supporting in this study is the everyday life of the body, emotions and identity of people with severe multiple impairments. Such supporting also intends that people with severe multiple impairments will belong in society, but on their own terms, not as a consequence of having tried to change so that they will fit.

It is the concept of support which is bringing together the concepts of quality of life and quality of care. When Borthwick-Duffy (1992, p.58) said that “quality of care is a necessary but not sufficient aspect of quality of life”, she best reflected the view found in this study, where participants indicated that quality resides in supporting. While, according to the participants, there can be no quality of life for people with severe multiple impairments without supporting, it seems that the support which is given may determine quality, in an evaluative sense, but that there is a further aspect of quality of life, and that is the life which one has and leads. The participants said quite clearly that the life of people with severe multiple impairments is of value, or, in other words, that quality is an essential attribute of life (Meeberg 1993), in the non-evaluative sense. Quality of life, then, is whatever one says it is (Atkins, 1994a), as well as attaining, through support, whatever it is that one wishes.
How, though, can we know what it is that people with severe multiple impairments, who do not communicate in the usual ways, wish?
Becoming Intimate: Mediating Quality of Life

The concept of becoming intimate emerged as a consequence of my investigation of how nurses know the wishes of people with severe multiple impairments who do not communicate in the usual ways. Becoming intimate mediates quality of life. The concept does not occur in the quality of life literature, although there are scattered references in the disability literature to the processes of becoming intimate found in this study: knowing (for example, Bogdan & Taylor, 1989), interpreting (for example, Goode, 1990b) and feeling (for example, Bailey, Matthews, & Leckie, 1986; Clark, Reed, & Sturme, 1991). It is this concept of becoming intimate, however, which can provide some understanding of why there exist different views of the quality of life of people with severe multiple impairments, for, as nurses become more intimate with individuals, they say that they know them and, through interpretation of their communications and through shared feelings, they know what they wish. They further say that people who do not become intimate with people with severe multiple impairments cannot know what they wish.

The similarity of the concept of becoming intimate with the quality of life literature is in the approach to measuring quality of life which asks people to answer questions about their quality of life, since it is in the intimate interaction of everyday life that nurses “measure” or understand the quality of life of people with severe multiple impairments. Nurses turn to these ways of understanding in response to people who do not communicate in the usual ways, although such understandings are common in nursing, even when people can talk. They continually assess how people with severe multiple impairments are conducting and responding to their lived experience, reflecting Lachs’ (1986) belief that quality of life is defined by everyday choices and measured by the tone and temper of everyday life.
The concept of situated belonging can be thought of as a meta-theme, or in grounded theory terms, the basic social process in nurses’ perceptions of quality of life for people with severe multiple impairments. It is the name given to the view of nurses about how quality of life for people with severe multiple impairments occurs. It derives from the three themes which together define quality of life, and is a response to the context of exclusion and inclusion. It explains how the situated definition of quality of life is different from other definitions of quality of life for people with severe multiple impairments. Situated belonging does not occur in the literature related to quality of life but has connections with the notions of marginalisation and of asylum. It has emerged as a consequence of nurses “listening” to the people with severe multiple impairments with whom they have become intimate:

They can’t speak to us, they can’t tell us of their feelings, their pain, their needs, their hopes, their fears. They can’t tell us of their isolation. But we can listen to them. With respect and dignity, and with our hearts as well as our minds and with every means at our disposal. And if we listen hard enough and diligently enough and long enough, I believe we will hear them (Mawson, 1998, p. 102).

**METHODOLOGICAL CRITICISMS**

While the methodology of symbolic interaction has been successful in doing what it set out to do, I would not recommend such a methodology to the beginning researcher. The theory of symbolic interaction is not clearly explicated (Meltzer, 1972) and there are no specific methods suggested by
symbolic interaction researchers. Further, research reports which have used symbolic interaction to guide the research do not report their methods in any detail. Having said this, symbolic interaction provides a flexibility which the researcher will find useful when seeking understandings of areas which are not well researched or when current research does not seem to have answered the questions. Two problems: escaping preconceived ideas and informed consent in fieldwork settings, which might coincide with any emergent technique, are discussed here.

The interview schedule for this study was developed from a review of the literature. There has been debate (Chenitz & Swanson, 1986a; Minichiello et al., 1995; Roberts & Taylor, 1998; Strauss & Corbin, 1990) in respect of the approach to the literature prior to undertaking a qualitative study. The chief concern is the accumulation of preconceived ideas of the area under study, with the subsequent limitation on the discovery of new concepts.

All researchers, however, come to a study with preconceived ideas. It therefore seemed that it was best to read in the area of quality of life to formulate and state my preconceived ideas at the outset of the study. I found as the study progressed, however, that this reading had influenced the probes in the interview schedule and, because I asked the questions in a particular framework, the participants answered them in the same framework. The prime example of this problem was the notion of well being. On returning to the interview tapes, I found that the participants had not mentioned well being in their responses to the initial broad question about quality of life. It was only mentioned when I began using the term during the interview. The data then suggested that well being had something to do with quality of life, but this was simply an artefact of the questions. It is difficult to know what to suggest as a remedy for this problem except for the
researcher to have a more acute awareness of how preconceived ideas can affect how questions are asked than I did.

The methods of symbolic interaction make the anticipation of informed consent difficult. This was most evident in the observation stage of the study. While I was observing three expert practitioners who had given their consent, their work occurred alongside others who had not given their consent. This initially presented no problems for me but, as the observation progressed and the participants were unable to articulate their practice, I observed the difference in their expert practice from the practice of beginners. This was a breakthrough in the research and fully within the methodology of symbolic interaction but, without the consent of the beginners, it would be unethical to use this data in the study. Fortunately, these practitioners had no dispute with my observation of them, but what does the researcher do if vital data cannot be used because people deny consent? Further, a number of people in the setting, who were not participants in the study by virtue of their not fitting the criteria of "expert" approached me to discuss the research question, thus giving their tacit consent. It would seem, then, that it might be best to seek the consent of all participants in the setting prior to the commencement of observation.

**IMPLICATIONS OF THE STUDY**

The articulation of nurses’ perceptions of quality of life for people with severe multiple impairments refutes the belief that there is no potential for quality of life for these people, disrupting the argument for euthanasia and withholding of treatment on the basis of severe multiple impairments. Like Dovey and Graffam (1987), nurses know that people with severe multiple impairments do not experience impairments, per se, rather they experience life. This life is a thing of quality in itself, no life being better or worse than
another. Further, this concept of quality of life clearly shifts the responsibility of quality to society when it says that quality resides in supporting. Nurses are saying, therefore, that society cannot avoid its responsibility to its members by making them non-members and then treating them accordingly, but rather that society is required to provide the necessary support for all its members.
The concept of quality of life found in this study is different from other models of quality of life for people with disabilities in a number of ways. The data suggest that quality of life is conceptualised by nurses as life and quality mediated by intimate interaction. Such a conceptualisation has a number of implications.

Firstly, life is not conceptualised as the array of adaptive skills which are generally believed to enhance well being, but rather as the everyday life of the body, the emotions and the identity, which is characterised by human interaction. Any formulation of quality of life for people with severe multiple impairments, therefore, may wish to consider observation of the individual in their everyday life before imposing categories which supposedly make up that life.

Secondly, quality, in the evaluative sense, resides in supporting. While support is recognised as important to other quality of life models, the intention of supporting in this model is different. The intention of the support described in the disability literature, including in models of quality of life, is that people with disabilities will change in order to better fit in society. Lindsay (1995/6) cites a variety of people and reports which state that disability policy has unrealistic expectations of people with severe multiple impairments. Cummins (1993), however, found "a remarkable enhancement in the life skill development" (p.65) of people with severe multiple impairments following deinstitutionalisation, but noted that we may be missing the point: "the achievement of optimum life quality for people returned to the community is still some way off, and optimal life quality cannot be achieved through the continuation of an ideology which focuses on objective indices and the imposition of lifestyle [emphasis mine]. Our next step must be to concentrate on the subjective needs of individuals" (p.67). In this study's model of quality of life, nurses describe supporting in a
way which allows people with severe multiple impairments to express their individual preferences for the ways they want to live.
Finally, current models of quality of life are moving towards asking people what they want, but only two describe how that might be done. Firstly, Borthwick-Duffy (1990) suggests that the way forward is to improve the communication skills of people with severe multiple impairments, a suggestion which is once more asking people with limited capacity to change. Secondly, Cummins (1991) uses an alternative to speech as a method of communication: wooden blocks which simulate a Likert scale. He tests people with severe multiple impairments on known items of importance to them to assess whether they can use the method but does not report how many people can. Goode and Hogg (1994), however, said that “determining the quality of life for people with profound cognitive disability will probably always rely on very fine judgments and forms of empathy, which are not easily operationalized and put to paper” (p. 205). Nurses in this study demonstrated that they communicate with people with severe multiple impairments through the empathising processes of knowing, interpreting and feeling. Such a way of understanding what it is that people with severe multiple impairments wish is not failproof, but may offer another way of tackling this problem.

