

**QUALITY SERVICE AND QUALITY NURSING CARE FOR
PERSONS WITH INTELLECTUAL DISABILITIES LIVING IN
RESIDENTIAL CENTRES IN THE REPUBLIC OF IRELAND**

**A Study of Issues and Influences Affecting the Quality of Nursing Care Provided
by Registered Nurses for the Mentally Handicapped in Residential Centres**

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ABSTRACT

Quality Service and Quality Nursing Care for Persons with Intellectual Disabilities Living in Residential Centres in the Republic of Ireland

Richard Redmond

This study is concerned with issues and influences affecting nurses' provision of quality care to people with intellectual disability in residential centres. The methodology is a descriptive study conducted through a two-phase mixed methods approach using a dominant-less-dominant design. Phase one, the less dominant phase consisted of a small-scale experience survey of non-nurse experts and two focus group interviews with nurses in clinical practice. Phase two, the dominant phase, consisted of a quantitative survey of a random sample of nurses. Sequential triangulation was employed for data collection where the outcomes of the first phase were used for planning the second phase and for exploring and generating the constructs and variables for the survey. The theoretical perspective for the study is based on the paradigm of care within which nurses operate. In particular, whether or not nurses use the medical and humanistic models to underpin their care of clients in residential centres. The study investigated the dimensions of client care that nurses considered were important to nurses and to clients based on the perception of nurses. Also investigated were the approaches nurses used to evaluate care, the organisational processes used for care and, the influences that organisational management practices has on the nurses' ability to provide quality care.

Results reveal nursing care is only provided at the most basic needs level with physical/health care, safety and emotional care seen as the most important dimensions. Evaluation of nursing care is carried out but is concentrated at the level of physical and personal care. These findings are important and indicate that:

1. Nurses do not consider other dimensions of care to be of significant importance for clients in residential centres and are not providing holistic care.
2. Nurses are predominantly utilising the medical model to underpin the care they provide to clients in residential centres.

This study makes an original contribution to knowledge in the following ways:

It is the only empirical study in the Republic of Ireland that has looked at quality care as perceived by nurses for persons with intellectual disability in residential centres.

It provides knowledge and insight into issues and influences affecting quality of nursing care for persons with intellectual disability in residential centres.

It shows that the predominant model that nurses use in centres is the medical model.

It advances both a typology and conceptual model useful for understanding, planning and evaluating dimensions of nursing care as needs and the relationship of these needs with dimensions of quality of life as the outcomes of meeting these needs.

While the model is descriptive it has a fivefold application:

1. It signposts and provides insights about care that is useful for policy making.
2. It shows relationships between dimensions useful for informing care practices.
3. It draws attention to important issues for professional education and training.
4. It provides management with a guide for planning services responsive to needs
5. It is useful for planning and deciding on areas for investigation and research.

Findings add to what is known about the service encounter in residential centres and make a contribution to evidence for practice for persons with intellectual disabilities.

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CHAPTER ONE

INTRODUCTION

1.1 Background

Service provision to persons with intellectual disability in the Republic of Ireland is spread across a range of services. In 2003, 25,557 people were registered on the National Intellectual Disability Database (NIDD) of whom 7,598 (29.72%) are in residential centres. Of these, 7,260 (95.55%) are over 19 years and there is a need for 1,597 additional residential places for children and adults (NIDD 2003). Within these centres the frontline professionals that care for the clients are, for the most part, registered nurses. These nurses are trained to provide care for people with all types of intellectual disabilities. They are part of a multidisciplinary team and care for clients with varying levels of needs and abilities across their lifespan (An Bord Altranais 2000). Traditionally, their training and practice has been geared towards providing high standards of physical care with an emphasis on health, hygiene and safety.

However, over the past two decades a paradigm shift has occurred in service provision for persons with intellectual disability. The essence of this paradigm is the concern with the rights of people with disabilities and the recognition of their quality of life, which are now established as legitimate aims and outcomes of service provision (Mercer 1992, Cummins 1997, Schalock 1997, Northway & Jenkins 2003). Based on these concerns, the practical implications of the paradigm are for supportive, normative lifestyles with opportunity for development through a humanistic or social model of care, community integration, meaningful employment and relationships. Contemporary writers in this area see modern responsive service provision to people with intellectual disabilities as being founded on this paradigm, which acknowledges

the abilities of people as against their disabilities (Schalock 1997, Stenfert Kroese et al 1998, Wolfensberger 2000). According to Kay (2003), an important difference in this paradigm is that it reflects a shift of power away from a paternalistic 'professions centered' care that fosters dependence and control to a 'person centered' care that emphasises independence and where the locus of control resides with the client. Given these considerations and to achieve these outcomes, nurses must recognize, value and respond to dimensions of care other than just physical and safety needs.

1.2 Quality Care and Quality of Life

Concern with quality care and quality of life are seen as fundamental to all human services and underpin the governments Health Strategy on Quality and Fairness (2001). While service quality has long been seen as important in service industries (Evans & Lindsay 2002), in services for persons with intellectual disability, quality is complex. This is because in part, clients in residential care require a service twenty-four hours a day and in part because the general aim of residential services is to enhance and promote the quality of life of clients. Quality care means a service provides needs-based holistic care that has an emphasis on outcomes (National Disability Authority 2003). It is also complex because intervention is most often qualitative as against quantitative and because organisational management strategies require a partnership with families, professionals and purchasers thus requiring a dynamic multi-user framework (Cass & Kruger 1999).

1.3 Residential Services

By residential services is meant a form of care where people live in residences that are usually designed or modified to cater for people with intellectual disabilities.

They are a different form of residence to the natural family home where, like everyone else, people live in natural domestic settings in the company of family and friends. They are also different from day care centres where clients attend only for specialist therapeutic services but return to their family home each evening (NIDD 2001). Residential centres vary in size and complexity. Some centres for example, are either special hospitals or homes that have been in existence for a long time and have a tradition in caring for people with intellectual disabilities. They provide a range of services and typically cater for large numbers ranging from 50 to over 300 in divided groups. In contrast, smaller residential centres are of more recent origin to the larger centres. They are usually located within the local community within domestic style housing or may constitute group homes. These smaller community-based residential homes may cater for as few as 5 to 10 residents (NIDD 2001).

These centres are the homes and provide the homelife for the people that live there. Residential centres provide care for people with wide ranging needs and abilities but particularly people with moderate, severe and profound intellectual disabilities (NIDD 2001). A primary reason for residential care is the specialist and complex needs and requirements of people. Some people have behavioural or psychiatric problems, others have physical or health related problems and most have problems relating to functional ability necessitating a twenty-four hour dependence on carers (NIDD 2001). Centres may provide five or seven day residential care for clients. Table 1.1 is a summary of the current service provision to people with intellectual disabilities in the Republic of Ireland. Currently there is a growing demand for residential places. This is due to a falling prevalence of children and those under 19 years old and an increase in adults over 55 years with intellectual disabilities (NIDD 2001).

Summary of Service Provision to People with Intellectual Disabilities		
	n	%
Receiving day services	15,335	60.0
Receiving 5-day or 7-day residential services	7,598	29.7
Residents in psychiatric hospitals	494	1.9
Receiving residential support services only	37	0.1
Receiving no services	356	1.4
No identified service requirements	1737	6.8
Total	25557	100.0

Table 1.1. Summary of service provision to people with intellectual disabilities in the Republic of Ireland. Source: National Intellectual Disability Database 2001.

There is also a decrease in the numbers of children in the more severe categories reflecting a decline in birth rate during the 1980s and improved obstetric care. There are at least four main reasons for the increased demand for residential places.

The first reason is that the new paradigm generally means that people live as normative a life as possible within an environment conducive to their development (Wolfensberger 2000). In most residential centres in Ireland, living arrangements approximate to normal domestic housing and have small numbers of clients living in a warm close, family atmosphere. In keeping with the ethos of smaller living arrangements, most centres see themselves as a part of the local community where clients have both a presence and participation. In this situation the nurse creates and maintains the warmth and constancy of a family unit while actively facilitating opportunities for clients to participate in the community (Department of Health and Children 1997, 2002).

The second reason is that in the vast majority of situations, people living in residential centres have multiple and complex disabilities. Many have general or psychiatric health conditions, in particular, challenging behaviour, requiring continuous care (NIDD 2001). To provide quality care for these people requires specialist interventions and treatment on demand. In residential centres, it is the nurse who is

specially trained and accountable for providing the specialist care responsive to the personal needs of clients (Department of Health and Children 2002, Gates et al 2003).

The third reason is the fact that in most residential centres, clients have very low levels of functional ability and are unable to live with minimal supports in mainstream community settings. Most clients in residential centres have either severe or profound disability with low intelligence, awareness and ability to protect themselves (NIDD 2001). This low functional ability is likely to manifest itself in poor social competence in the areas of self-help skills (e.g. feeding, dressing, toileting), and in communication. Nurses are the frontline professional staff who are entrusted with the day-to-day care of clients and this includes teaching clients self-help and communication skills while at the same time being responsible for the nutrition and hygiene needs of clients through feeding, bathing and toileting.

The fourth reason concerns the increasing numbers of clients in residential centres and the changes taking place in the ages of clients in centres. In 2003, over seven thousand (29.7%) of all clients receiving a service were in residential centres. This figure is likely to rise with nearly two thousand people currently on waiting lists (NAMHI 2004) and an immediate urgent demand for 1,597 new places (RTE Prime Time Television 2004). The reasons for this include the fact that some people are currently receiving no services while at the same time, many are living longer and thus fewer residential places are becoming available. People living in their family home or in community settings are also living longer and are likely to require residential accommodation when they advance in age or their parents die (NIDD 2001). There is also a need for specialist therapeutic places for people with autism,

severe behavioural disorders and sensory impairments. In addition to these reasons, many people born in the last two decades with severe congenital malformations are now living longer because of obstetric, paediatric or surgical treatments. Based on these considerations about residential care, nurses are more likely than ever before to be caring for people who are elderly as well as for people with severe and complex disabilities.

1.4 Research Problem

In residential centres, important stakeholders in service quality are service users, their parents//families, the professionals who provide services and the managers of centres. Registered Mental Handicap Nurses (RMHN), are one group of professionals trained to provide frontline care for people with intellectual disabilities across their lifespan. The majority of nurses work in residential centres where they provide hands-on care to clients' with wide ranging needs twenty-four hours a day. While they work as part of a multidisciplinary team, as registered nurses they are responsible for the care they provide as well as for the quality of that care (An Bord Altranais 2000). Although they collaborate with other professionals and liaise with the families of clients, nurses are the professionals who provide the continuous day-to-day care for clients. In addition to their responsibility for nursing care, nurses are also likely to be important mediators of the interventions other professionals provide for clients since in many cases it is the nurse that will implement and help evaluate many of these. Despite these considerations, there is a dearth of information on what nurses do for clients, if their care is guided or influenced by any particular ideology or model, or of how they perceive their level of participation in overall service quality. In particular, little information exists on the dimensions of care they see as important or the approach

they adopt to evaluating their care of clients. For example, various dimensions and attributes of quality have been identified in the literature (Felce & Perry 1995, Maes et al 2000, Alaszewski et al 2001) but whether nurses recognize these or see them as important is not known. This situation is particularly the case in the Irish context, as no studies on nursing quality in residential centres have thus far been published.

1.5 Rationale for the Study

The rationale and justification for this study is grounded in the foregoing discussion, the expanding role of residential care for people with intellectual disabilities, and the involvement of the registered nurse as the frontline provider of care. The researcher acknowledges that families, other professional groups and service managers all share an involvement in service quality. However, because the nurse provides the frontline personal and continuous care for clients, this study is focused on the nurse. In particular, issues and influences that affects nurses providing quality of care for clients. This study is important and necessary. It is important as nurses are the frontline professionals responsible for caring for the large numbers of people living in residential centres and little is known about what they do for clients. The study is necessary because service quality is clearly established on the agenda for service providers. No other similar study has been done in Ireland and this study will make a significant contribution to support evidence-based practice in this discipline of care.

1.6 Purpose of the Research Study

Is to describe nurses' perceptions of service quality by investigating dimensions of care they see as important; the management processes they see as facilitating quality

and, their level of participation and involvement in decision-making in residential centres.

To develop a model and typology from the theoretical literature and confirm and develop this as a conceptual model in light of the findings from the present study.

To use the findings to indicate the extent to which nurses in residential centres use a particular service model to underpin their nursing care of clients.

1.7 Contribution of the Literature

The literature on quality is divided between the general services quality and the discipline specific areas of intellectual disabilities quality. The general literature is predominantly concerned with theoretical and measurement issues with a smaller number of empirical studies in the form of applied research. The discipline specific literature is concerned with theoretical and applied research issues, in particular, the relationship between approaches to quality and quality of life as an outcome of service provision. The purpose of summarising the literature is to explain the issues involved; identify gaps and help develop the research questions. It also allows for the development of a theoretical model from a synthesis of the literature. This model is later confirmed and developed as a conceptual model in light of the studies findings.

1.8 Research Questions

From critical factors identified in the literature, gaps were found relating to service quality where little or no knowledge relevant to residential services was available. The present study seeks to provide understanding and closure of these gaps by answering the following research questions:

1. What if any, are the differences between dimensions of care that nurses see as important for nursing and dimensions that nurses see as important for client care?
2. How do the dimensions of care that are the focus of nurses' interventions compare with the dimensions of care nurses evaluate most often?
3. In what ways are nurses' involved in organizational care processes used for planning and delivering care to clients in residential centres?
4. What organizational management practices do nurses identify as facilitating and inhibiting their ability to provide quality care to clients?
5. How does participation and involvement in organizational decision-making relate to nurses provision of quality care for clients?

1.9 Methodology and Design

This research is a descriptive study. The design employs a two-phase, mixed methods approach using a dominant-less-dominant design.

Phase one, the less-dominant phase, involved two empirical investigations: a small-scale experience survey of non-nurse experts in centres, and two focus group interviews with nurses in clinical practice. Sequential triangulation was employed with the outcomes of the first phase of the study used for planning the second phase. Sequential triangulation involved using the two smaller empirical investigations sequentially for the purpose of developing the constructs and variables for phase two.

Phase two, the dominant phase, involved a survey questionnaire that was sent to a random sample of nurses working in frontline (clinical practice) care in residential centres. Questionnaires for the pilot study for the dominant phase were sent to 30 nurses and for the main study, questionnaires were sent to 460 nurses.

1.10 Overview of Chapters in the Research Report

As the dominant paradigm for the study is a quantitative survey, the literature is used deductively and is presented at the beginning of the study. The approach is an

integrative review summarizing past theoretical and research studies (Creswell 1994). Chapter two reviews the general quality literature including conceptual, theoretical and historical developments in the field. These areas are important in order to understand quality management. In addition, consideration of the general service quality literature is important since many of the quality-related developments in the intellectual disabilities field is grounded in the general service quality literature.

Chapters three and four summarise the literature on service quality, quality care and quality of life in the area of intellectual disability and discusses the role and function of the nurse in residential services. Similarities and differences in approaches to service quality between the general service area and the intellectual disability area are outlined and chapter four provides an overall conclusion to the review of the literature.

Chapter five consists of two sections. Section A presents the theoretical perspective for the study and is based on service models derived from specific paradigms of care. Findings are used to indicate whether and to what extent these models influence nurses' practice in caring for clients in residential centres. Section B presents a model and typology derived from a synthesis of the literature reviewed for the study. Following the analysis of findings in chapter seven, this model is confirmed and developed as an integrated conceptual model of needs based quality in chapter eight.

Chapter six presents the methodology and design for the study. The purpose of the study is outlined, the research questions are stated and the design and method of data collection explained. The construction, testing and piloting of the data collection

instruments are discussed. A rationale is provided for using a mixed-methods approach developmentally and for the paradigm in which the study is framed. Sequential triangulation is explained and the format and process for conducting and using the two smaller, less-dominant studies developmentally is discussed.

Chapter seven is divided into two sections. Section A presents the findings from the main survey questionnaire sent to the sample of nurses working in residential centres. Findings are presented for all sections of the questionnaire and are summarised in the form of frequency tables or figures. Section B presents the analysis of findings pertinent to answering each of the research questions in turn. A thematic approach is used for the analysis and results are cross-referenced with the findings from the experience survey of experts on quality. Theme one is dimensions and processes of care. Theme two is organisational management practices.

Chapter eight presents a discussion of the findings with reference to the literature and in light of current practice issues. In the final part of the chapter, the model that was developed from a synthesis of the literature and presented in chapter five is confirmed. From this and the findings from the study, an integrated conceptual model of needs based quality care is developed. This model is descriptive and not predictive. Two typologies on needs based and services based quality are developed and confirmed from the findings.

Chapter nine presents the summary and conclusion of the research study. The main findings for the study are summarised and the limitations and implications of the research for practice and management are outlined. The outcomes of the research and

their original contributions to knowledge are stated and recommendations are made for further research in the area.

1.11 Clarification and Definition of Terms

The term mental handicap is well known and has been in existence for a long time in Ireland. However, for over a decade now, new terms have emerged to replace mental handicap (Department of Health Needs & Abilities 1990) that are more in keeping with the paradigm shift to inclusion and integration of persons into the community. Alternative terms include learning disability, mental retardation and intellectual disability. The American Association on Mental Retardation (AAMR) define the concept as:

“Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable skills: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests itself before age 18. The following four assumptions are essential to the application of the definition:

1. Valid assessment considers cultural and linguistic diversity as well as differences in communication and behavioural factors
2. The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual's age peers and is indexed to the person's individualized needs for supports.
3. Specific adaptive limitations often coexist with strengths in other adaptive skills or other personal capabilities.
4. With appropriate supports over a sustained period, the life functioning of the person with mental retardation will generally improve (AAMR. 1992. p. 1).”

In Ireland the most common term seems to be intellectual disability. While the current title for nurses in this discipline is Registered Mental Handicap Nurse (RMHN). At the time of writing, An Bord Altranais is in the process of changing this to Registered Nurse Intellectual Disability (RNID).

CHAPTER TWO

SERVICE QUALITY

2.1 Introduction

It is almost impossible in today's health care and disabilities services not to be aware of the growing concern with quality. Reference to the topic is regularly encountered in professional journals, books and newsletters. The media report and run features relating to quality of care and services, especially when such services fall short of what they consider to be reasonable or when access is denied or mistakes occur. Professionals in health care espouse quality through publications and conferences at local, national and international levels and governments underpin many of their reports and official documents with the rhetoric of quality.

The modern health care service with its demand for more and more resources is being increasingly required to demonstrate efficiency and effectiveness in the way care and treatment is provided. Professional groups are committed to quality through professional ideals, standards and seeking evidence for their practice. Such quality initiatives find expression in the way an individual professional delivers care to a client and in the way the professional collaborates with other professionals since client services are typically multi-professional and holistic. Clients too, are more educated and informed consumers and have expectations for how services should be delivered. Clients require a service' which is responsive to their needs, available on request and which fulfil their expectations. In addition to meeting clients' needs for general and specialist care; service provider-organisations must also fulfil the requirements of funding agencies be they governments, insurers or private fee-paying clients. That is, they must be cost effective and provide value for money.

All these human services are high contact personal encounters. Their uniqueness lies in the fact that they are usually provided not in a set standardised fashion, but on an individual customised basis. The client is part of the service encounter, and is involved in the consumption and evaluation of the care and service delivered.

In this review, the general service quality literature will be addressed first, followed by the literature on quality in intellectual disability services. Approaching the review in this manner is important for two reasons. The first is that the quality movement as an organised attempt at improving products and performance began in manufacturing organisations (Dale & Plunkett, 1990).

The second reason is that literature dealing with quality in intellectual disability services is also rooted in the general service quality movement. Quality in this area is probably the most complex of all given that it's a concept most often viewed in relation to quality of life (Felce & Perry, 1995, Ramcharan et al., 1997). The fact that clients and their families usually require a service for all of their lives, and in many cases are unable to communicate their needs and expectations, makes this service a challenging one for both provider organisations and professionals. Placing the literature in this order will enable the review to be seen in context and will facilitate the development of the major area, intellectual disability.

The purpose of this chapter is to review the literature on conceptual issues, dimensions/components issues and organisational management issues for quality within the general service quality arena as many of the issues in the intellectual disability area stem from this. Figure 2.1 is a map that traces the arrangement of the theoretical and empirical literature reviewed in this chapter on general service quality.

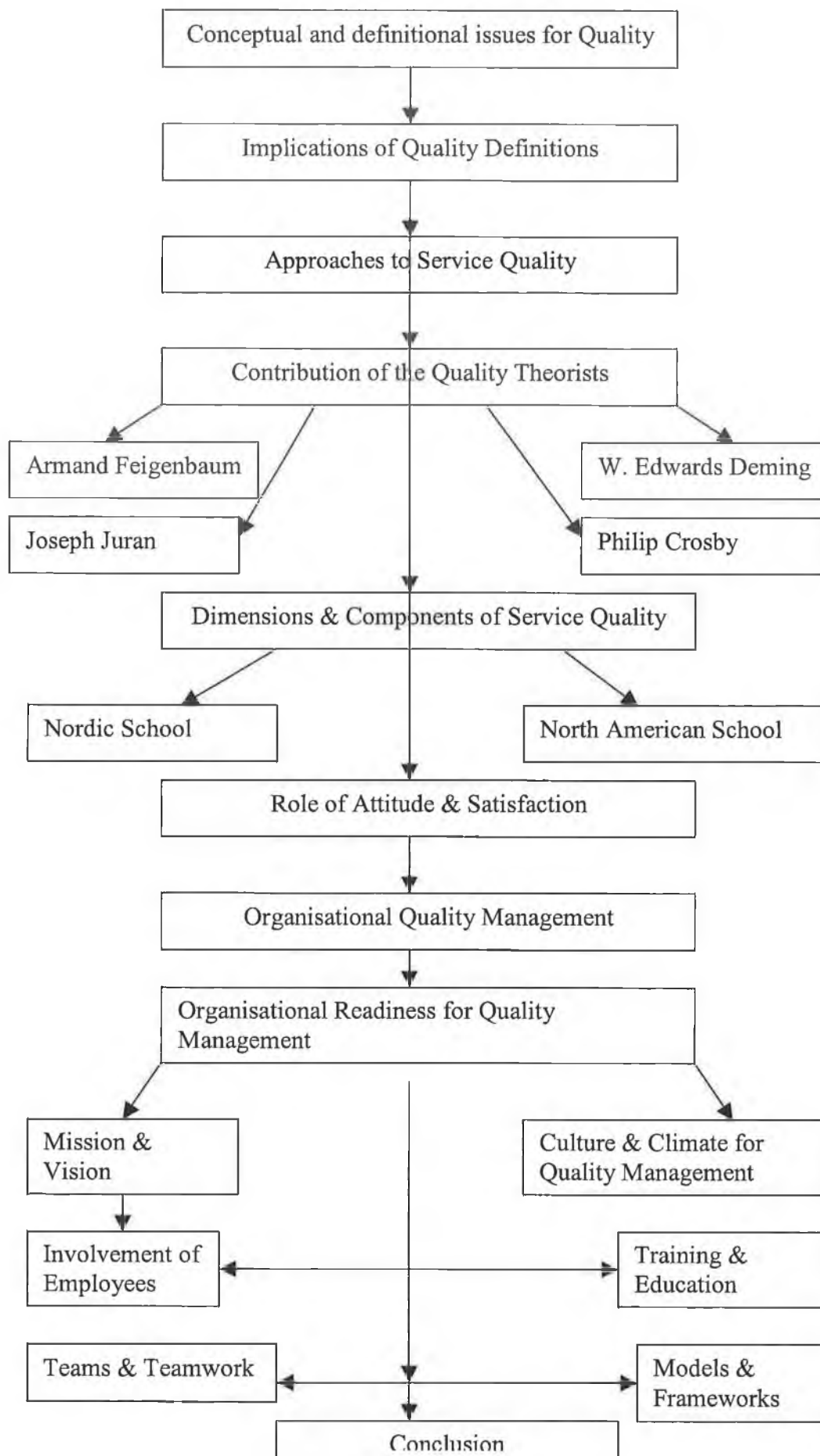


Figure 2.1. A research map of literature reviewed on general service quality

2.2 Concept and Nature of Quality

The concept of quality has been contemplated throughout history and continues to assume ever-increasing importance in today's manufacturing and service industries (Bednar & Reeves 1994). It is an issue that is addressed in professional and academic publications as well as in management and employee training programmes (Hames 1991; Fatih Yavas 1995; Pietenpol & Gitlow 1996; Goodale et al 1997). In the health care arena, one of the many issues facing administrators and professionals is that of quality of care (Shaw & Brooks 1991, Stiles 1994). Within the nursing profession, quality assurance and related activities are established parts of nurses' vocabulary and practice (Parsley & Corrigan 1999, Sale 2000) and in the area of intellectual disability, quality is recognised as an important component of service provision for all clients receiving a service (Maes et al 2000, National Disability Authority 2003).

2.2.1. Defining Quality

Quality as a term means different things to different people. It is an abstract construct for which many definitions exist. To a large extent, the multiplicity of definitions advanced as an attempt to explicate the meaning of the concept, have produced confusion in the minds of professionals and managers as well members of the public. As pointed out by Hardie and Walsh (1993), these differing definitions of the concept have resulted in fragmentation, confusion and uncertainty in the field of quality. The following definitions illustrate the range and diversity of attributes or dimensions used to explain the concept:

- Quality is meeting the customer's expectations (Kehoe, 1996. p.1)
- Quality is fitness for use (Juran, 1989, p. 15)
- Quality is a degree or standard of excellence (Collins English Dictionary, 1995).
- Quality is conformance to requirements (Crosby, 1979).