Nurses have demonstrated in this study that their perceptions of quality of life as “just little things” speaks of the everyday and occurs against a background of complex nursing knowledge. This thesis has provided developmental disability nurses with a way to conceptualise and articulate their practice which, these days, is most often with people with severe multiple impairments. The themes which emerged from the data: humans being, supporting and becoming intimate, and the theme which explains their relationships: situated belonging, have implications for nursing practice, education and research.

In their practice, nurses support the everyday life of the body, emotions and identity of people with severe multiple impairments through a process
of empathising which incorporates processes of knowing, interpreting and feeling. In response to a wider context of exclusion versus inclusion, nurses make a place where people who are dependent and vulnerable are humans being, where they feel physically protected and emotionally secure, where they can belong. This is the practice which has been devalued by developmental disability nurses’ employers in the wake of reports in the early 1980s (for example, Richmond, 1983) which fuelled the deinstitutionalisation movement in Australia. This is the practice which developmental disability nurses’ peers in Nursing have little understanding of or respect for (Nehring, 1991). If developmental disability nurses move from a fragmented view of their practice and use this model, both to hang their everyday actions on and to articulate their practice, they will have a weapon to correct the lack of understanding, the lack of respect for, and the devaluing of their practice.

The unique knowledge held by developmental disability nurses was in danger of being lost forever in the transition of nurse education to the tertiary sector in Australia. It clings tenaciously, however, in some form or other in most tertiary institutions. With deinstitutionalisation of people with severe multiple impairments, all nurses are more than ever coming into contact with these people in their work (Atkins & Dalley, 1988). It is therefore vital that the knowledge which developmental disability nurses hold is passed on to all nurses, as all nurses are now subject to legislation (Disability Services Act, 1986) which requires them to provide accessible and appropriate generic and specialist health care to all people with disabilities. This study’s model of nursing practice with people with severe multiple impairments (Atkins, 1994b) can assist nurse educators to develop curricula, enhance classroom teaching and point to clinical experiences for students of Nursing.
There is very limited published research regarding people with severe multiple impairments. Nurses who work with these people are in a unique position to conduct such research because of the ways in which they already know them and because of an attitude which respects their humanity. Many questions have arisen from this study alone, for example, how do people with severe multiple impairments interact with their peers, how do the families of people with severe multiple impairments perceive the latter’s lives, how do the interpretations of the communications of people with severe multiple impairments affect their lives, how can nurses accelerate the process of becoming intimate, is the process of role-taking really a process of role-making (Palmer & Noble, 1985) and how does this affect the lives of people with severe multiple impairments? While there is little research in the area, nurses often tell each other stories about people with severe multiple impairments and occasionally write them (for example, Horten, 1980; Kearney, 1996), as I felt compelled to do in this study. A recent story about Neal (Richardson, 1997) not only validated much of the findings of this study but also triggered the thought that such stories may be an excellent place to begin research in this area.

A RETURN TO THE BEGINNING

At the outset of this study, I recorded a story about David and me. I knew David through my work as a developmental disability nurse, and the story is full of confusion, anger and sadness, as a result of David’s death following withholding of treatment for a blocked shunt. As I return to the story, I find that I can make more sense of it, but this in no way has lessened my anger and sadness. If anything, my anger and sadness have been exacerbated by what is now more clear to me and are heightened by the contrast of my sad but not angry feelings about the recent death of Patrick,
whose story was included in Chapter 6. Nevertheless, I will now retell the
story through my new lens of the grounded theory of situated belonging.

Over time and through shared experiences, I came to know David in his
situation. David was an attractive twelve year old when we met, with
lustrous black hair, deep blue eyes, clear pale skin and sparkling white teeth.
How I loved to wash and style that hair and help him brush those teeth!
David would examine himself in the big bathroom mirror after he had
finished grooming and would smile at what he saw. He luxuriated in a deep,
warm bubble bath and together we would get him dressed in clothes which
gave him ease of movement and which highlighted his colouring. David
smiled and laughed a lot which made him a joy to be with. He did not speak
but I came to understand the communications of his facial expressions, his
movements and his sounds. He could feed himself because of his good head,
trunk and arm control and eat and drink most things because of his
integrated swallow, bite and gag reflexes and controlled breathing. He
tended to suck rather than chew his food, however, so I would cut his food
into small pieces and manipulate his jaw to simulate chewing while he was
eating. He had no control over his bladder and bowels, as a result of spina
bifida, which meant that he wore nappies which I would change when
necessary, paying particular attention to his skin which was constantly
threatened by soiling and immobility.

David enjoyed going out in the fresh air and sunshine but his skin burnt
easily, so we did it in short bursts on mild days and used sunscreen. He
liked a rest in the afternoon and usually slept well at night if I made him
comfortable with pillows. He was generally healthy and occasionally had
seizures which were related to his hydrocephalus, which disrupted his
consciousness, breathing and movement, and for which he took medication.
He would typically have a seizure while he was eating, so I was vigilant
during these times in anticipation of his choking. He loathed pills, so I was
forever finding ways to disguise them. There were a couple of occasions when his erupting teeth were troublesome which caused him to cry and to be irritable. Some tender, loving care thrown in with some gum anaesthetic soothed him.
He was sensitive to changes in temperature and distressed by shivering and sweating. The trick was to alter his clothing or move him somewhere warmer or cooler before these signs began. He was comfortable in his wheelchair, which supported his hips and heavy head, as well as on a mat on the floor. Spina bifida prevented David from standing but he could lift his head and roll over. He did things with his hands like throwing a ball, banging a drum and painting at which he would persist for an hour or more, and was eager to join in whatever was going on, like picnics, films and concerts. I took him to school when I was there, a short trip from his home. We would look at flowers and birds, and just feel the day. Sometimes I would stay with him at school where he enjoyed sand and water play as well as musical games. He hated swimming, so, on the days that his class went swimming, David would stay at home and we would do something else that he liked. David spent time with two of the other boys, Alan and Mark, who lived with him. They would sit and watch television together, and no-one would dare take one of them on an outing without taking the others. David enjoyed visits from his family, usually on special occasions such as birthdays. I would talk with his family about what David had been doing and check their responses, then leave them to have time with each other, commenting on how pleased he was to see them.

He seemed to like most of the staff but had two favourites: Denise, a woman who maintained the clothes of people who lived there, and me. Denise and I would often confer about David, telling each other stories to learn more about him and checking with each other when we were unsure what David had meant. Whenever David and I were out together, people would see him and make patronising remarks to the effect that it was a pity that such a good looking boy was so physically deformed and had to use a wheelchair. I do not know whether David understood what they said but he would become miserable. I would glare at them and distract David by pointing out features in the environment and talking about them. It was
difficult to manage such comments: I talked with other nurses and we agreed that it was easier when I was introducing David to people because I could focus the conversation on David's strengths and everyday activities.

One day, when he was fourteen, David was "off colour". His face was passive and he made no effort to engage. I checked his body for anything unusual and measured his temperature, pulse, respiration and blood pressure. There being nothing unusual that I could detect, I discussed it with the other nurses and with Denise. We agreed that it was unusual and that David had best stay in bed while we monitored any developments. The doctor who attended David, as well as the other people who lived with him, visited every day but could find nothing in particular wrong with David. Everything stayed much the same until the next morning when David had a seizure. He seemed a little brighter after that, not unusual for David or for other people who have seizures. After his bath, he went back to bed and smiled at me when I positioned his pillows. That was the last time I saw that smile and the memory of the communication of trust remains vivid today. David slept for a few hours and then had another seizure, what was to be the first of many over the next few weeks.

The doctor was called to see David and he ascertained that David's shunt was blocking. I was waiting for the doctor to tell us to arrange David's transport to hospital but he said nothing and was about to leave. When I questioned him, he said that this might be the best thing for David. In shock, I let him walk away. When I had recovered, and the other nurses and I had talked about it (Denise was away that day), I rang the doctor, only to be told that it would be cruel to put David through the surgery and hospital experience. Although I argued, I was getting nowhere and, when I told him that I was going to talk with the nursing supervisor, he did not reply and hung up. I did go to the nursing supervisor who essentially told me that the doctor knew best. I then went to the medical superintendent who told me
that I was too emotionally involved. I did not wish to involve David's family who had already been told by the doctor that David was critically ill and had agreed with him that it was probably for the best that there was no treatment. Both the nursing supervisor and the medical superintendent implied that if I did not get my act together, they would move me to another residential unit away from David. I went home and thought about it and eventually decided that I could do nothing for David except be with him while he died.

The next twenty five days were torturous because David was comatose and therefore unable to drink. Parenteral feeding and medication were considered heroic measures and were therefore not administered. He seemed unaware of what was happening but, of course, we do not know. I consoled myself with doing the things for him that I knew he liked such as keeping his hair clean and combed and brushing his teeth. I also talked with him about the things we had always talked about, such as his painting and his friends. When David had become so ill, he was moved from his bedroom which he shared with Alan and Mark. Consequently, they had not seen him for some time and many of their behaviours indicated that they missed him. A few of us took them to see him, explaining what was happening. They seemed to settle down after this but remained quiet for quite a while after David's death. David finally died quietly one early morning when I was not there. One of the other nurses cried when she told me of his death and I cried too. I attended his funeral a couple of days later with Denise, Alan and Mark to say my final goodbye.