- Quality is meeting all the requirements and expectations of customers at an acceptable price (Moullin, 1995. p.613)

Garvin (1984) has analysed the range of definitions for quality and classified them into five groups:

1. Transcendental: excellence, this is the highest standard.
2. Product-based: the attributes of a product.
3. User-based: satisfying the wants of a customer, fitness for use.
4. Manufacturing-based: this is conformance to requirements.
5. Value-based: this is providing value for money.

These definitions are related but are not saying the same thing. Hardie and Walsh (1993) argue that it is possible for a product or service to meet a specified requirement (Crosby, 1979) yet not satisfy the customer (Juran, 1985); or for something to be free from defects (Juran 1985) but not meet the requirements of customers (Moullin 1995).

In his theoretical paper, Smith (1993) puts forward the view that quality definitions are inadequate and problematic since early attempts at definitions were not based on any deep conceptual analyses. He sees deficiencies in many of the contemporary definitions and cites how Garvin (1984), in his attempt at an integrated conceptualisation of quality, failed to ground his work in deep conceptual analyses. In Smith's review of the concept, he views quality as a property term or an attribute that refers to a characteristic of some thing. It (quality) has an object thing or state or process since in its normal usage we mean the term to characterise some entity.

He states that quality differs from other property concepts in at least two respects. First, it is not directly measurable since quality is not a physical characteristic of an object and so consequently it cannot be directly measured by physical means. Quality is but an abstract characteristic that encompasses a variety of physical attributes and

assessing or determining the quality of some thing will involve taking measurements of many of its attributes. Thus, such measurements can serve as indicators or proxy measures of quality but they are not measures of quality itself.

Second, quality is a relational attribute. Attributes pertain to an entity but characterise it only in relation to something else. Quality indicates the relationship between certain of the entity's attributes rather than itself being an inherent attribute of things. Smith's conclusion is that since quality cannot be directly measured, its assessment is a judgmental process – a scaling activity that requires comparison, mental weighing and the consideration of partial results into conclusions (Smith, 1993).

Quality assessment then, involves assessing user needs, identifying entity attributes or quality characteristics that relate to those needs, and assessing the entity's merit on each of the attributes. The final part is to consolidate each of the partial scores into an overall judgement of quality. From his conceptual analyses, Smith (1993, p.237), defines quality as “the goodness or excellence of some *thing*, it is assessed against accepted standards of merit for such *things* and against the interests/needs of users and other stakeholders.”

2.2.2. Quality as a difference between two states

From this conceptualisation it can be seen that quality is a difference between two states. Such a view was also proposed by Crosby (1979) and has been discussed in the writings of Garvin (1984), the service quality analyses of Parasuraman et al., (1988,1994) and by Zeithaml et al., (1990). In the service quality writings of Parasuraman et al, quality is viewed as “quality gaps” between states. The two states *are how things are* and *how things ought to be*.

Many of the contemporary definitions of quality reflect this comparison between the preferred and actual states (Hardie & Walsh, 1994, National Disability Authority, 2003). For example, a requirement specification states *how it ought to be* and the difference from the actual performance, *how it is*, indicates the degree of quality. In a customer/expectation type definition, how the customer *thinks it ought to be* by comparison with what is *actually received* constitutes the quality perception of the customer (Evans & Lindsay, 2002).

2.2.3 Difference between Product and Service Quality

According to Lovelock and Wright (1999), the sheer diversity of services makes them difficult to define. Added to this is the complexity associated with the creation and delivery of services since many of the inputs and outputs of services are intangible.

Lovelock and Wright (1999, p. 5) define a service as:

“An act or performance offered by one party to another. Although the process may be tied to a physical product, the performance is essentially intangible and does not normally result in ownership of any of the factors of production”

Like the quality concept, service quality is an abstract construct but is more elusive than product quality. Services are usually described as being more intangible than goods (Gummesson, 1992, Iacobucci & Ostrom, 1996, Lovelock & Wright, 1999). In a paper that reviews conceptual models for service quality, Ghobadian et al., (1994) identified four important differences between product and service quality. These differences relate specifically to the characteristics of a service encounter between service provider and service user. These four characteristics of services are summarised in table 2.1.

Characteristic	Description	Author
1. Inseparability of service product and its consumptions	During service encounter, performance/delivery of service and its consumption occur at the same time	Haywood-Farmer (1987), Morris & Johnston (1987) Ghobadian et al (1994)
2. Intangibility of services	Most services are intangible and consumer cannot experience the service in advance of consumption or delivery	Dotchin & Oakland (1993), Ghobadian et al (1994)
3. Perishability of services	Services cannot be stored. Service production and service delivery occur simultaneously and consumer must be present for the service delivery to take place	Dotchin & Oakland (1994), Ghobadian et al (1994)
4. Heterogeneity of services	Difficult to deliver a service with absolute consistency and exactness because: service providers influence consumers perception of services, service depends on consumers ability to make their needs known, and there is variability of services as service employees and organisations differ.	Ghobadian et al 1994) Dotchin & Oakland (1994)

Table 2.1. Summary description of four characteristics of service encounters

Services then, are performances rather than objects. In another theoretical paper, Chase and Tansik (1983) used the extent of consumer contact in a service encounter as a means of classifying types of service. They identified three types, which are summarised in table 2.2.

Classification of Types of Services Based on Level of Consumer Contact		
1	Pure Services	The consumer must be present for production and consumption. Examples include nursing homes and restaurants.
2	Mixed Services	There is 'back office' contact with the consumer as well as face-to-face pure service delivery. Examples include passenger airlines.
3	Quasi-Manufacturing Service	This type requires no face-to-face contact with the consumer. Examples include telephone and credit card companies.

Table 2.2 Summary of a classification of services based on level of consumer contact (Chase and Tansik 1983)

Distinctions between services however, are not as straightforward as might appear. According to Shostack (1977), there are few pure products or services. Services may be placed on a continuum with regard to their tangible elements. In high contact services (e.g. nursing) the quality of the service is inseparable from the quality of the service provider. Human performance is part of the service and therefore its quality (Cook et al., 2002).

2.2.4 Implications of Quality Definitions.

Quality differentiates a product or service as being 'better than' a comparable service or product in some way. Asubonteng et al., (1996) say that the determination of this often-intangible difference depends on how quality is defined. These writers put forward the view that how an organisation clarifies and defines quality may be the chief determinant of organisational success. Other writers on the subject including Garvin (1987), Ghobadian (1994) and Johns (1993), also echo this view. A search for a universal definition of quality has produced inconsistent results.

Bednar and Reeves (1994) undertook a detailed review and analyses of the construct and suggest that a global definition does not exist. They suggest that different definitions are appropriate under different circumstances. In their theoretical paper, the authors trace the evolution of definitions and examine the implications and trade-offs for organisations using one definition as against another.

From their analyses, what has emerged is that no single definition is ‘ best’ in all situations; rather, each one has strengths and weaknesses for its application, measurement and generalizability. They argue that an understanding of extant definitions along with their origins provides an essential building block for theory development. Bednar and Reeves analyse four broad definitions of quality and these are listed in table 2.3

1	Quality as Excellence (Garvin 1984)
2	Quality as Value (Bolton & Drew 1991)
3	Quality as Conformance to specifications (Crosby 1979)
4	Quality as Meeting/Exceeding Customer Expectations (Evans & Lindsay 2002)

Table 2.3. List of four broad definitions for service quality (Bednar and Reeves, 1994).

Defining quality as meeting and/or exceeding customers’ expectations, according to Bednar and Reeves (1994) and Evans and Lindsay (2002), is the most relevant definition of quality for consumers. Quality in this sense is frequently operationalised as being associated with attributes such as customer attitudes and satisfaction

(Muffatto & Panizzolo 1996, Pitt et al., 1994), the relationship between expectations and perceptions (Zeithaml et al., 1990, Cronin & Taylor 1992,1994, Ghobadian et al, 1994, Dotchin & Oakland 1994, Gupta & Chen 1995), and in the nature of the service encounter and service relationships (Berry & Parasuraman, 1997, Cook et al., 2002).

According to Bednar and Reeves (1994), customers can (and do) say how well a service encounter meets their expectations. However, they are unable to make a similar judgement of how well a service conforms to specifications. In service organisations, this is largely the definition that operationalises service quality today (Parasuraman et al, 1985, 1990, Schneider and Bowen 1999, Cook et al., 2002).

Bednar and Reeves (1994) conclude that this definition of quality permits managers and researchers to recognise factors such as helpfulness, courtesy and appearance. These are subjective factors but are seen as critical to any service encounter though difficult to measure objectively. Such a definition of quality focuses on consumers wants and needs rather than on management's perception of those needs through standards that may or may not be correct. Bednar and Reeves point out that this is an externally focused definition and all-inclusive since organisations can include many attributes and weights when attempting to measure expectations. Based on this definition of quality, figure 2.2 summarises the processes involved in a consumer-driven or met-expectations framework.

Despite its importance, meeting and /or exceeding customers' expectations are difficult. Customers may have different preferences and place a weighting on the various attributes thus making this definition of quality the most difficult to measure.

Added to this is the fact that many customers (e.g. people with severe intellectual disability) do not know what their expectations are, especially when encountering a new service. Meeting the requirements of a definition does not necessarily mean that a service will be of adequate quality. Requirements can rarely be defined in sufficient detail to exclude all possibilities of errors or omissions in meeting customers' expectations.

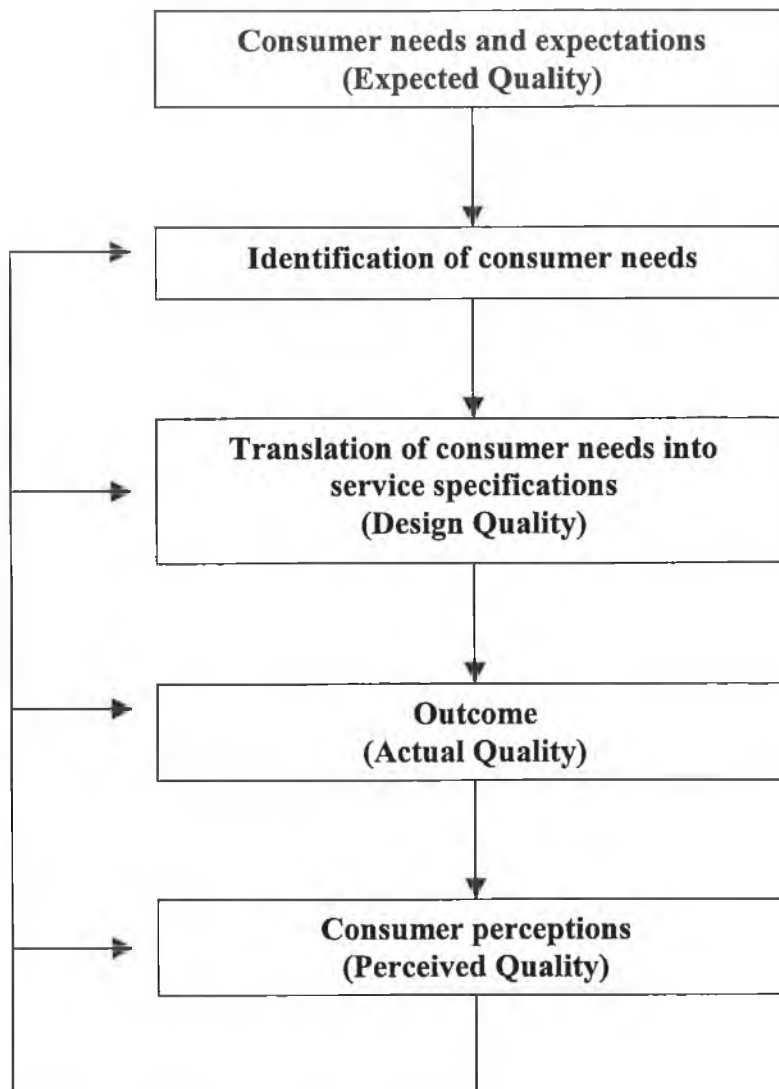


Figure 2.2. Summary of processes involved in a consumer-driven quality or a met-expectations framework (adapted from Lindsay & Davis, 2002:160).

Hardie and Walsh (1994) have pointed out that a service may be of the highest standard and meet the quality definition but a customer's expectations might be so unreasonable that they cannot be met by any means at all.

In response to the limitations of the met-expectations framework depicted in figure 2.2 above, Schneider and Bowen (1999) introduced a needs – based framework. The premise of this framework is that consumers are people first and consumers second. In addition, people are driven to meet some core needs in their life at a level more fundamental and compelling than just meeting their expectations as consumers. Schneider and Bowen base their core needs on the hierarchy of needs theory of Maslow (1943) and the philosophy of Aristotle for fair and just treatment:

1. Security – the need to feel free from physical and economical harm
2. Esteem – The need to protect and enhance one's self – concept
3. Fairness – The need to believe that just treatment is deserved.

Security is a basic need and consumers cannot be satisfied with a service until they feel safe. Esteem requires that consumers can protect their self-concept during the service encounter. Fairness in the service encounter requires that consumers believe they are dealt with in a just and honourable manner.

2.2.5 Developmental Approaches to Quality

Several writers have discussed historical and developmental approaches to quality (Evans and Lindsay 2002, Xavier 2002, Beckford 1998, Chasse 1989). In a review of differences between approaches, Chasse (1989) has summarised developments in terms of their scope, organisational requirements and implications. These approaches are summarised in table 2.4 below. In addition to showing the differences between

levels or approaches to quality, the essential conceptual, operational and implementation characteristics between approaches can be seen.

	Quality Control	Quality Assurance	Total Quality Control	Total Quality Management
Philosophy	Inspecting quality in	Building quality in	Organising quality in	Managing quality
Starting Point	Production specification items & costing	Adoption of procedure manual, introduction of variance analysis e.g. SPC	Blueprinting operations. Use of problem solving techniques	Understanding customers, establishing quality management structure, culture change
Benefits	Few. Causes more problems than it solves	Improved product quality, evidence of procedures, market entry	Cost reduction (waste inventory) production to customer specification, Fewer suppliers	Guaranteed quality, ability to manage change, customer satisfaction, Habitual improvement
For which companies	Those that don't know any better	Those with survival problems	Those competing on cost & quality with long term profitability goals	Those with "market leaders" vision competing on quality, first looking for sustained growth & increased market share
How long to install?	Days	6 mths – 1 year	1 – 3 years	3 – 5 years
Responsibility for quality	QC department Through inspectors	QA department i.e. centralised staff function	Systems & operations through design & installation of controls	Organisation-wide responsibility through devolved strategic vision
Goals	Defect detection	Production to design specification, defect preventor	Cost reduction & conformity to specification through continual improvement	Habitually & competitively meeting customer requirements

Table 2.4. Summary of differences between approaches to quality.

Chasse (1989, p.22)

2.2.6 The Contribution of Quality Theorists

A number of acknowledged and influential writers have contributed to understanding and managing quality. Among these are the “classical writers” who have provided much theoretical insight to the subject. As Beckford (1998) says, their individual and collective contributions have laid the foundation for contemporary thinking on quality management. Of the many theorists on quality management, four have made particular and important contributions. These are Philip Crosby (1979), W. Edwards Deming (1986), Joseph .M. Juran (1989), and Armand Feigenbaum (1991).

Each of these have approached the subject in their own style and from a particular perspective but as Beckford (1998) points out, they all share a common aim – the attainment of quality. For these theorists, quality is the concern of everybody; quality requires management commitment; quality means understanding the processes and characteristics requiring control; quality means standards, monitoring, measuring, prevention and improvement; quality means training and involvement of employees, managers and customers. Table 2.5 provides a summary of the theoretical positions of these gurus together with the broad implications their approaches have for managing service quality. Summaries of the work of these theorists provide a basic insight into their ideas about quality. Each has written extensively on their philosophies, theories and frameworks. Their writings are mostly motivational in nature and put forward checklists and broad-based ideas for quality management. Brocka and Brocka (1992) refer to them along with Peters, Ishikawa and Taguchi as the pacesetters for the quality management movement. In their review, Brocka and Brocka (1992) concluded that the philosophies and frameworks of Crosby (1979), Deming (1986), Juran (1989) and Feigenbaum, (1991) agree to within 95 percent but that it is the last 5 percent that may be most appealing.

Theorist	What Quality Means for them	Implications for Managing Quality
Armand Feigenbaum, 1991	Total Quality Control. Involves standards, measuring standards and improving standards Employee involvement It is a way of managing. Must be management's number one priority	Management responsible & must commit to quality Quality concerns all in the organisation Must be a quality system in place Employees must feel they participate
Joseph M. Juran, 1989	Total Quality Management Involves standards, measuring standards and improving standards Employee involvement	Management responsible & must commit to quality Must be a quality system in place Employees must feel they participate
Philip. B. Crosby, 1979	Management Leadership Teams and teamwork Abandon inspection Constant improvement Employee involvement and Employee Recognition Doing the right things right first time every time	Direction & leadership from management Set up teams & teamwork Create quality awareness Set up quality councils Listening & responding to employees
W. Edwards Deming, 1986	Management Leadership Constant improvement Teams and Teamwork Employee Training Abandon inspection	Direction & leadership from management Set up teams & teamwork Break down barriers Drive out fear

Table 2.5. Summary of theoretical positions of quality gurus and their implications

Kathawala (1989) undertook a comparative analysis of the approaches of these theorists. According to this writer, all four agree that quality commences at the design stage and that management and not the employee is responsible for most of the quality-related problems.

On costs for quality, Crosby (1979) says that quality and costs complement each other. Deming (1986), Juran (1989) and Feigenbaum (1991) believe there are costs for quality but quality pays for these costs. Deming and Crosby emphasise the commitment of management. Deming and Feigenbaum take the view that co-ordination between departments is necessary, whereas Crosby and Juran see quality as somewhat dependent on departmental co-ordination. Feigenbaum (1983) and Deming (1986) disagree with Crosby's use of posters and slogans and emphasise training and motivating employees. All four theorists see co-operation between suppliers and organisational management and conformance of suppliers' standards as being as important as the commitment of the managers and employees of an organisation (Kathawala, 1989).

2.2.7 Summary and Conclusions on Conceptual Issues for Quality

Quality means different things to different people and this can be seen in the multiple definitions of the concept. However, most writers agree that quality is a relational concept that involves a judgemental process. In a service-led encounter, the service provider on behalf of the customer/client will make the judgemental process. In contrast, in a customer/client-led encounter it will be the customer/client who will initiate the judgemental process based on their expectations and perceptions of service. It is the view of this writer that for most people with an intellectual disability, an expectations/perceptions definition is appropriate.

There are two main reasons for this. First, disability services are not just what Chase and Tansik (1983) describe as pure services. They are also human services with their processes focused on what people want and need from a service. Second, a definition of quality based on expectations/perceptions of clients is the only logical way of conceptualising quality that is in keeping with the current paradigm of service delivery based on rights, person-centred care and enhancement of quality of life as an outcome of service.

2.3. Dimensions & Components of Service Quality

Research on product quality has been ongoing since the early part of this century (Dale & Plunkett, 1990). Service quality however, has only been extensively researched since the 1980s. Cheng and Ngai (1994) found only a small number of articles and books on service quality during the period of their writing. Seven years later, using both electronic databases and manual searches, this writer has unearthed a substantial increase in literature on the subject. This English language literature stems predominantly from the United Kingdom, the United States of America and Australia. Like Cheng and Ngai discovered, much of the general service quality literature still emanates from the marketing profession. The interest by academics, quality consultants and marketing experts has led to the formulation of concepts and theories and to the understanding and classification of services (Dotchin & Oakland, 1993, Evans & Lindsay, 2002).

Efforts to identify and describe attributes and dimensions of quality along with important critical factors, has led to the development of models and frameworks. From the extant literature, and based on how it is defined, many different approaches have been adopted in service quality practice. According to Brogowicz et al., (1990),

these various approaches can be divided into two distinct streams. The Nordic and North American Schools represent these broad conceptualisations and approaches. The principal contributors to the Nordic School have been Gronroos (1982, 1983, 1984), Lehtinen (1985), Gummesson & Gronroos (1987) and Ghobadian et al, (1994). The North American School has been led by Parasuraman et al., (1985,1988,1990), Garvin (1987) and Haywood–Farmer, (1988). Brogowicz et al., (1990) view these two schools as representing most of the contemporary thinking within the general service quality arena.

2.3.1 The Nordic School

Gronroos, (1988) explains that quality is a function of a range of resources (see Smith, 1993). He argues that too often the term “quality” is used as if it was a variable itself and not a function of a range of resources and activities. He points out that exhortations for organisations to compete on quality is meaningless unless they can first define how service quality is perceived by the customer and second, determine how and in what way service quality is influenced.

Gronroos (1983) divided service quality into two dimensions: technical quality and functional quality. Technical quality refers to what the customer/client is given in a service encounter (e.g. a bath by a nurse). Functional quality refers to how and in what manner the service is delivered (e.g. pleasant, safe surroundings and the attitude and behaviour of the nurse). While both dimensions are present and are clearly related, Gronroos concludes that the functional dimension is more important for the customer’s/client’s perception of quality. He points out that the customer’s experience of a service can be expected to influence his/her post-consumption evaluation of the service received. According to Gronroos then, the perceived quality of a given service

will be the outcome of an evaluation process where the customer/client compares his expectations for a service with the service he perceives he has received. The service quality is a measure of how the service delivered meets the customer's expectations. This conceptualisation of service quality is based on the 'meeting/exceeding customer expectations' definition and the relationship between a customer's expectations and perceptions of a service encounter. Ghobadian et al., (1994) conceptualise their Expectations- Perception Relationship as summarized in table 2.6.

Prior customer expectations (PCE)	Actual process of quality (APQ)	Actual outcome of quality (AOQ)	Perceived quality (PQ)
PCE + APQ + AOQ = PQ			

Table 2.6 Summary of relationship between process and outcome quality in terms of customer expectation and perception for service quality in the Perceived Service Quality (PSQ) model (Ghobadian 1994, p.49).

Ghobadian et al., (1994) argue that since the customer is present in the delivery process, then the perception of quality is influenced not only by the service outcome but also by the service process. This relationship leads to the conclusion that prior expectations are compared with the actual service delivery process and the service outcome and that it is through this comparison that the perceived quality is structured.

Swan & Comb (1976) adopted a similar approach. In a very early paper, they identified two dimensions for perceived performance of a product or service: Instrumental performance and Expressive performance. Instrumental performance refers to the physical characteristics of a product and is similar to Gronroos' (1983)

technical dimension. Expressive performance refers to the psychological characteristics of a product or service and is similar to Gronroos' (1983) functional dimension. Like Gronroos (1983), Swan & Comb (1976) argue that while satisfactory instrumental performance is necessary for customer satisfaction it is not sufficient. Unless the expressive performance of a product or service is satisfactory and despite satisfaction with the instrumental performance, the customer will feel dissatisfied. Swan & Comb (1976) also put forward the view that a satisfied customer will be more likely to comment on expressive (functional) attributes as against instrumental (technical) attributes as a reason for satisfaction.

In a later paper, Gronroos (1987) discussed the importance of the skilful and service oriented employee for both manufacturing and service industries. He points out that manufacturers also live in the service economy and must learn the rules of services. He advanced five rules for service quality and these are summarised in table 2.7.

- | |
|---|
| <ol style="list-style-type: none"> 1. That employees promote and maintain good contact with customers. Employees are responsive to the needs and wants of customers. 2. The employee in direct contact with the customer must be allowed to do their own analysis of the needs and wants of the customer at the time of service delivery. 3. That the contact employee will control the quality of service at the time he/she produces the service. 4. The contact employee will have to be a marketer of the service in addition to producing and delivering the service. 5. That necessary organisational, technical and management support be provided to employees to motivate and enable them to give good service in customer relations. |
|---|

Table 2.7. Summary of Gronroos Five Rules for Service Quality (Gronroos, 1987)

2.3.2 The North American School

Like the writers from the Nordic School, these writers make their contributions from an academic and marketing research perspective. Among the contemporary and prolific writers are the contributions from Parasuraman et al., (1985, 1988, 1990). As part of the developments in service quality, they undertook their exploratory research during the decades of the 1980s and 1990s. These researchers developed a multi-item scale for measuring consumer perceptions of service quality. This scale in its original form consisted of 10 dimensions made up of 97 items. With further development and refinement using computer analysis, many items were compressed or deleted. Factor analysis was used to reassign and restructure dimensions. In their 1988 paper and 1990 book, the scale was reduced to 22 items across 5 dimensions. The authors say the conceptual foundation for the scale was derived from the work of American writers, Sasser et al., 1978 and European writers, Gronroos 1982, Lehtinen & Lehtinen 1982. The five dimensions are summarised in table 2.8.

1	Tangibles	Appearance of physical facilities, equipment, attitude and behaviour of personnel, and communication materials
2	Reliability	Ability to perform the promised service dependably and accurately
3	Responsiveness	Willingness to help customers and provide prompt service
4	Assurance	Knowledge and courtesy of employees and their ability to convey trust and confidence
5	Empathy	Caring, individualised attention that the organisation provides to its customers/clients

Table 2.8. Summary of the 5 dimensions of the SERVQUAL Scale, the GAP Analysis model (Zeithaml et al., 1996 p. 26)

The 5 dimensions are spread across 22 questions that concern customer expectations for a particular service and 22 matching questions concerning customer perceptions of the service they received. The scale is based on a “gaps” model that looks at the discrepancy between expected service and perceived service. These gaps are summarised in table 2.9 below. According to Zeithaml et al., (1990), the conceptual model serves as a framework for measuring and improving service quality.