When I argued for treatment for David, I did it because I knew that he enjoyed his life. I knew this because I had become intimate with him through our shared experiences and feelings. Others, who did not know him as I did, presumed that David's impairments made his life not worth living, although I note that this study does not explain how his family viewed the
situation. They also implied that my knowledge was not valuable, because it came from the emotions. Lawler (1991) commented on this rejection of such knowledge when she said that “nurses deal with what people do not want to know about... [and such knowledge is] regarded as the sort of thinking women do - that is, it is perceived as more emotional than rational and not relying heavily on intellect” (p. 226). While society does not want to know about people with severe multiple impairments, these people and the nurses who work with them will be marginalised. Being marginalised consists of both knowing (rationally) that one is, and experiencing the emotion of persistent rejection, of not belonging. When one knows (rationally) that there is a limited amount one can do to change rejection by the overwhelming majority, one seeks a place where one can feel that one belongs. When that place where David and I felt safe was invaded by people with murderous intent, there was nothing that I could do for us except feel our way through it. David and I had become like family, and whatever he knew or felt about his imminent death, it did not rely heavily on intellect that David was going to die when he wanted to live, and that I would feel the pain of his death as I would that of a close brother. Further, no amount of rational thought on my part can ever justify his death or the death of anyone who can be treated and who wishes to live.

As long as society continues to exclude people with severe multiple impairments on the basis of their difference, nurses become intimate with them and, through the process of empathising, which includes knowing, interpreting and feeling, nurses discover the inhumanity of letting people die and of changing people so that they can belong in a society which does not want them because they can never change enough, and make a place where they can support humans being, a place of situated belonging. Together, these endeavours reflect nurses’ perceptions of quality of life for people with severe multiple impairments as “just little things”.

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APPENDIX I: EXPLANATION OF RESEARCH PROCEDURES:
STAGE ONE

My name is Chris Atkins. I am a nurse. I have worked in Developmental Disability Services between 1969 and 1985 as a clinician and nurse educator. I have been a lecturer at University of Western Sydney, Nepean since 1985 and am currently the Head of the Department of Developmental Disability Nursing. I am also the Secretary of P.A.N.D.D.A. (NSW).

As a major part of my Master of Applied Science (Nursing) at Cumberland College of Health Sciences, I am conducting research about what constitutes quality of life for totally dependent, multiply handicapped people. The research protocol has been approved by the Ethics committee of Cumberland College of Health Sciences, The University of Sydney and your Director of Nursing has given me permission to do this research.

I believe that nurses have a great deal of insight into this area. I want to talk with nurses at four different hospitals who have worked with this group of residents for at least one year. This would mean an interview of substantial length with you at a time convenient to you. I would be audio-taping the interview to ensure that my recording of your opinions is accurate. The only people who will have access to this tape are my two supervisors; one a lecturer at Cumberland College of Health Sciences and the other a lecturer at University of Western Sydney, Nepean. I am the only one who will know whose voice is on the tape. I am bound by strict rules of confidentiality not to reveal this information to any other person. I may have to talk with you again to clarify points raised in your interview as the research
progresses. You never have to answer any questions that you find distressing or that are an invasion of your privacy.

The information on the tapes will be analysed by me in conjunction with my supervisors and turned into a thesis report as well as several articles for possible publication. While I have every intention of acknowledging nurses' participation, I repeat that neither you personally nor your place of work will be identifiable. At the conclusion of the study, the tapes will be kept by me in a secure area, separate from identifying information, for the required seven years.

You may not personally derive any benefit from this research but you will help the whole area of developmental disability nursing and its clients in the following ways:

1. An increased awareness of quality of life issues for people with severe multiple disabilities; and

2. An increased awareness of nurses' knowledge about, and work with, this group of people.

Other than the time you contribute, there are no risks to anyone involved in the research anticipated. You may withdraw from the study at any time without penalty.

Thank you. If you have any further questions please contact me.

Chris Atkins
(047) 512-564
APPENDIX II: EXPLANATION OF RESEARCH PROCEDURES:
STAGE TWO

My name is Chris Atkins. I worked at Western Sydney Developmental Disability Services: Marsden between 1975 and 1985 and have been employed at University of Western Sydney, Nepean since then teaching developmental disability nursing. In 1991, some registered nurses from several residential centres agreed to talk with me about their work. This was to help write my thesis for a Master of Applied Science (Nursing) at Cumberland College of Health Sciences. A short paper, which I presented at the 9th World Congress of the International Association for the Scientific Study of Intellectual Disability, on the outcomes of those interviews is attached for your perusal.

I am now trying to expand on this work for my thesis for a PhD at The University of Sydney, Cumberland College of Health Sciences. I am particularly interested in interactions between nurses and residents. To try to understand this, I would like to observe registered Mental Retardation Nurses (who have worked with people who are totally dependent for at least one year) at work and to interview them about that work.

This would mean my being with and observing the registered nurse (while s/he works) for periods throughout the day and talking with the nurse about what I have seen (in quieter times during the day). I would expect this to happen over the period of a month or two.

During the observations and the interviews, I would be taking notes and/ or using a small audio tape-recorder. Each nurse observed and interviewed is welcome to read the notes and/ or listen to the tapes regarding him or her self. The only other people with access to the notes and tapes will
be my two supervisors at University of Western Sydney, Nepean and The University of Sydney, Cumberland College of Health Sciences, but I will be the only person who knows which notes and tapes belong to which nurse. All identifying material will be stored in a safe place.

The information I receive will be analysed by me in conjunction with my supervisors and turned into a thesis report and hopefully, some articles for publication. While I have every intention of acknowledging nurses' participation, no individual or their place of work will be identifiable.

You may not personally derive any benefit from this research, but you will help the whole area of developmental disability nursing and its clients in the following ways:

1. An increased awareness of quality of life issues for people with severe, multiple impairments; and
2. An increased awareness of nurses’ knowledge about, and work with, this group of people.

Other than the time you contribute, there are no risks anticipated to anyone involved in the research. You can withdraw from the study at any time without penalty simply by telling me. You never have to answer questions which distress you or are an invasion of your privacy.

Your Director of Nursing and Nursing Unit Manager have given me permission to conduct this work. I anticipate being on your unit at different times during April/May. I will be approaching you to discuss this information sheet and to seek your participation. If you have any questions or concerns, please talk with me while I am on the unit or contact me per telephone.
Thank you,

Chris Atkins
(047) 218 716

March 1994.

"Sharing a Vision of the Future"

9th World Congress

International Association for the Scientific Study
of Intellectual Disability
Co-sponsored by the WHO

Conrad International,
Broadbeach, Queensland
5-9 August 1992

QUALITY OF LIFE
FOR
PEOPLE WITH SEVERE MULTIPLE IMPAIRMENTS

Chris Atkins, RN, BEd (Nurs)
Decisions about where people with severe multiple impairments live and, indeed, whether they live are based on quality of life arguments. Yet there is no consensus in the literature on the meaning of quality of life. This presentation will report on a study which explored nurses' perceptions of quality of life for people with severe multiple impairments living in large residential centres in New South Wales, Australia. It will describe how symbolic interactionism guided the interpretive method used to discover nurses' perceptions. Firstly, however, let me describe the population to which I refer. People with severe multiple impairments are those people whose I.Q. is less than twenty or unassessable, who have a movement disorder (generally cerebral palsy), and who have a neurological (for example, epilepsy) or sensory (for example, visual, hearing) disorder. As a consequence of these disorders, they are unable to care for themselves in any way and can only communicate by facial expressions or body postures familiar to those who care for them.

With a background in both health and disability services, I have been concerned about two arguments related to quality of life:

1. That active/passive euthanasia of people with severe multiple impairments was approved because they had no potential for quality of life;
2. That deinstitutionalisation was equated with quality of life.

Literature Review
An extensive literature review in 1989 demonstrated that there was no clear agreement among health and social service providers about the concept of quality of life, let alone quality of life for people with severe multiple impairments. The literature review identified that the subjects of quality of life studies have been people with severe to mild intellectual disabilities or physical disabilities but not both. Research had been unplanned with no effort to build on previous work, while subjective measures produced more consistent findings, the majority of studies used objective measures (Campos & Johnson, 1990, 167), and there had been no attempt (until Parmenter, 1988) to construct a theoretical framework.

**From Literature Review to Theoretical Framework**

From that review there were four identified problems to consider:

1. Defining quality of life for people who cannot communicate in the usual way
2. Building on previous research
3. Subjective versus objective measures
4. Lack of a theoretical framework

The first was resolved at the ASSID Conference in 1990. I asked Robert Cummins who had been working on a quality of life scale for people with disabilities how I might access the views on quality of life of this population. He suggested that the most likely method would be interviews with the carers of this group. The second problem was resolved through a review of the quality of life literature which identified five domains:

1. Physical well being
2. Emotional well-being
3. Freedom and ability to choose and act
4. Relationships with others
5. Resources to facilitate the above categories
The third and fourth problems of measures and theoretical framework were resolved by the use of symbolic interaction which would provide both a subjective measure through the use of a qualitative method of inquiry, as well as a theoretical framework for the study.
Theoretical Framework

Because I was concerned with the meanings that nurses gave quality of life, this led me to interpretive perspectives which are concerned with the study of meaning as it is experienced by interacting individuals. One of the many perspectives within the interpretive framework is symbolic interaction. It is both a theory about human behaviour and an approach to the study of that behaviour. H. Blumer (1969), who elaborated on the work of G. H. Mead, stated that symbolic interaction rests on three basic premises:

1. Humans behave on the basis of meaning which they give to objects rather than simply reacting to external or internal stimuli.
2. Meanings arise from the process of interaction rather than simply being present at the outset.
3. Meanings are the results of interpretive procedures employed by humans within interaction contexts.

Thus the meanings that guide behaviour arise in the context of interaction via a series of complex interpretive procedures.

Implications for Method

Symbolic interactionists share the view that people construct their realities in a process of interaction with other people. Methodologically this necessitates "getting inside" the reality of the person in an effort to understand reality as that person does. Central to this understanding are the range and variety of symbols and symbolic meanings shared, communicated and manipulated by interacting individuals in social situations through language, non-verbal gesture, and manner of speech.

This theoretical stance, then, calls for interaction between the researcher and people who share meanings about the research question, and further, requires
a way of thinking in the approach to those interactions, during those interactions and throughout the interpretations of the emerging meanings.

Research Question

Having determined ways to address the four identified problems, the research question became: How do nurses who work in residential centres with people who have severe multiple impairments perceive quality of life for them?

Method

Sample

The sample was judgemental, i.e., nurses who were willing to talk about their understanding of quality of life for people with severe multiple impairments. There were nine (9) nurses in the study, eight (8) females and one (1) male (co-incidentally reflecting the population). They had been Registered Nurses from 5 - 31 years and had worked with people with severe multiple impairments from 1 - 16 years.

Date Collection/ Analysis

True to the qualitative method, data collection and analysis were conducted concurrently. An interview schedule based on the content analysis of the literature and changing as themes emerged, was used to guide semi-structured interviews. Interviews were conducted with the intention of involving the participants in a collaborative approach to the research. After nine individual indepth interviews, data saturation had occurred, i.e., no new
themes were emerging, each theme was well developed and relationships among the themes were established.

My interpretations of the data were validated in two focal interviews with the participants. The theoretical formulation was generalisable to a group of nurses in a third institution who were not part of the sample pool.

Findings

Figure 1 represents the findings of this study.

![Diagram of nurses' perceptions of quality of life for people with severe multiple impairments]

*RNI = Resident/nurse interaction

Figure 1 Model of nurses' perceptions of quality of life for people with severe multiple impairments

The overall model which emerged was simple. Quality of life meant physical well being, emotional well being and individual preferences. Quality of life was perceived as an abstract concept which only had meaning when thought
of interdependently with quality of care. Quality of life and quality of care were mediated by the interaction between people with severe multiple impairments and nurses. There is much to be said here about reciprocity and attribution, but not today. So in this model what you want and what you get is interdependent and is also dependent on the interaction. Finally this model exists in a context of resources and attitudes.

The detail of the model is much more complex. Due to time constraints I will focus on the two areas which relate to my original concerns:

1. Quality of life;
2. Attitudes and resources.

Quality of Life

By physical well being the nurses meant physical health, physical comfort and physical development. Physical health meant adequate nutrition, appropriate elimination of waste, breathing freely, and rest and sleep. These are the key areas of potential health problems for people with severe multiple impairments and were therefore, not surprisingly, priorities for the nurses interviewed.

Physical comfort meant clean, dry, intact skin, physical appearance, appropriate body temperature, and physical safety. The first three are reasonably self-explanatory. As for safety, the nurses were emphatic that it was a right and an issue of great magnitude for people with severe multiple impairments. Concerns for physical safety included the risk of choking, injury during seizures, accidents in wheelchairs, developmental behaviours such as eye-poking, scratching and headbanging, as well as physical abuse and neglect, however subtle.
Physical development meant correct body alignment and posture, exercise of muscles and joints and motor development. One participant said:

Quality of life is development, perhaps from holding a spoon to holding a knife and fork.

The nurses defined the second constituent of quality of life, emotional well being, as positive feelings enhanced by participation in life. Positive feelings described were those of liking, loving, enjoyment, excitement, acceptance, self-esteem, delight, being loved, being needed, belonging, safety, security and happiness. Participation in life, which the nurses perceived enhanced positive feelings, included involvement in individual and group interests, a degree of independence in self help and recreational activities, relationships with other people, and freedom from emotional abuse and exploitation. Pertaining to interests, there was a description of the difference a bus trip made for one of the residents:

I thought he's looking, he's really looking. So a couple of other times I've said "oh, lets take Paul because he was looking". I don't know whether he was enjoying it but at least he was looking. He never smiled. I've never seen Paul smile. But this day he was in the bus and he was looking.

Independence, no matter how little, was important: he's trying to scratch his nose and, to me, I think it is a voluntary action and it takes him so long to do it yet he's so determined to do it. I mean we're probably talking about three or four minutes to lift his hand up.

Relationships with each other, with their families and with staff resulted in positive feelings for many people with severe multiple impairments.

There's a couple here that like each other, they give each other cuddles ... how long have they been here? About 20 years. Because of their closeness of being sat together, it just makes them feel better.
For those people who had relationships with their families, that relationship contributed to their emotional well being and hence to quality of care. As soon as you start changing them, no matter what hour, or tidying them up, they know they're going home, they know that someone's coming, their relatives are coming. One nurse spoke of a special relationship with one young man: I park my car under his bedroom window every morning and I see him actually looking for that car. For those people who did not participate in relationships, nurses said that their quality of life was reduced. People with severe multiple impairments were also vulnerable to emotional abuse/neglect through deprivation and ignorance both in institutions and in the community.

By individual preferences the nurses meant those preferences expressed by individual people with severe multiple impairments for the manner in which they conducted their activities of daily living. The nurses said that people with severe multiple impairments know what they like to eat, how they like to be lifted, what positions they like being in, how they like to sleep and whether they prefer a bath or a shower. Different individuals preferred different environments. Some like sitting in the sun, some love the grass, the trees. Interests were a matter of individual preference. One man had a passion for football, one an obsession with the moon, another with Sale of the Century. Some individuals preferred a lot of interaction and others required a lot of personal space. Many of the participants thought that individual preferences were probably much broader than this but that the institution limited the opportunity to express those preferences. The nurses added that they perceived physical well being and emotional well being as interdependent and individual preferences as affecting both physical well being and emotional well being; e.g., if you're offered food that you like you will feel OK, and, being relaxed, you can get control of your musculature and eat well.

Attitudes and Resources
A second outcome of the study was a concern expressed by the nurses about the context in which quality of life exists. The participants perceived that residential centres, government departments and the community were without the resources to provide quality of care and lacked the willingness to change attitudes and policies to make available the resources which would enhance quality of life.

The government department responsible for people with severe multiple impairments in New South Wales has a policy of community integration. This policy provided two sources of frustration for nurses working with people with severe multiple impairments living in institutions. Firstly, the policy meant that institutions were not adequately funded which led to poor resources in terms of ratio and quality of staff as well as procurement of learning aids, and hence, in their perception, reduced quality of life for people with severe multiple impairments. Secondly, while the nurses agreed that group home living had the potential to increase quality of life, they had no evidence that the necessary resources to enable that would be available.

One of their major concerns was the difficulty for people with severe multiple impairments in physically accessing the community without the appropriate numbers of staff or appropriate transport. They were worried that as a consequence people with severe multiple impairments would be confined to a house in the community rather than being part of the community and that caregivers would experience all the stresses of families who were not supported and who were finally forced to place their children in institutions.

**Conclusion**

Returning to the original concerns which prompted this research, the study has implications for ethical and service decisions. The chief argument for
euthanasia of people with severe multiple impairments is that they have no potential for quality of life. This study has shown that nurses perceived that people with severe multiple impairments do have potential for quality of life and that quality of life is dependent on attitudes and resources. Hence their argument that euthanasia is not a solution for poor resources. The argument that there is no potential for quality of life is a very circular one because, if a person comes from this value base, they will not have the willingness to provide the resources to ensure quality of life. Finally, the main argument for group home living is that there is improved quality of life. Nurses who work with people with severe multiple impairments agree that the venue for care may make a difference to quality of life but, without the appropriate resources, the venue is an irrelevant detail in their concept of quality of life for people with severe multiple impairments.

References


## APPENDIX III: CONTENT ANALYSIS OF THE LITERATURE ON QUALITY OF LIFE FOR PEOPLE WITH DISABILITIES

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APPENDIX IV: INTERVIEW SCHEDULE: VERSION THREE

1. How would you describe the group of residents with whom you work?
   Probes: Their abilities/qualities?
   Their disabilities?