Gap 1	Discrepancy between customers/clients expectations and management perceptions of these expectations
Gap 2	Discrepancy between management perceptions of customers/clients expectations and service quality specifications
Gap 3	Discrepancy between service quality specifications and actual service delivery
Gap 4	Discrepancy between actual service delivery and what is communicated to the customers/clients about it
Gap 5	The link between customer/client perceived quality shortfalls and gaps 1-4

Table 2.9. Summary of gaps from the SERVQUAL GAP Analysis model (Zeithaml et al., 1999).

The SERVQUAL Scale was developed on retail, banking and for profit organisations and not for high contact human services. The authors report the Scale as having sound psychometric properties and provide reliability and validity data. They also assert its usefulness for application across different types of services (Parasuraman et al., 1988, Zeithaml, 1990). The SERVQUAL measure has been applied across a diversity of services (Carman 1990, Johns 1993) including hospitals in the USA (Babakus & Mongold 1992) and in Britain (Youssef et al., 1996).

However, this writer has found no evidence of its use in disability services. SERVQUAL has been reviewed and criticised by a number of writers (Carman 1990, Bolton & Drew 1991, Cronin & Taylor 1992, 1994). Many of the issues currently debated concern the relationship between expectation and perception components of quality. Some writers advance the view that customer perception is the most important component of the two and the only one that can be measured with relative ease (Cronin & Taylor 1992, 1994, Teas 1994). Parasuraman et al., (1994) has responded to this ongoing debate and the SERVQUAL is benefiting from further refinement. The general criticism of SERVQUAL is that quality is a performance construct that is more accurately measured from perceptions rather than expectations (Carman 1990, Asubonteng et al., 1996, Brady & Cronin, 2001).

Haywood-Farmer (1988) agrees that customers judge quality by comparing their perceptions of what they receive with their expectations of what they should receive. He suggests that this observation is important for understanding and providing quality since both expectations and perceptions are experiential states of mind rather than being real.

In comparison with the Perceived Service quality model from the Nordic School (Gronroos 1993, Ghobadian 1994) and the GAP Analysis model from the North American School (Parasuraman et al., 1985, 1988), Boulding et al., (1993), advance what they call the Dynamic Process model. They conceptualise service quality as performance based and take perceptions and not expectations as the foundation for their dynamic model. However, Boulding et al base their model on the perceptions element of Parasuraman et al., (1988) five dimensions of the SERVQUAL Scale.

2.3.3 A Critique of Service Quality Dimensions/Components

Some consensus exists between the Nordic and American schools on their dimensions/components of service quality. Both for example, view the service encounter as crucial for service quality. Both conceptualise service quality in terms of disconfirmation theory, which suggests that quality results from a comparison of perceived with expected performance. In addition, Brogowicz et al., (1990) also see a consensus between the functional and technical dimensions of quality as advanced by the Nordic School with the tangibles (technical) and intangibles (functional) dimensions advanced by the North American School. Other writers however, see flaws with the current conceptualisations of service quality and criticise existing models.

Brady and Cronin (2001) have summarised the debate and conceptual developments in service quality as divergent. At the core of the debate are the two competing perspectives of the Nordic and American schools. They see the point of contention as the Nordic school's conceptualisation of quality in categorical terms whereas the American school defines quality in descriptive terms. In a qualitative study to break the stalemate, they adopted Rust and Oliver's (1994) theory that perceived quality is based on customer evaluation of three dimensions of the service encounter: (1) customer-employee interaction (Gronroos's functional quality), (2) the service environment (Parasuraman et al's tangibles dimension), and (3) the outcome (Gronroos's technical quality).

Findings of Brady and Cronin (2001) are that customers do form service quality perceptions based on evaluating the three dimensions of interactions, environment and outcomes, thus providing empirical evidence for Rust and Oliver's (1994) three-

component conceptualisation of service quality. Findings also indicate that the three primary dimensions consist of multiple sub dimensions the combination of which constitutes a customer's overall perception of service quality. Findings also indicate that reliability; responsiveness and empathy from the American school (Parasuraman et al., 1985, 1988) are important as modifiers of sub dimensions of service quality as distinct from direct determinants of service quality but are necessary for the customer's perception of superior service quality.

Schembri and Sandberg (2002) summarise service quality based on three models:

1. Perceived service quality (Gronroos 1993, Ghobadian 1994)
2. Gap analysis (Parasuraman et al 1985, Zeithaml, Parasuraman & Berry 1990)
3. Performance-based dynamic process model (Boulding et al., 1993).

Schembri and Sandberg criticise the limitations of these approaches, which they see as third party based. By this they mean that service quality is determined and driven by the conceptualisations of researchers about the perceptions of consumers and not about how consumers conceptualise and experience quality as first-party based. Schembri and Sandberg acknowledge that the perceived service quality and the gap analysis models both measure quality relative to expectations. However, as conceptualisations of quality comes from the third party, these expectations may be misinterpreted and will not reflect the true needs, wants and values of the consumer.

Schembri and Sandberg (2002) view these models as static and unable to develop further understanding - a possible reason for the absence of recent writings. In response to this, they advance a model of service quality based on an interpretive approach to the consumer's experience. Such an approach focuses on how a

consumer makes sense of service quality and in a specific context, what their expectations are for service quality. They propose phenomenography as a methodology for researching and finding out about the experiences of consumers. Using interviews, written accounts and observations, this research approach allows researchers to study how consumers conceptualise service quality and the variations in how it appears to them. The task is to arrive at the widest variation of quality conceptions as fundamental guides to actions in the consumer (Sandberg, 2000). In principle, this approach appears similar to that employed as part of the personal outcome measures used in intellectual disability services.

2.3.4 The Role of Attitude and Satisfaction

Both attitude and satisfaction are related but distinct concepts that bear on the meaning of quality. Oliver (1981) views attitude as the consumer's relatively enduring affective orientation for a process or service, while satisfaction is the emotional reaction following a disconfirmation experience which acts on the base attitude level and is consumption specific. In relation to service quality, attitude is seen as linked to the consumers more general long-term perception of quality.

The consumer's "feeling" about a specific service encounter is linked to satisfaction. This view is taken by Bolton & Drew (1991) when they say that service quality is an outcome of customer satisfaction. However, empirical research conducted by Cronin and Taylor (1992) seems to support the opposite of this. Their findings support the view that perceived service quality leads to satisfaction but satisfaction with a service on its own does not lead to perceived quality. Either way, satisfaction appears to be an indicator of quality but not itself quality. Satisfaction is an important component of quality systems and is included in both the Malcolm Baldrige National Quality

Award (1995) and the European Quality Award (1994). It is central to definitions that emphasise customer expectations and perceptions of quality (Zeithaml et al., 1996).

2.3.5 Patient/Client Satisfaction

Pascoe (1983) reviewed conceptual and measurement issues and sees satisfaction as a type of evaluation, a multidimensional construct that involves affective and cognitive components. According to him, satisfaction is a patient's reaction to salient aspects of the context, the process and the results of a service experience.

Patient satisfaction is complex with a diversity of approaches taken to it. Hall & Doran's (1988) meta-analysis for example, found the most frequently studied dimensions of satisfaction to be humanness, informativeness, and competence. The least studied dimensions were outcome, continuity and psychosocial problems. Hall & Doran (1988) say that irrespective of which dimensions are studied more than others, the disparities only serve to limit our understanding of what satisfaction is.

Vuori (1991) asked the question: *has patient satisfaction improved the quality of care?* He concluded that there was no evidence for believing this. At the time of his writing, Vuori put forward four reasons for the lack of evidence (pp.184-185):

1. Few studies published up to that time used a before and after design to look at the level of quality following patient satisfaction measurement. Published studies failed to:
 - Remeasure patient satisfaction after improvements.
 - Make comparisons before and after changes with other indicators of quality care.
2. Most studies at the time focused on evaluations as apposed to reports; they focused on how satisfied a patient was with some aspects of care and not on whether certain things did or did not occur.

3. Patient/public relations' departments (60%) health care administration (30%) and quality assurance departments (10%) carried out satisfaction surveys.
4. While patient satisfaction surveys are important, their interpretation requires analytical skills beyond the capabilities of routine quality assurance programmes.

Carr – Hill (1992) expressed similar views but in particular he saw difficulties in executing patient satisfaction surveys because of problems with their measurement. Carr-Hill pointed out that satisfaction is a complex concept related to a number of factors including life style, past experiences and future expectations along with the values of the individual and society. From his factor analysis he derived six dimensions of patient satisfaction: medical care and information; physical facilities; non-tangible environment; quantity of food; nursing care; and visiting arrangements. He saw satisfaction as a derived concept that should be investigated alongside a search for sources of dissatisfaction.

Scott & Smith (1994) saw problems with interpreting the results of patient satisfaction as being due to a poor conceptual foundation of the concept. They examined the components of categories of patient satisfaction and pointed out that for in-hospital patients, the main categories were interpersonal relationships, information, access/convenience, hospital environment and hotel services. Scott & Smith (1994) argue that the impression is given that satisfaction surveys are seen as an end in themselves rather than a means to an end. This view concurred with that of Vouri (1991) and his comments that most satisfaction surveys did not conduct a before and after study. A point these writers make concerns the categories of service satisfaction with which patients are least satisfied and which may be considered as priorities for improvement. This makes an assumption that the least satisfied areas are also the areas patients would most prefer to improve if given the choice. According to Scott &

Smith (1994), when patients complete a satisfaction survey, they are not asked to compare categories and so preferences are not taken into account.

Walsh & Walsh (1999) reviewed the Newcastle Satisfaction with Nursing Scale developed by McColl et al., (1996). This Scale is a self-administered questionnaire looking at experiences of care and satisfaction with that care. What Walsh and Walsh (1999) found when they implemented this Scale in a general hospital was that patients considered a happy ward atmosphere, privacy and individualised care to be the most satisfying forms of care.

In the past, satisfaction-related surveys in intellectual disability focused on structures like accommodation (Emerson, 1985, Davies, 1989, Rose, 1990) or processes dealing with lifestyle (Donegan & Potts, 1988, Whittaker et al., 1990, Jahoda & Markova, 1990). Studies are now more people-centred though many still focus on accommodation (Gregory et al., 2001) or future accommodation (Barr et al., 2003). Concern with quality of life has spawned studies dealing with personal client outcomes (Felce & Perry, 1996, Chapman, 1997, Cummins 1997, Northway & Jenkins, 2003).

Few of these studies however, deal with residential care. There are two possible reasons for this. First, most people have severe or complex disabilities thus making it difficult to ascertain their views directly. Second, in many countries fewer people now live in this type of accommodation resulting in less research being done. That said, people are living in residential accommodation and despite cognitive or communication disability, a proxy may be used in order to ascertain their views.

2.3.6 Summary Evaluation of Dimensions/Components of Service Quality

Section 2.3.3 provided a critique of dimensions of service quality. This section evaluates the applicability of these dimensions to intellectual disability services. It is important to re-iterate that while there are increasing numbers of empirical studies on service quality, much of the literature is still ideological or theoretical. Perhaps this is because service quality is still developmental. Early writings from the quality theorists for example, were concerned with their own philosophies and theoretical positions on what ought to constitute quality. In contrast, contemporary writers who are still concerned with theoretical issues have moved on to operational issues, in particular, dimensions of service quality, measuring quality and service evaluation. In view of this and the fact that in the general service arena, most of the limited and often single empirical studies are in retailing, not all their dimensions may be applicable to human services and to avoid being misled, their findings should not be accepted uncritically.

Despite this caution, many of these models and their dimensions have utility for people with intellectual disability. However, for people with severe and profound intellectual disabilities (the majority of clients in residential centres), most will be unlikely to appreciate and communicate their expectations. In contrast, all clients are likely to perceive and respond to the care they receive. To this extent, a model based on perceived quality such as the Dynamic Process Model (Boulding et al., 1993) based on the perception element of the SERVQUAL Scale (see table 2.8) may have utility. Rust and Oliver's (1994) theory that perceived quality is based on the three dimensions of customer/employee interaction (processes), service environment (structures and amenities) and, service outcome also has much to recommend it as it facilitates thinking about structures, processes and outcomes.

It is appropriate to comment again on the limitations that Schembri and Sandberg (2002) see with the models advanced by the Nordic and American schools. They see these as third party-based and service-led and as such are unable to advance developments in the service quality field. They put forward an interpretive approach based on customers/clients needs. Such an approach is client-led and similar to the quality initiatives based on personal outcome measures now being considered in many residential centres and which are discussed in chapter four.