2. What do you mean by quality of life for this group?
   Probes: What do you mean by "knowing them"?
   How does their communication affect quality of life?
   What do you mean by "little things"?
   What do you mean when you say their quality of life is lost?
   What are the reasons for effects of institutionalisation and how does that relate to quality of life?
   How does terminology/labelling relate to quality of life?
   How does gender relate to quality of life?
   How does the job:
      (i) hard work,
      (ii) staff burnout,
      (iii) job satisfaction,
      (iv) qualifications,
      (v) rights versus duty of care,
      (vi) roles of nurse, and
      (vii) attitude
   relate to quality of life?

3. Categories in literature
   How does physical well being relate to quality of life for people with severe multiple impairments?
   Probes: How does
      (i) age,
      (ii) health, and
      (iii) number of disabilities
   relate to quality of life?

   How does emotional well being relate to quality of life?
   Probes: How does
      (i) satisfaction with life,
      (ii) privacy,
      (iii) interests, and
      (iv) individuality
   relate to quality of life?

   How does ability to choose relate to quality of life?
   How does ability to act relate to quality of life?
   How does freedom to choose relate to quality of life?
   How does freedom to act relate to quality of life?

   How do relationships with others relate to quality of life?
   Probes:
      (i) other residents?
      (ii) family?
      (iii) staff?
      (iv) community?

   How do resources relate to quality of life?
   Probes:
      (i) residence?
      (ii) income?
      (iii) leisure/ recreation opportunities?
4. How do you compare your quality of life and quality of life for people with severe multiple impairments?

5. Would you change your perception of quality of life if a person had only one impairment?

6. Anything else?
APPENDIX V: DEMOGRAPHIC DATA QUESTIONNAIRE

Name
Address
Telephone
Sex
Age
Years as a Registered Nurse
Years working with people with developmental disabilities
Years working with people with severe multiple impairments
Educational qualifications

Additional Questions

1. How much has quality of life been discussed in your work/education?

2. Do you have any children?, and

3. Is there anyone among your family/significant others with a developmental disability?
QUALITY OF LIFE

QUALITY OF CARE

PHYSICAL WELL BEING

INDIVIDUAL PREFERENCES

EMOTIONAL WELL BEING

* RNI

PHYSICAL CARE

SUITING INDIVIDUAL PREFERENCES

EMOTIONAL CARE

INFLUENCES ON INTERACTION

Resident

Nurse

UNIT - Staff Qualities

CENTRE - Resources

DEPARTMENT - Policies

COMMUNITY - Attitudes

SOCIETY
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use footer page no. in Palatino 9 at right at bottom of page

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<td>2. Grooming</td>
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<td>3. Body temperature</td>
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<td>4. Safety</td>
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<td>5. Pain free</td>
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<td>1. Positioning</td>
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<td>2. Exercise</td>
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<td>3. Motor development</td>
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</table>

Getting to Know Individual Preferences

Manipulating Situations to Suit Individual Preferences
APPENDIX VII: CATEGORIES & THEIR COMPONENTS
ATTITUDES

QUALITY OF LIFE
- Physical well being
- Individual preferences
- Emotional well being

QUALITY OF CARE
- Physical care
- Suiting individual preferences
- Emotional care

*RNI

RESOURCES

Key
*RNI = resident-nurse interaction
## APPENDIX IX: FIELDWORK ANALYSIS

<table>
<thead>
<tr>
<th>WHAT THEY INTERPRET</th>
<th>HOW THEY INTERPRET</th>
<th>RESPONSE</th>
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<tbody>
<tr>
<td><strong>ACTIONS</strong></td>
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<tr>
<td>Picks his bum, puts it to his face</td>
<td>Doesn't like it</td>
<td>Sits him up</td>
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<tr>
<td>Blows water around face</td>
<td>Revolting</td>
<td>Sarcastic remark</td>
</tr>
<tr>
<td>Splashes</td>
<td>Likes it</td>
<td>Spa bath</td>
</tr>
<tr>
<td>Pulls away, head from side to side</td>
<td>Hates it, protesting</td>
<td>Dries hand because of skin care</td>
</tr>
<tr>
<td>Slips down bath</td>
<td>Involuntary</td>
<td>&quot;Going down plughole - come up&quot; (slides him up bath)</td>
</tr>
<tr>
<td>Opens his mouth</td>
<td>Likes presented food</td>
<td>Puts medication in it</td>
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<tr>
<td>Wont open his mouth</td>
<td>Doesn't like presented food</td>
<td>Tries alternatives</td>
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<tr>
<td>Clamps his mouth, turns nose up, turns face away</td>
<td>Doesn't like presented food</td>
<td>Tries alternatives</td>
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<tr>
<td>Not coughing or spitting</td>
<td>Likes presented food</td>
<td>Continues feeding him</td>
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<tr>
<td>Doesn't fight you</td>
<td>Little, delicate</td>
<td>Likes bathing her</td>
</tr>
<tr>
<td>Throws away items</td>
<td>Doesn't like them</td>
<td>Tries alternatives</td>
</tr>
<tr>
<td>Stiff, tight</td>
<td>Humiliated</td>
<td></td>
</tr>
<tr>
<td>Arms up</td>
<td>Unhappy</td>
<td></td>
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<tr>
<td>Arms flail</td>
<td>Angry</td>
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<td>Kicks, swims</td>
<td>Loves water</td>
<td>Long bubble bath</td>
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<td>Smashing side</td>
<td>Unhappy</td>
<td>Try to find why</td>
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<tr>
<td>Thumb up</td>
<td>Fascinated by it</td>
<td>Imitates</td>
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<tr>
<td>Raspberry</td>
<td>Frustrated, bored</td>
<td>&quot;Need a raincoat&quot;</td>
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<tr>
<td>Pushing other's wheelchair</td>
<td>Curious, making trouble</td>
<td>Monitors</td>
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<tr>
<td>Banging head on chair</td>
<td>Doesn't like chair pushed</td>
<td>Separates residents</td>
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<td>Pushing sandwich out of mouth</td>
<td>Had enough</td>
<td>Encourages a bit more (thin)</td>
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<tr>
<td>Throwing away sandwiches</td>
<td>Doesn't like them</td>
<td>Finds alternative</td>
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<td>Hands up to face, pulls away</td>
<td>Really has had enough</td>
<td>Stops feeding</td>
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<td>Moves away</td>
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<td>&quot;Come back&quot; (rolls him)</td>
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<td>Kick</td>
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<td>Pushing own chair</td>
<td>Likes to get around</td>
<td>&quot;Run around&quot;</td>
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<td>Biting clothes</td>
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<td>&quot;Settle down&quot;</td>
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<td>&quot;What are you doing over here?&quot;</td>
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<td>Resisting dressing</td>
<td>&quot;Settle down&quot;</td>
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<td>VERBALS</td>
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<td>HOW THEY INTERPRET</td>
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<tr>
<td>Cries</td>
<td>Doesn't like being touched</td>
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<td>Gives him &quot;dangles&quot;</td>
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<td>Likes particular staff</td>
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<td>Gentle drying</td>
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<td>Soothing</td>
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<td>Likes attention</td>
<td>Teasing</td>
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<td>&quot;Have your lunch and I'll get you out of chair&quot;</td>
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<td>&quot;Just wait- have patience (lunch is late)&quot;</td>
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<td>&quot;If you ate sandwiches, you would be finished&quot; (still waiting)</td>
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<td>Wants food or nurse</td>
<td>Tries food (refuses). Nurse moves. Sitting too close</td>
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<td>Little noise 3</td>
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<td>Louder noise</td>
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<td>Noise 12</td>
<td>Tries to get your attention</td>
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<td>Noise 13</td>
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<td>Noise 14</td>
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<td>Noise 15</td>
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<td>&quot;It's all right&quot;</td>
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<td>Noise 17</td>
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<td>&quot;Who's the best looking boy?&quot;</td>
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<td>Noise 18</td>
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<td>&quot;Settle down&quot;</td>
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<td>HOW THEY INTERPRET</td>
<td>RESPONSE</td>
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<td><strong>Expressions</strong></td>
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<td>Likes it</td>
<td>Spa bath</td>
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<td>Smile 2</td>
<td>Likes &quot;dangles&quot;</td>
<td>Gives &quot;dangles&quot;</td>
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<td>Smile 3</td>
<td>Watches herself</td>
<td>Hairstyle as she likes(?)</td>
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<td>Bottom lip down</td>
<td>Dislikes</td>
<td></td>
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<tr>
<td>Eyes bulging</td>
<td>Dislikes</td>
<td></td>
</tr>
<tr>
<td>Smile 4</td>
<td>Likes</td>
<td>Clothes/ attention</td>
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<tr>
<td>Smile 5</td>
<td>Likes</td>
<td>Bubble bath</td>
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<td>Facial expression</td>
<td>Same as kid on street</td>
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<td>Facial grimace</td>
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<tr>
<td>Smile 6</td>
<td>Smile (I like him)</td>
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<td>Smile 7</td>
<td>Smile (My favourite)</td>
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<td>Smile 8</td>
<td>Smile (That's funny - I don't like him at all)</td>
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<tr>
<td>Looks in mirror, watches herself</td>
<td>Aware of herself</td>
<td>Dress, groom her as she likes(?)</td>
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<tr>
<td>Eye contact</td>
<td>Likes attention</td>
<td>Keep teasing her</td>
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<tr>
<td>Look in mirror</td>
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<td>&quot;Look how silly you look&quot;</td>
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<tr>
<td>Eye contact</td>
<td>Tries to get your attention</td>
<td>Praise</td>
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<tr>
<td>Eyes trying to make contact</td>
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<td>Eye contact</td>
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<tr>
<td>Tracking toy</td>
<td>Hopes it is for him</td>
<td></td>
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<tr>
<td>Tracking spoon</td>
<td>Loves food</td>
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| **Other**           |                   |          |
| Burp                | Asocial           | "Charming!" |
| Dribble 1           | Messy (involuntary)| Wipes mouth. "Why don't you wipe your chin?" |
| Dribble 2           | Messy (involuntary)| "Oh, look what you've done." (cleans face and clothes). |
| Red face            | Humiliated        |          |
| Tears               | Human, lots of feelings personality | Out of wet clothes, bath. |
| Cough               | At risk           | Check    |
| Burp                | Involuntary       | Check    |
### SUMMARY OF ACTIONS, VERBALS, EXPRESSIONS, OTHER

<table>
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<th>ACTIONS</th>
<th>VERBALS</th>
<th>EXPRESSIONS</th>
<th>OTHER</th>
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<tbody>
<tr>
<td>Movement (static / over distance)</td>
<td>Whinge, cry, sob</td>
<td>Smile</td>
<td>Burp</td>
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<tr>
<td>Movement (voluntary/ involuntary)</td>
<td>Giggle, laugh</td>
<td>Look (track)</td>
<td>Cough</td>
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<tr>
<td>Non-movement (rigid / relaxed)</td>
<td>Noises (quiet, loud, medium, intermittent, continual)</td>
<td>Bottom lip down</td>
<td>Dribble</td>
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<td></td>
<td>Eyes bulging</td>
<td>Tears</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Red face</td>
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### SUMMARY OF ACTIONS & INTERPRETATIONS

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<th>: static</th>
<th>revolting, likes, dislikes, unhappy, angry, fascinated, frustrated, bored, had enough</th>
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<tr>
<td></td>
<td>: over distance</td>
<td>involuntary, curious, making trouble, likes to get around,</td>
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<tr>
<td>Movement</td>
<td>: voluntary</td>
<td>all on list</td>
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<tr>
<td></td>
<td>: involuntary</td>
<td>something to be managed</td>
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<td>Non-movement</td>
<td>: rigid</td>
<td>humiliated</td>
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<tr>
<td></td>
<td>: relaxed</td>
<td>fragile</td>
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</table>

### SUMMARY OF VERBALS & INTERPRETATIONS

<p>| Whinge | pain |
| Cry | dislikes, humiliated, upset |
| Sob | likes |
| Giggle | aware of self, likes |
| Laugh | discomfort, usual |
| Noise : quiet | usual, happy, unhappy, trying to get your attention |
| : medium | wants |
| : loud | |
| : intermittent | |
| : continual | |</p>
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<th>Action</th>
<th>Interpretation</th>
<th>How They Interpret</th>
<th>Response</th>
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<tbody>
<tr>
<td>Picks his bum, puts it to his face</td>
<td>Doesn't like it</td>
<td>Sits him up</td>
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<tr>
<td>Blows water around face</td>
<td>Revolting</td>
<td>Sarcastic remark</td>
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<tr>
<td>Slips down bath</td>
<td>Involuntary</td>
<td>&quot;Going down plughole - come up&quot; (slides him up bath)</td>
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<tr>
<td>Stiff, tight</td>
<td>Humiliated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arms up</td>
<td>Unhappy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arms flail</td>
<td>Angry</td>
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<tr>
<td>Smashing side</td>
<td>Unhappy</td>
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</tr>
<tr>
<td>Thumb up</td>
<td>Fascinated by it</td>
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<tr>
<td>Raspberry</td>
<td>Frustrated, bored</td>
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</tr>
<tr>
<td>Pushing other's wheelchair</td>
<td>Curious, making trouble</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Banging head on chair</td>
<td>Doesn't like chair pushed</td>
<td></td>
<td></td>
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<tr>
<td>Moves away</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Kick</td>
<td></td>
<td>&quot;Come back&quot; (rolls him)</td>
<td></td>
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<tr>
<td>Pushing own chair</td>
<td>Likes to get around</td>
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<td></td>
</tr>
<tr>
<td>Moving own chair</td>
<td></td>
<td>&quot;Run around&quot;</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>&quot;What are you doing over here?&quot;</td>
<td></td>
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<tr>
<td>WHAT THEY INTERPRET</td>
<td>HOW THEY INTERPRET</td>
<td>RESPONSE</td>
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<td><strong>VERBALS</strong></td>
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</tr>
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<td>Usual</td>
<td>Imitate</td>
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<tr>
<td>Noise 2 (continual)</td>
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<td>No response</td>
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</tr>
<tr>
<td>Cry 2</td>
<td>Humiliated</td>
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<td>Noise 3</td>
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<td>Imitate</td>
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<td>Sobbing</td>
<td>Upset</td>
<td>Out of wet clothes, bath</td>
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<tr>
<td>Noise 5</td>
<td>Not happy</td>
<td>Imitate</td>
<td></td>
</tr>
<tr>
<td>Noise 6</td>
<td>Not happy</td>
<td>&quot;Have your lunch and I’ll get you out of chair&quot;</td>
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<td>Noise 7</td>
<td>Not happy</td>
<td>&quot;Just wait- have patience&quot; (lunch is late)</td>
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<td>Noise 8</td>
<td>Not happy</td>
<td>&quot;If you ate sandwiches, you would be finished&quot; (still waiting)</td>
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<tr>
<td>Noise 9</td>
<td>Wants food or nurse</td>
<td>Tries food (refuses). Nurse moves. sitting too close</td>
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</tr>
<tr>
<td>Noise 10</td>
<td></td>
<td>No response</td>
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</tr>
<tr>
<td>Noise 11</td>
<td></td>
<td>Checks</td>
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<tr>
<td>Little noise 3</td>
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<td>Continues bowel chart</td>
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</tr>
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<td>Louder noise</td>
<td>Tries to get your attention</td>
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<td></td>
</tr>
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<td>Noise 12</td>
<td>Tries to get your attention</td>
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<tr>
<td>Noise 13</td>
<td></td>
<td>Imitate</td>
<td></td>
</tr>
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<td>Noise 14</td>
<td></td>
<td>No response</td>
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</tr>
<tr>
<td>Noise 16</td>
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<td>Imitate</td>
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</tr>
<tr>
<td>Noise 17</td>
<td></td>
<td>&quot;Who's the best looking boy?&quot;</td>
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</table>

| **EXPRESSIONS**     |                   |          |
| Facial expression   | Same as kid on street |          |
| Facial grimace      | Imitate            |          |
| Smile 6             | Smile (I like him) |          |
| Smile 7             | Smile (My favourite) |          |
| Smile 8             | Smile (That's funny - I don't like him at all) | Praise |
| Eye contact         | Tries to get your attention |          |
| Eyes trying to make contact |          |          |
| Eye contact         |                   |          |
| Tracking toy        | Hopes it is for him |          |
| Tracking spoon      | Loves food         |          |
# OTHER

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<th>Burp</th>
<th>Asocial</th>
<th>&quot;Charming!&quot;</th>
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<tbody>
<tr>
<td>Dribble 1</td>
<td>Messy (involuntary)</td>
<td>Wipes mouth. &quot;Why don't you wipe your chin?&quot;</td>
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<tr>
<td>Dribble 2</td>
<td>Messy (involuntary)</td>
<td>&quot;Oh, look what you've done.&quot; (cleans face and clothes).</td>
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<tr>
<td>Red face</td>
<td>Humiliated</td>
<td></td>
</tr>
<tr>
<td>Tears</td>
<td>Human, lots of feelings personality</td>
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<tr>
<td>Cough</td>
<td>At risk</td>
<td>Check</td>
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## WHAT THEY INTERPRET