2.4 Organisational Quality Management

For quality to be incorporated into an organisation it must be managed. Brocka & Brocka (1992) define quality management as “a way to continuously improve performance at every level of operation, in every functional area of an organisation, using all available human and capital resources”. According to Brocka & Brocka, quality management is both a philosophy and a set of guiding principles. It is grounded in the notion of a continuously improving organisation, all the processes within the organisation and the extent to which present and future needs of customers are met. Most of the ideas and approaches to TQM are based on the philosophies and writings of the classic writers (Crosby, 1979, Feigenbaum, 1983, Deming, 1986).

Other writers have contributed to the theoretical and practical concerns for understanding and applying TQM in the organisation (Porter & Parker, 1993, Morrison & Rahim, 1993, Tummala & Tang, 1996, Thiagarajan & Zairi, 1997). Porter & Parker (1993) for example, while agreeing there was consensus that TQM is a way of managing quality in organisations, found less agreement on the most important of the elements of TQM or the critical factors for its implementation.

Their empirical research on ten randomly chosen organisations employed in-depth interviews with managers and employees to obtain qualitative data. From this they identified the eight critical factors listed in table 2.10. These are arranged in a hierarchical order with 1 being the most important, 2 the next important and so on.

1. Necessary management behaviour	2. Strategy for TQM implementation
3. Organisation for TQM	4. Communication for TQM
5. Training and education	6. Employee involvement
7. Process management and systems	8. Quality technologies

Table 2.10. 8-Critical factors for implementing TQM (Porter & Parker, (1993. p.14).

They then compared these 8-factors with the 8-factors found to be important by Saraph et al (1989) and with the seven criteria employed in the Malcolm Baldrige National Quality Award (MBNQA 1992). Tables 2.11 and 2.12 lists the 8-factors found important by Saraph et al., (1989) and the seven factors employed as the criteria for the Malcolm Baldrige National Quality Award respectively.

1. Role of management leadership and quality policy	2. Role of quality departments
3. Training of employees	4. Service / product design
5. Supplier quality management	6. Process management
7. Quality data and recording	8. Employee relations

Table 2.11. 8-critical factors for TQM advanced by Saraph et al., (1989)

1. Leadership	2. Information and analysis
3. Strategic quality planning	4. Human resource development and management
5. Management of process quality	6. Quality and operational results
7. Customer focus and satisfaction	

Table 2.12. 7- factors employed as the criteria for the MBNQA (1992)

Porter & Parker (1993) found that the factors were similar on all three counts though in many cases agreement was implicit. The number one critical factor identified in all three groups of factors was management behaviour. While these factors have been found necessary for TQM they are not exhaustive. Van De Wiele et al., (1996) for example, in a major survey of managers in general service organisations identified 10 most important factors out of a list 15 that participants were asked to rank. These are summarised in table 2.13.

1	Satisfying external customers
2	Reducing costs
3	Partnerships between an organisation and its customers
4	Each employee satisfying their internal customers
5	Employee involvement and development
6	Team work
7	Improving process capability
8	Each person dedicated to process improvement
9	Quality of working life
10	Partnership between organisation and its suppliers

Table 2.13. A list of the 10 most important aspects for TQM (Van De Wiele et al., 1996).

As can be seen from table 2.13, while many of the factors are similar to those Porter and Parker draw attention to, other factors were identified by Van De Wiele et al. In particular, their research identified employee involvement, teamwork and partnerships as among the most important. It is interesting to note that management behaviour and leadership was not seen as important. Perhaps this can be explained by the fact that the respondents in their research were senior managers.

As if to emphasise the importance of all these factors, the European Foundation for Quality Management (EFQM) as part of the European Quality Award (1994) included these among its nine criteria. The criteria are listed in table 2.14. As can be seen, many of these, at least implicitly, are the same as those identified by Porter and Parker (1993), Saraph et al (1989), the MBNQA (1992), and Van De Wiele et al., (1993). Of importance is the observation that they all recognise people management, leadership, and processes for care, people satisfaction and the involvement of employees.

1. Leadership	2. Policy and strategy	3. People management
4. Resources	5. Processes	6. Customer satisfaction
7. People satisfaction	8. Impact on society	9. Business results

Table 2.14. Nine criteria featured in the European Quality Award (1994)

Thiagarajan & Zairi (1997) reviewed critical factors for TQM that have been addressed by both quality gurus and implementation case studies. They point out these factors are usually reviewed from the perspective of the “how and why” but with less consideration of “the what”. Their review of literature is based on criteria similar to those used by the MBNQA and the EQA. Many writers (Juran, 1993, Kehoe, 1996, Evans & Lindsay, 2002) stress leadership and commitment of senior management as the most singularly important factor for TQM implementation.

These writers say that management must be obvious in their attitude and behaviour as well as committed. According to these writers, commitment is necessary but not sufficient, management must also understand TQM and what it involves. They also emphasise the organisation’s vision and mission for business success and quality improvement programmes.

2.4.1 Organisational Readiness for TQM

Weeks et al., (1995), point to organisational readiness as a fundamental requirement for organisations planning to implement total quality management. They advance what they see as seven key characteristics, which are summarised in table 2.15 below.

Characteristic	Explanation/Implication	Author/s
Sphere of Influence	If employees perceive they have no influence they will resist change, be less persistent, committed or accepting of responsibility	Week's et al., (1995), Morrison & Rahim,(1993), Evans & Lindsay, (2002)
Responsibility/autonomy	Employees need clarification of job roles and authority to make decisions	Week's et al., (1995), Marquis & Huston, (2000), Evans & Lindsay, (2002)
Satisfaction	Employees need to achieve to be given recognition, to have group identity and to feel they can exercise influence	Week's et al., (1995), Marquis & Huston, (2000), Evans & Lindsay, (2002)
Desire to change	Organisations where employees have a low desire to change, will be less innovative	Week's et al., (1995), Evans et al., (2002)
Vision/benchmarking	Organisations should have a common vision and employees should be encouraged to benchmark to enhance the common vision	Week's et al., (1995), Beckford, (1998), Evans & Lindsay, (2002)
Innovativeness	Organisations in which employees are free to experiment and can advance ideas are more likely to be innovative	Week's et al., (1995), Beckford, (1998), Evans & Lindsay, (2002)
Teamwork	Teamwork is a critical factor for TQM where employee skills are combined to create synergism to respond to opportunities or solve organisational problems	Week's et al., (1995), Beckford, (1998), Marquis & Huston, (2000), Evans & Lindsay, (2002)

Table 2.15. Summary of key employee-characteristics for organisations planning to introduce total quality management (Weeks et al 1995).

As can be seen from table 2.15, all seven characteristics are grounded in the part employees should have within the organisation; their sphere of influence, scope of responsibility and level of involvement in the organisation. Similar characteristics for the role and involvement of employees are also identified in the area of nursing management (Marquis & Huston, 2000) and in management for service quality (Beckford, 1998, Evans & Lindsay, 2002). While a great many criteria or factors have been identified as variables necessary for managing quality, several of these are repeatedly discussed in the service quality literature. As these criteria or factors have particular relevance and application to the area of high contact human services like disability care, they require further discussion.

2.4.2 Mission and Vision

Central to any organisations readiness for managing quality is that senior management must agree or reaffirm the mission and vision of the organisation (Evans & Lindsay 2002). The mission of an organisation defines the reason for its existence and asks the question ‘Why are we in business?’ Greengarten-Jackson et al., (1996, p.59) say that a mission statement reveals the current reason for the existence of an organisation and is developed by top management on the basis of the stated vision. Mission is related to the bottom line for the organisation and is important for corporate strategy, culture, the integration of employees and the performance outcomes of the organisation. However, according to Asher (1991), if the mission statement is to be useful and drive the quality improvement process it should be reviewed annually.

In contrast to the mission, the vision of an organisation describes where the organisation is going in the future. Greengarten-Jackson et al., (1996, p. 59) define an organisation’s vision as:

“ A statement developed by top management to define the organisation’s future state, it is a dream – the overarching purpose of an organisation and the means it intends to use to achieve that end.”

2.4.3 Employees’ Participation and the Service Encounter

The interaction between a service provider and a customer is the service encounter.

Gutek et al., (1999) distinguish between service encounters and service relationships.

An encounter occurs when a customer interacts with a different provider each time. A relationship occurs when a customer has repeated contact with the same provider.

Cook et al., (2002) view service encounters as a triad with the consumer (client) and the service provider (nurse) exercising control over the service process, which takes place within an environment that is defined by the service organisation. For a positive service encounter, it is mutually beneficial for the three parties to work together.

Morrison & Rahim (1993) have discussed the implications for participation and involvement of employees in quality management. They view such involvement as a central variable for successful quality programmes. Participation is widely accepted as a management strategy with many writers emphasising employee involvement as a critical factor at both individual and collective levels (Crosby, 1979, Juran, 1988, Deming, 1986, Guimaraes, 1997, Evans & Lindsay, 2002). The quality gurus dictate it, empirical evidence supports it, and of most importance according to Morrison & Rahim, organisational experience demonstrates it.

Related to the TQM literature and employee participation is commitment and empowerment. Both are seen as necessary for motivating employees and getting them to commit to quality. Gardner & Carlopio (1996) point out that at its most basic level, empowerment means giving employees authority to make decisions based on what they feel is right, to have control over their work, to take risks, learn from mistakes

and, to bring about change. These writers see all managers as having a responsibility for empowering employees.

Morris et al., (1992) make the point that claims of high commitment leading to lower labour turnover, improved quality, employee flexibility and innovation are usually accepted uncritically. They point out one reason for this is that most claims are not tested empirically and those studies that have been carried out have been once-off cross-sectional studies. They demonstrate correlations between work practices and organisational policies and employee commitment at particular points in time and their impact over time are not well monitored. The empirical research of these writers was conducted over five years. They identified factors seen as important for commitment. In summary, Morris et al., (1992) found that:

1. Human resource policies influence organisational commitment (as compared to those employees who stayed with their organisation and those who left to work elsewhere)
2. Human resource policies had a differential impact over time on commitment
3. Intentions to stay and attitudinal commitment were influenced by different human resource policies.
4. The most important factor influencing commitment after five years in the organisation was career prospects (Morris et al 1992).

From this, one can only wonder about the level of commitment of nurses in long stay institutional type residential services with little autonomy in their work and limited prospects for career advancement. Many writers consider empowerment of employees as a critical factor for quality programmes (Evans & Lindsay, 2002, Goodale et al., 1997, Kondo, 1997). It is a form of intrinsic task motivation and for TQM may be viewed as a relational concept to participation and commitment.

Goodale et al., (1997) refers to empowerment as a perception of the employee that comes largely from the support they receive from the organisation. These writers point out that managers will behave differently with individual employees based on their judgement of how employees can behave on behalf of the organisation. This, they say, will be important for identifying perceptual links between empowerment variables for individuals and the service quality they are able to deliver to customers.

From another perspective, Kondo (1997) in looking at quality as a human and personal activity viewed worker empowerment as creativity. Kondo emphasises the need for a strong sense of responsibility in the worker if the work aims are to be achieved. This requires that two conditions be fulfilled:

1. The aims of the work must be clearly stated
2. Workers must be given as much freedom in the means and methods through which they can achieve the aims.

Pietenpol & Gitlow (1996) advanced a method to move from an unempowered environment to an empowered environment that is consistent with Deming's (1994) theory of management. This method is advanced at two levels. Level one involves the employee developing and documenting best practice through a cycle of activities involving: *standardising* (a process/activity), *doing* (implementing a process), *studying* (monitoring) and *acting* (evaluating/responding). This SDSA cycle is built on in level two by facilitating the employee to improve best practice. This cycle is similar to the nursing process cycle of assessment, problem/need identification, planning, implementation and evaluation that empowers both the nurse and the client.

Wilkinson & Willmott (1996) adopt a critical perspective on the contemporary thinking on quality and the employees' position within the organisation. They point

out that while many organisations have quality initiatives in place, much of the theory and philosophical positions of the quality gurus are taken on board uncritically - a point this writer has already raised. On commitment, participation and empowerment of employees, they point to the current hierarchical relationship between employees and management. Since management are the owners and employees the workers, they suggest that exhortations for employee involvement are means of exerting control. Wilkinson & Willmott acknowledge the importance of worker involvement but say empowerment and participation will prompt questions about the extent to which employees are treated and rewarded as full members of the organisational team. Participation they suggest raises questions concerning opportunities for employees to contribute to key decision-making and their exercise of control over their work.

2.4.4 Teams & Teamwork

Participation of employees at the level of individual involvement is clearly important. However, most writers on the subject of quality see more benefits accruing from employees working as teams (Maslow, 1954, Deming, 1986, Thiagarajan & Zairi, 1997, Beckford, 1998, Evans & Lindsay, 2002). Teams and teamwork form an essential approach to working in human services and are well established in intellectual disability care where they form part of the fundamental processes for care provision for clients (NAMH1, 1999).

Thiagarajan & Zairi (1997) refer to two types of formal team. First is the natural or functional team and second is the cross-functional team. Table 2.16 summarises the functions and membership of the two types.