## HOW THEY INTERPRET

## RESPONSE TO NURSE

### ACTIONS

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<tr>
<th>Splashes</th>
<th>Likes it</th>
<th>Spa bath</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pulls away, head from side to side</td>
<td>Hates it, protesting</td>
<td>Dries hand because of skin care</td>
</tr>
<tr>
<td>Opens his mouth</td>
<td>Likes presented food</td>
<td>Puts medication in it</td>
</tr>
<tr>
<td>Wont open his mouth</td>
<td>Doesn't like presented food</td>
<td>Tries alternatives</td>
</tr>
<tr>
<td>Clamps his mouth, turns nose up, turns face away</td>
<td>Doesn't like presented food</td>
<td>Tries alternatives</td>
</tr>
<tr>
<td>Not coughing or spitting</td>
<td>Likes presented food</td>
<td>Continues feeding him</td>
</tr>
<tr>
<td>Doesn't fight you</td>
<td>Little, delicate</td>
<td>Likes bathing her</td>
</tr>
<tr>
<td>Throws away items</td>
<td>Doesn't like them</td>
<td>Tries alternatives</td>
</tr>
<tr>
<td>Kicks, swims</td>
<td>Loves water</td>
<td>Long bubble bath</td>
</tr>
<tr>
<td>Pushing sandwich out of mouth</td>
<td>Had enough</td>
<td>Encourages a bit more (thin)</td>
</tr>
<tr>
<td>Throwing away sandwiches</td>
<td>Doesn't like them</td>
<td>Finds alternative</td>
</tr>
<tr>
<td>Hands up to face, pulls away</td>
<td>Really has had enough</td>
<td>Stops feeding</td>
</tr>
<tr>
<td>Biting clothes</td>
<td>&quot;Settle down&quot;</td>
<td></td>
</tr>
<tr>
<td>Resisting dressing</td>
<td>&quot;Settle down&quot;</td>
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### VERBALS

<table>
<thead>
<tr>
<th>Verbal</th>
<th>般</th>
<th>非</th>
<th>非</th>
<th>特别工作人员</th>
<th>特别工作人员的澡</th>
<th>特别工作人员的澡</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cries</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quiet</td>
<td>Likes it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whingeing</td>
<td>Pain</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Giggle</td>
<td>Likes &quot;dangles&quot;</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Laughs</td>
<td>Watches herself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laugh 2</td>
<td>Likes particular staff</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Giggle 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Little noise</td>
<td>Discomfort</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Gentle drying</td>
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<tr>
<td>Laughing 3</td>
<td>Likes attention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Teasing</td>
</tr>
<tr>
<td>Noise 4</td>
<td>Happy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Continues dressing</td>
</tr>
<tr>
<td>Noise 15</td>
<td></td>
<td></td>
<td></td>
<td>&quot;It's all right&quot;</td>
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<tr>
<td>Noise 18</td>
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<td></td>
<td></td>
<td>&quot;Settle down&quot;</td>
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### EXPRESSIONS

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<th>特别工作人员的澡</th>
<th>特别工作人员的澡</th>
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<tr>
<td>Smile 1</td>
<td>Likes it</td>
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<tr>
<td>Smile 2</td>
<td>Likes &quot;dangles&quot;</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Smile 3</td>
<td>Watches herself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bottom lip down</td>
<td>Dislikes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Eyes bulging</td>
<td>Dislikes</td>
<td></td>
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<tr>
<td>Smile 4</td>
<td>Likes</td>
<td></td>
<td></td>
<td></td>
<td>Clothes/ attention</td>
<td></td>
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<tr>
<td>Smile 5</td>
<td>Likes</td>
<td></td>
<td></td>
<td></td>
<td>Bubble bath</td>
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<tr>
<td>Looks in mirror, watches herself</td>
<td>Aware of herself</td>
<td></td>
<td></td>
<td></td>
<td>Dress, groom her as she likes(?)</td>
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<tr>
<td>Eye contact</td>
<td>Likes attention</td>
<td></td>
<td></td>
<td></td>
<td>teasing her</td>
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<tr>
<td>Look in mirror</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&quot;Look how silly you look:&quot;</td>
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## SUMMARY OF INTERPRETATIONS AND RESPONSES

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<thead>
<tr>
<th>Likes</th>
<th>Dislikes</th>
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<tbody>
<tr>
<td>Gives (if able), continues, proceeds</td>
<td>Does not give, stops, finds alternative, overrides &amp; explains</td>
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<table>
<thead>
<tr>
<th>FRAIL &amp; ?NOT FRAIL</th>
<th>AWARE &amp; NOT AWARE</th>
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<tbody>
<tr>
<td>Likes personal care, gentle</td>
<td>Hard work, not so gentle</td>
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<tr>
<td>Groom /dress as per wishes</td>
<td>Groom /dress as per wishes/routine</td>
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<table>
<thead>
<tr>
<th>Looks (at self and others)</th>
<th>Happy &amp; Unhappy (sad, upset)</th>
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<tbody>
<tr>
<td>Speaks, smiles, ignores (why?)</td>
<td>Seeks reason, alters situation, continues &amp; explains</td>
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<table>
<thead>
<tr>
<th>Seeks (likes) attention</th>
<th>?does not seek attention</th>
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</thead>
<tbody>
<tr>
<td>?Gives attention, teases</td>
<td>?routine</td>
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<table>
<thead>
<tr>
<th>Humiliated</th>
<th>Frustrated</th>
<th>Bored</th>
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<tbody>
<tr>
<td>Comments, explains</td>
<td>Comments, explains</td>
<td>Comments, gives something to</td>
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</table>

<table>
<thead>
<tr>
<th>Do</th>
<th>Angry</th>
<th>Fascinated</th>
<th>Curious</th>
<th>Trouble making</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Imitates</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<table>
<thead>
<tr>
<th>Had enough</th>
<th>Really had enough</th>
<th>Hopeful</th>
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<tbody>
<tr>
<td>Encourages more food (thin)</td>
<td>Discontinues</td>
<td>Gives item to him if it’s for him</td>
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<table>
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<tr>
<th>In pain</th>
<th>Discomfort</th>
<th>Wants</th>
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<tbody>
<tr>
<td>Soothing, gentle</td>
<td>Soothing, gentle</td>
<td>Tries to find what and gives/does</td>
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<table>
<thead>
<tr>
<th>At risk (choking)</th>
<th>Revolting</th>
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<tr>
<td>Check</td>
<td>Manage to get around it, sarcastic</td>
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</table>

<table>
<thead>
<tr>
<th>Messy (involuntary)</th>
<th>Involuntary</th>
<th>Usual</th>
<th>Greeting</th>
<th>Asocial</th>
<th>Human (lots of feeling)</th>
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</thead>
<tbody>
<tr>
<td>Comments, cleans</td>
<td>Jokes, manages</td>
<td>Imitate, no response</td>
<td>Return smile, imitate noise</td>
<td>Sarcastic</td>
<td>Remedy situation</td>
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APPENDIX X: FIRST THEMES FROM FIELDWORK ANALYSIS

**Theme 1:**

Interaction proceeds on the basis of knowledge of people generally.

Australians follow a routine within the day. They are generally clean and well-groomed. They dress for the climate. They usually perform these activities in private. They eat, usually three times a day, with snacks in between. They sleep in beds for about eight hours in twenty-four, usually from late evening to early morning. These activities underlay anything else in the day.

It is not unusual, then, that nurses approach residents with these activities in mind. The day is guided by them. Activities of daily living permeate the education of nurses.

**Theme 2:**

Interaction proceeds on the basis of knowledge of the body of people with severe multiple impairments.

Because people with severe multiple impairments are totally dependent on others for activities of daily living, nurses perform those activities for them. In order to do that, nurses have to know about the implications of severe multiple impairments for activities of daily living.
Therefore, they approach this group with certain information. They know that generally they cannot initiate and/or regulate movement. This means that to move from one point to another, the nurse has to do it. The resident cannot be left in places that put them at risk, i.e., anywhere but on the floor, without some safety device, e.g., bed rails, chair straps, etc. They know that contractures and spasms complicate any movement associated with undressing and dressing, bathing and grooming, changing from one position to another. They use proximal-distal techniques and reflex-inhibiting positions to reduce spasms and ease contractures during these activities.

Eating and drinking are very complicated activities for people with severe multiple impairments. They have little control of their oral musculature with the consequence of not being able, to a greater or lesser degree, to control food in their mouths with their tongue, bring their lips together, chew, swallow or cough. Nurses then must control residents’ mouth closure, tongue movements, chewing and swallowing. They do this by using reflex-inhibiting postures with the aid of specially designed chairs, pre-feeding relaxation (or stimulation, for people with hypotonia), by using a spoon to control the tongue, by manually manipulating the lips, jaw and pharynx. They also approach a resident very calmly to reduce stimulation which might induce spasm and are conscious of potential aspiration which may lead to asphyxiation or pneumonia. If the residents have sufficient movement in the arms and hands, they may be encouraged to feed themselves, which is of course complicated by the problems previously discussed in relation to movement.

Food has to be of the correct consistency to facilitate eating and reduce tongue thrust, the biting reflex and the gag reflex. The size of spoons and the amount of food on the spoon also affect eating. Given the difficulty of the
activity for the residents and the poor range of food offered, they usually have very little appetite. Given their poor weights, nurses spend a lot of time encouraging eating. Cups have to be specially shaped and fluid balance has to be maintained. Drinking is a high-risk activity and requires time and concentration.

People with severe multiple impairments rarely have any control over their bladder and bowel sphincters. Nurses protect them with nappies, monitor their output, and assist with bowel function when necessary.

It takes, on average, half an hour to give a resident a meal. It takes about the same time to bathe, groom and dress someone. Given that a nurse usually has six people to care for, a bath and a meal for those six takes her six hours. With nappy changes (or toileting, for those who can) and a drink between meals, an eight hour shift is readily consumed.