Team Type	Functions	Membership	Scope
Functional	Discuss/review specific/local work-related problems	Departmental level employees from a particular area	Limited to problem solving in a local area
Cross-Functional	Discuss/review issues across departments	Inter-departmental staff/ professional disciplines within the organisation	Unlimited insofar as it can engage in organisational problem solving

Table 2.16. Summary of functions, membership and scope of team-types (Thiagarajan & Zaire, 1997)

Functional teams are localised and involve themselves in work related problem-solving activities, for example quality circles. Membership of this type of team comes from the employees in a particular area who have unique and common problems to resolve. This type of team, according to Thiagarajan & Zairi (1997), is limited in scope inasmuch as it does not see the wider all-organisational picture. These writers argue that if functional teams are the only types of team, they may possibly bring about resistance to an all-departmental integration and might compromise the creation of a quality culture in the organisation.

Cross-functional or inter-departmental teams unlike the functional team, have their members drawn from different areas or professional groupings in the organisation. Cross-functional teams according to Price & Chen (1993) can address wider issues affecting the organisation. They can also flatten the pyramid structure of organisational decision-making and remove departmental boundaries that can act as barriers to managing quality.

2.4.5 Training and Education

Ishikawa (1985) says quality begins and ends with training and both are linked to motivation, participation and empowerment of employees (Oakland, 1993, Porter & Parker, 1993, Thiagarajan & Zairi, 1997). According to Thiagarajan & Zairi, it is

critical for training and education to be explicitly linked to the implementation of any organisation's quality improvement programmes to have maximum effect.

Oakland (1993), takes the view that after commitment, training and education is the most important factor for quality improvement programmes. He sees training as necessary for employees, management and the organisation. Thiagarajan & Zairi (1997) agree with this but go further by insisting that in addition to training employees to do their jobs, they need training in quality awareness, leadership, problem-solving skills and interactive skills. Intellectual disability nurses receive training for their job of caring but it is less clear if they receive training in any of these areas. Thiagarajan & Zaire suggest a cascading approach where senior managers are trained first; they then train middle managers and then train frontline workers.

Approaches to training differ but according to Porter & Parker (1993) training for managers with their subordinates creates teamwork and avoids the label that quality management is for managers only. From a survey of training in organisations, Porter & Parker identified common characteristics between the organisations in their study:

- Organisations viewed training as a continuous process.
- Organisations used a focus approach with a level of detail to match the particular needs of workers and managers.
- Organisations planned for future training needs and for future skill development of workers and managers.
- Organisations developed and utilised training materials that were customised for their particular needs.

Finally, the European Society for Quality in Healthcare (1999) identified the need to gather data on the extent to which professionals receive educational preparation on quality matters during their training.

In their preliminary survey of educational and training colleges, information is being collected on whether, and to what extent, formal modules on quality form part of training.

2.4.6 Summary Evaluation of Participation Teamwork and Education

The sense to which employees feel involved in their organisation is clearly important as their perceived level of participation is linked to their commitment and motivation. Education and training is seen as necessary and as something that should be ongoing. One possible means of motivating employees, getting their commitment and facilitating their ongoing education is through the use of teams and teamwork. While the importance of teamwork in intellectual disability services is discussed in chapter four, it is useful to make the point here that since no single professional group has a monopoly on caring for clients; service provision is founded on teamwork.

2.4.7 Frameworks for Quality in Health Care

There are several frameworks for conceptualising and operationalising quality management in the healthcare arena. In this section four frameworks are reviewed.

1. Ovretveit (1992,1997) in his 'quality approach' bases his framework on what he describes as the three dimensions of health service quality and the relationships between them. These are theoretical dimensions and are not empirically based. Rather, Ovretveit advances these as indicative of the major interest groups and from whose perspectives the quality of a particular service can be specified. The dimensions are summarised in table 2.17.

Dimension of Health Service Quality	Characteristics
Client Quality	What clients and their carers need and want from a service
Professional Quality	Extent to which the service meets the needs and wants of clients as defined by professionals and extent to which they perform processes and procedures to meet the needs and wants of clients
Management Quality	The extent to which management employs the most efficient and productive use of resources to meet the needs and wants of clients within the limits set by higher authorities

Table 2.17. Summary of three dimensions of health care service quality (Ovretveit 1992, p.4).

Ovretveit's 'quality approach' involves having a system in place (quality assurance or total quality management) with service standards, monitoring/auditing of standards and outcome measurement based on these standards. Ovretveit's approach is based on the structure, process and outcome framework developed for health care by Donabedian (1961). For Ovretveit, a necessary requirement for the success and continued use of a sustained quality approach is the application of business strategy and the use of a quality management cycle. Ovretveit (1992, 1997) emphasises a management infrastructure for a quality approach, the presence of key quality features for the organisation, the importance of management leadership and the importance of staff being involved.

2. Maxwell (1984, 1992) in his quality approach also relies on standards based on the structure, process and outcome framework of Donabedian (1961). Maxwell's dimensions are based on what he considers the six important dimensions for health care quality. As with Ovretveit's (1992, 1997) quality approach, Maxwell's six dimensions are theoretical. Both Ovretveit's quality approach and Maxwell's six

dimensions of health care quality are based on health services being responsive to the needs of clients, are available on request and which fulfil their expectations.

Maxwell's six dimensions for health care quality are:

1. **Effective**-treatment and care provided which is technically the best, which is based on sound evidence, and with clear, specified outcomes.
2. **Acceptable**-treatment and care provided with consideration of the clients' needs and dignity, in pleasant settings and with regards to privacy and confidentiality.
3. **Efficient**-treatment and care provided with the output maximised for a given input or, conversely, the input minimised for a given level of output.
4. **Accessible**-treatment and care provided as and when required by clients and without barriers, for example, inability to pay, long waiting lists or waiting times.
5. **Equitable**-treatment and care provided in a fair manner and without discrimination.
6. **Relevant**-treatment and care provided with a balance of services taking account of the population as a whole.

Both Ovretveit and Maxwell see the uniqueness of health care services as being customised to the needs and wants of clients where the client is part of the service encounter and involved in the consumption and evaluation of the care and service. Neither Ovretveit's or Maxwell's approaches to quality constitute conceptual models. They are frameworks useful for developing quality management approaches for patient/client care.

3. Donabedian (1966, 1986) developed his framework, which is widely used in healthcare and disability services. This framework consists of three interrelated components: structure, process and outcome. A considerable literature exists on this framework in nursing services (Masso, 1989, Kitson, 1990, Koch, 1992, Stiles and Mick, 1994, Sainfort et al., 1995, Boyce, 1996, Attree, 1996, Sale, 2000). Each of the

three components are intricately related and influence each other. They are concepts for understanding, planning and evaluating care.

Structure is explained by Kitson (1990) as management systems, staff, skill mix and the physical properties of the organisation. Structure refers to the rules that govern how the service is provided. Donabedian (1989) expresses the view that while good structure is probably the most important means of protecting and promoting quality of care, it is relatively unimportant in the assessment because this is usually done based on processes and outcomes and the relationships between these two components.

Process encompasses all the activities provided by the service (Katz & Green, 1992). Assessing quality through process elements means looking at the performance of the nurse in relation to the patient's needs.

Outcome refers to the end result of a service intervention. Outcomes may be professional or service-centred such as clinical outcomes that are defined by Parsley & Corrigan (1999 p.173) as the 'cumulative effect of one or more processes on a patient at a defined point in time.' They may also be personal or client-centred outcomes like the personal outcome measures developed by Chapman (1997). Figure 2.3 summarises the relationship between structure, process and outcome.

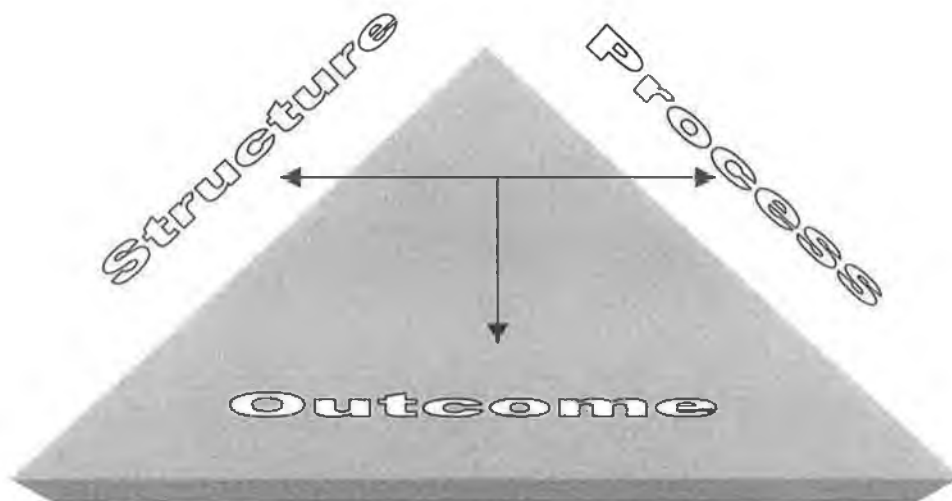


Figure 2.3. Summary of relationship between the three components of structure, process and outcome (adapted from Parsley & Corrigan, 1999, pp. 47-52).

Boyce (1996) argues for using structure and process measures at the same time as outcome measures. The writer suggests that outcome measures have explicit objectives that will determine the framework for measurement and identifies a number of problems if outcomes are used alone:

1. Certain outcomes might be so infrequent and so provide little statistical power for comparison analyses.
2. Analysing outcomes may fail to inform clinical practice and contribute to quality improvement if they have been used alone. In this sense, outcomes provide information on how well something worked not why it worked.
3. Some outcomes may occur long after intervention and this can mean difficulty in professional consensus as to the optimal time for outcome measurement.
4. Health care users wish to know at the time of service delivery, that the means of providing a service maximises their chances of favourable outcomes. In short, health care users are concerned about structure and process aspects of care, not just the probable outcomes of care (p.103).

According to Boyce (1996), using measures of structure and process in conjunction with outcomes will reduce these problems and optimise more favourable outcomes.

Parsley & Corrigan (1999) see the combined effect of structures and processes

working together to bring about outcome but Boyce (1996) warns that it may be difficult to prove a link between structure and process attributes and outcomes of care. A similar view was expressed by Renwick (1992) who suggested the reason that outcome provides only an indirect measure of quality is because it is impossible to prove that the care provided (processes), and facilities/resources (structures), were responsible for all or part of improvement (outcome).

Few published studies exist on the relationship between nursing processes and patient care outcomes. Sainfort et al., (1995) undertook a review of 24 nursing-facility quality models, all of which are based on Donabedian's (1966) structure-process-outcome framework. From their review, they failed to find one study or model where a causal analysis was undertaken to provide linkages between indicators or measures of the quality dimensions. Donabedian (1980) has said that when a causal relationship is established between process and outcome, then either may be used to make inferences whereas when no causal relationship has been established neither can be used to assess quality.

Lee et al., (1999) point out that the structure of nursing care has been studied quite thoroughly but specific nursing processes that impact on patient outcomes has been studied less often. In a review of the nursing quality literature they identified some 3,700 articles out of which only 17 were selected as meeting the inclusion criteria of process related to outcome. Only data based studies were chosen for review and the authors identified a number of gaps in the research concerning the processes of nursing assessment, problem identification and patient management.

4. Stiles & Mick (1994) reviewed the relationship between the structure-process-outcome dimensions of Donabedian's framework and considered process as the most complex due to the multiplicity of elements involved. They suggested the concept of "equifinality" where many paths and procedures may lead to a common conclusion. Stiles & Mick present a framework based on a typology of quality dimensions with considerable influence from Donabedian's (1980) model of care. Their framework is presented as a matrix with *structure-process-outcome* dimensions located on the horizontal axis. Three other dimensions: *technical*, *interpersonal*, and *amenities* are located on the vertical axis. *Technical* refers to the abilities/expertise of staff and would seem to correspond to the Nordic school's technical dimension and to the tangibles/reliability dimensions of the North American SERVQUAL Scale. *Interpersonal and amenities* refer to staff/customer relationships and to the facilities/pleasantness of the service surroundings respectively and would seem to correspond to the Nordic school's functional dimension and to the intangible dimensions of responsiveness, assurance and empathy of the North American SERVQUAL Scale.

Table 2.18 shows the framework for the typology. While this framework facilitates description it clearly emphasises a service-led approach to quality. Nonetheless it would appear to be useful for health care and general services quality and especially in the areas of thinking, planning and identifying quality attributes. However, given the complexity of intellectual disability services quality and the concern with needs-led services and quality of life, it would be likely to have only a limited application in this area.

	Structure	Process	Outcome
Technical			
Interpersonal			
Amenities			

Table 2.18. Summary of a Typology of Quality Dimensions (Stiles & Mick, 1994 p. 313).