Theme 3:

Interaction proceeds on the basis of the individual's body.

As a nurse gets to know a particular resident, she becomes aware of the idiosyncrasies of that individual's body. A resident may have a greater or lesser degree of spasticity, many or few spasms, tight contractures or none, more or less control over gross and fine movements, greater or lesser oromusculature control, differing sphincter control or particular problems additional to motor control, e.g., sensory deficits, epilepsy and the adverse effects on the body of anticonvulsants. A resident may be recognised as more at risk for pneumonia, or skin breakdown, or fractures, or seizures, or
particularly sensitive to heat or cold. An individual may have particular health problems not necessarily related to their primary diagnosis, e.g., diabetes, colostomy, asthma.

At any particular time, a resident may have had surgery, most likely orthopaedic, dental or ophthalmic. Sometimes, like all of us, they may have a cold or flu, or just be very tired, or have a headache or body pain, e.g., colic.

The nurse relates to the familiar body and is alert to potential problems. She handles different bodies differently, roughly with a healthier, robust body and gently with a more fragile body. She knows the particular movements of a body: judging just the right amount of assistance to provide during activities, she skilfully complements the body of the resident. She differentiates between active and reflex movement. She is aware of the tiniest change in the body - a little tighter, a little flopper, more or less head control, mouth control, tense abdomen, increased spasm. She becomes intimately aware of the actions of the individual body.

**Theme 4:**

Interaction proceeds on the basis of taken-for-granted individual actions, facial expressions and vocalisations.

So too, the nurse becomes familiar with the facial expressions and vocalisations of the individual. Actions, expressions and vocalisations might occur singly or in combination. Their absence is as significant as their presence.
The nurse goes about the activities of daily living with certain expectations about an individual's responses. Once familiar with the individual, the nurse expects particular actions, facial expressions and vocalisations.

G. actively participates in dressing by not resisting his position being changed and by moving his limbs through clothing. His facial expression is usually neutral and he vocalises in a monotone most of the time.

M. splashes in a deep bath, smiles and is quiet. He cries if he is touched.

P. opens his mouth, does not cough or spit, has a less anxious expression and is quiet when eating weetbix in the morning.

A. looks in mirror, smiles and laughs, while she is dressed and groomed. She laughs and giggles when particular staff attend to her.

These examples are the usual expectations for these residents, their taken-for-granted acts. The nurse interprets these actions, facial expressions and vocalisations as usual, interprets that the resident "likes" it and continues the activity. The nurse frequently imitates the sounds and returns the facial expressions. Any deviation from these usual responses brings about a response from the nurse.

Theme 5:

Interaction proceeds in novel ways.
During activities of daily living, the resident may perform an action, make a facial expression or a vocalisation that is different from those expected and which has negative connotations. The resident may pull away, turn his head from side to side, clamp his mouth shut, throw food, bang his head on the chair, put, cry, hit himself, make sounds, bite his clothes. The initial interpretation by the nurse is that the resident "does not like" whatever is happening at the time.

In most cases, the nurse alters the situation by stopping what is happening and finding alternatives, e.g., changing the food presented, bathing differently. In some instances, the nurse continues the activity but explains, e.g., when T. does not like his contracted hand dried, the nurse continues to dry it but explains why. When R.? does not like being changed, she tells him to "settle down", that "it's all right". When K., who has a fractured scapula, was "whingeing" during her bath, the nurse made soothing noises, was gentle with her, performed the bath as quickly as possible, told her that they were "nearly there".

**Theme 6:**

Interaction initiated by the resident.

Not all interaction occurs within the context of activities of daily living. For a large part of the day, any one resident is not involved in activities of daily living. During this time, the residents still perform actions, make facial expressions and vocalise. Some of these occur between residents (but that's another study). Those actions, expressions and vocalisations made within the
"scan" of the nurse generally elicit a response from the nurse, as do the absence of them.

An action, expression or vocalisation interpreted as "happy" is often met with a comment about that emotion, with perhaps an accompanying smile or laugh, and no further/ different action on the part of the nurse. If there is a perceived negative change, it is interpreted as "unhappy" and the nurse seeks an explanation and/ or explains why the situation must continue.

E. was lying in bed in the morning sobbing, with tears running down her face. The nurse, concerned, wondered why she was "upset". She checked her body and found that she had wet the bed and her clothing. She undressed her and gave her a warm bath. E. smiled and kicked, her "usual" response to a deep bath.

R. made an unusual noise while he was sitting in the dayroom before lunch. The nurse thought he was "unhappy" about something. Lunch was late so she thought he might be hungry. She offered him some food from the kitchen but he refused. She thought another nurse might be sitting too close to him because "he likes his personal space". The nurse moved and R. became quiet, his "usual" verbal state.

E. was sitting in her posture chair, all set up for lunch, which was late. She began making an unusual noise, frowning and hitting the side of her body. The nurse knew she was "not happy" because she was hungry and does not like extended time in her chair. The nurse explained that lunch was late, that if she would eat sandwiches she could be finished lunch, that she would have to wait. The nurse tried to distract her by playing a game with her where she imitated a "thumb up" action initiated by the resident.
Each of these examples suggests that the nurse interprets acts, expressions and noises as emotions but checks the body to find the source of that emotion. So too the absence of usual actions, expressions and vocalisations is commented on, e.g., when someone who is usually active is listless, when someone who often smiles does not, when someone who usually makes a lot of noise is quiet. These absences are interpreted as "unhappy" and if they persist, the body is checked to seek the cause of the change.

These examples also suggest that the nurse relies on the context to interpret the communication, e.g. hungry when waiting for lunch. That is, the action only indicates an emotion. It is then up to the nurse to try to interpret the emotion within the context.

There are some actions interpreted as "trying to get your attention". They seem to consist of eye contact and noises. They are often met with eye contact, imitation of noises and/or greetings and/or comments such as "yes, I know you're there", "you are looking good today".

There are also a number of actions which are interpreted as involuntary, e.g. burping, dribbling, urinating, erections, slipping. These situations are commented on, usually in a joking manner, and managed, e.g., the nurse says "whoops, you're going down the plughole" while she manoeuvres the resident back to where she can bathe him.

Two residents can move their own chairs to a degree and are encouraged to do so. One resident moves his own chair and others' chairs and is variously interpreted as "curious" and "trouble-making". The response is consistent, however, in that he is monitored and, if there is a safety risk, it is managed by
moving him to a safer place. One resident has habits which most nurses find unpleasant: he rubs spittle on his face and in his hair and manually evacuates his rectum. The nurses have various techniques for reducing this behaviour as much as possible but find it difficult to relate to him. One nurse, however, confided that when he was recently ill, she realised that she did like him and felt sorry for him - feelings she did not think she had for him.

While nurses indicated to me that they interpret communications as they would for "any kid on the street", this was sometimes difficult to see. When A. has a red face, is stiff and tight, and makes a particular sound, this is interpreted as "humiliated". When her arms flail, she is "angry". When E. "blows a raspberry", she is "frustrated and bored" but sometimes it is a "happy" raspberry. When G. tracks with his eyes something in the nurse's hand, he "hopes it is for him". When K. pushes food out of her mouth with her tongue, she has "had enough" but she will eat more if encouraged, and when she puts her hand up to her face and pulls away, she has "really had enough". Sounds and coughs within the "scan" of the nurse generally cause the nurse to look at the source (checking).

Theme 7:

"Presenting" the resident.

When nurses groom and dress residents, they choose particular hairstyles and clothing for each resident, even within the limitations of institutional living. They choose colours and styles which are "individual", which seem to be related to the personality of the resident. They are more careful with this when residents are "aware" and "smile" and "watch
themselves in the mirror", and think that the way they do it draws attention from staff and visitors to the individual residents which is "nice for them".
23 November 1994

Dear

I am sorry that it has taken so long to get back to you. It has taken me all this time to come up with a rough draft of the results of the work that we did together. It is enclosed for your comments which I hope that you can return to me before Christmas. I have included a stamped, addressed envelope for you to return your comments.

I would ask that you do the following

1) As you read the draft for the first time, mark it with a "yes" or "no" whenever you have a heightened response; for example, "yes, that's exactly how it happens!" or "no, that's not right!".

2) When you have finished reading the draft, go back to any mark you have made and scribble near it what was so good or so bad about it.

3) Add examples at any point of the draft, if you think of them.
4) Write down anything you think that I have left out.

5) Make a comment at the end about whether this draft makes sense to you.

6) Make any other comments that you like.

I know that this will take up some of your time, and I will be very grateful for anything that you can manage. If you would rather talk to me than write it down, or if you have any questions, please ring me on (047) 218716 anytime between 10 a.m. and 10 p.m. If the answering machine is on, please leave a message telling me where and when I can contact you at your convenience.

Thank you,

Chris Atkins
APPENDIX XII: EMERGENCE OF CONCEPTS OF QUALITY OF LIFE FOR PEOPLE WITH SEVERE MULTIPLE IMPAIRMENTS
NOTE: Print appendix as landscape, then print with Appendix label on it in portrait.
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<td>what it means to be a human being with severe multiple impairments</td>
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