2.4.8 Summary Evaluation of Frameworks for Quality in Health Care

If organisational quality initiatives are to have any practical use they must be framed in such a way that they can be understood, communicated and operationalised. The previous section summarised four frameworks specific to health care quality. While each framework is different, all were developed for application to health care and there are similarities and connecting threads between them. Each constitutes a framework as against a conceptual model and all are theoretically based. The frameworks appear connected on two levels.

First is that each consists of dimensions/components that seem to be grounded in the dimensions/components discussed in section 2.3.2 above since they incorporate both the technical (tangible) as well as the functional (intangible) dimensions of service quality. These observations are not just a matter of semantics but demonstrate at a practical level how concepts from the general service quality are applied to health care.

Second, is that all four frameworks are based on standards grounded in a structure, process and outcome. Such an approach recognises the inter-relationship between processes, structures and outcomes and in particular, the significance of structures and processes for outcomes.

Each of the four frameworks contributes to the present study by providing an understanding and an explanation of general dimensions/components for quality. However, given the complexity of intellectual disability services with its concern for a needs-based service and with quality of life as a personal outcome, none of these four frameworks are sufficiently comprehensive as to capture all the dimensions or components of service quality in this area.

2.5 Conclusion

This chapter reviewed issues emanating from the general service quality literature. This was necessary for two reasons. First was to provide insight and understanding about quality and quality management generally. Second was to provide a foundation for understanding quality in intellectual disability services since many of the issues and concerns in this area stems from concerns grounded in the area of general service quality. What has emerged for this study is a clarification of important conceptual, operational and organisational issues for service quality, which can now be used as a foundation for reviewing and discussing the specific issues relating to service quality in the intellectual disability arena.

Conclusions to the review can be centred on the three broad areas of literature looked at: conceptual, dimensions/components of quality and organisational management issues. These areas are summarised below.

Conceptual and theoretical issues have centred on the meaning and purpose of quality. Quality is not a product-thing but is an attribute of a product or service. While several definitions have been advanced for service quality, it is generally agreed that the most appropriate one is 'meeting and/or exceeding customers expectations.

Conclusion from this definition put the customer first and are centred on the requirement for organisations to have a customer-driven or a needs based approach to service delivery. In general, it is a useful definition for people with intellectual disabilities particularly when one considers that the majority live within the community where most utilise generic services like non-disabled people. However, as mentioned above, many people with severe/profound intellectual disabilities may not be aware of their expectations or be limited in how to communicate them to anyone. Also, in the intellectual disability arena generally, writers on the subject seem to attach little meaning to the concept of quality except in relation to quality of life. While an expectations definition of quality might be appropriate for many people with intellectual disabilities it will have limitations in being able to address the complex concepts and issues of quality of life. Also, for most people with severe and profound disabilities, it may be unrealistic to consider clients will have the cognitive ability to be able to express personal expectations from the service.

Dimensions/components of service quality are complex and multiple but there is general agreement among writers that there is both a tangible or objective dimension and an intangible or subjective dimension and both must be considered in practice.

Conclusions here are that service quality is more than the product-element of a service (objective component), it is also about how the consumer perceives the service is performed, and the extent to which it meets their expectations and their needs.

Attitude and satisfaction of consumers, be they patients or clients, are seen as the consumer's 'feelings' about a specific service encounter or the consumer's reaction to salient aspects of the context, process and outcomes of a service encounter.

Satisfaction is seen as a type of evaluation that is multidimensional and complex and while it is generally agreed that it is a necessary component of service quality, it is viewed as an indicator of quality and not a measure of quality.

Organisational management issues have centred on the level of quality in the organisation, the management of quality and, its measurement. Quality management and in particular, total quality management, is seen in the literature as the highest level of quality and as an approach that involves the organisation and everyone in it. Quality management requires that critical factors be in place if organisations are to be successful in introducing and maintaining service quality. Many of these factors have to do with management leadership and commitment to quality, but many more have to do with the role and involvement of employees in service delivery and with having a continuous consumer-focus.

Conclusions drawn from this emphasise the importance of management planning, and leadership in the organisation. They also stress organisational readiness for quality management; in particular, ensuring employees have some level of influence. Lastly, a number of distinct but related employee-management issues were discussed.

The triad of the service encounter, employee participation and involvement, especially in decision-making, is seen as critical if employees are to commit to quality and this is repeatedly stated in the literature. Teams and teamwork is seen as important for collective problem solving at both local and organisational levels as well as a means of facilitating employees working together.

Training and education is seen as central to quality improvement programmes and is necessary for employees, management and the organisation. Training and education is linked to motivation, participation and empowerment of employees.

Conclusions drawn from this is that management and employee collaboration is of central importance. Whereas management is at the head and ultimately responsible for the quality of its service, it is the employees who are at the heart of the organisation since they provide the service encounter. Thus the operation of service quality requires that employees participate in the organisation and share in decision-making. To enhance the service encounter and maximise employees' sense of involvement, ongoing education or training will be required for all employees as well as opportunities for them to participate in teamwork.

CHAPTER THREE

QUALITY IN INTELLECTUAL DISABILITY SERVICES

3.1 Introduction

In contemporary services for people with intellectual disability, quality is seen as an essential ingredient of service delivery (National Association for the Mentally Handicapped of Ireland 1999, Department of Health White Paper on Intellectual Disability 2001, National Disability Authority 2003). While many of the important but general issues for understanding and implementing quality were discussed in the preceding chapter, this chapter reviews issues relating to service quality in intellectual disability. In particular, the philosophical rhetoric of services, service ideologies, quality of life as outcomes of service provision and, the purpose of quality in intellectual disability services generally. Also reviewed here is the role of the nurse in services as this is the group of professionals with which this study is concerned.

The aim in reviewing the literature in these areas is twofold: one, to provide a foundation for understanding the complexity of quality in the area and two, to locate the present study in intellectual disability services. Chapter four will review approaches to quality care in residential centres. It will also review literature dealing with other important variables for the service encounter, in particular, the involvement of service users and their families. Figure 3.1 is a map that traces the theoretical and research literature reviewed in this chapter. Quality and service evaluation for people with an intellectual disability is complex. Similarities exist between other high contact services like acute nursing services where the patient perceives quality at the level of personal and customised care. Intellectual disability care however, moves beyond this level of short-term illness model of care, to a level of care that is usually for life (Wake, 2003).

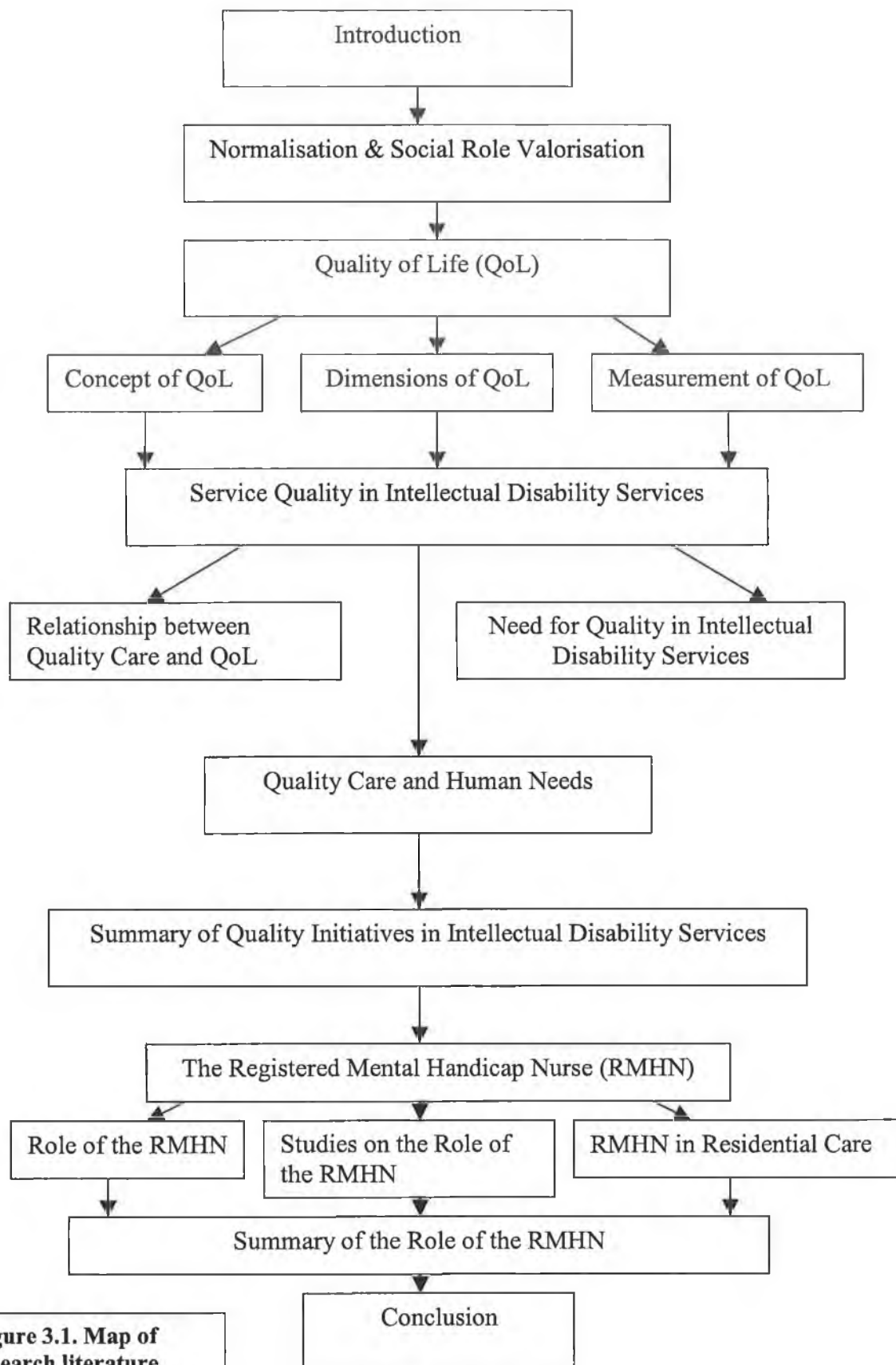


Figure 3.1. Map of research literature reviewed on quality in intellectual disability services

Unlike the illness-related model of nursing/health care that is often referred to as the medical model (Mercer 1992, McKenna 1997), the rhetoric on service provision in intellectual disability endorses a social-developmental approach to care (Felce & Perry 1995, Wolfensberger 2000). To a large extent this model is grounded in the principles of normalisation and social role valorisation.

3.2. Normalisation and Social Role Valorisation

Normalisation as a concept was developed and articulated by Nirje (1969) and has become one of the most widely used concepts and a major influence on service developments for people with an intellectual disability worldwide. Nirje (1969) sees the normalisation principle as making available to all persons with an intellectual disability, patterns of life and conditions of everyday living that are as close as possible to the regular circumstances and ways of life in society. Bank-Mikkelsen (1976) views normalisation as meaning the acceptance of people, with their disability, offering them the same conditions as are offered to other citizens, inclusive of treatment, education and training needed to provide for optimal development.

Seed & Lloyd (1997) interprets normalisation as reflecting a stage in the development of the movement to break down the boundaries between the “normal” and those perceived as “defective” in special schools, long-stay hospitals and sheltered work. Normalisation he argues is about challenging and changing institutions, attitudes and terminology and the concept required and foreshadowed care in the community. Wolfensberger (1972, 1980, 2000), one of the most prolific writers on normalisation later developed the term to incorporate “social role valorisation” which refers to developing and facilitating socially valued roles for people with disabilities.

Implicit in the principle of normalisation is the belief that people with intellectual disabilities are entitled to the same rights and opportunities as are available to others in their society, including opportunities to exercise personal preferences and freedom of choice. According to Craft (1985), it is normalisation as a philosophy and goal, and multidisciplinary teamwork as the process for pursuing that goal, that are the two most appropriate approaches to care for people with intellectual disabilities.

However, Brown & Smith (1992) have argued that conceptualisations of normalisation have denied women with intellectual disabilities knowledge of feminism and have tied them into conventional and frequently subordinate roles. Their criticism extends to a rejection of normalisation, which they see as having done nothing to eradicate and may even sometimes facilitate racism, heterosexism and sexism. Ramcharan et al (1997) add a further criticism, which is that normalisation implies that disabled people are not normal and the value placed by normalisation on relationships with people who are not disabled only serves to devalue disabled people. Proponents of normalisation have responded to these criticisms and fears by suggesting they are due to misunderstanding and confusion about the concept. Wolfensberger (1983, 2000) and Flynn & Lemay (1999) for example, repeatedly reiterate that the principle of normalisation applies to the services provided for the individual and is not meant as a description of the individual himself or herself.

Social Role Valorisation (SRV), a concept developed by Wolfensberger in the mid 1980s, is both a development of, and replacement for, normalisation. Wolfensberger (2000) explains SRV as a systematic schema based on social role theory with the key premise being that people's welfare, is to a very great extent, dependent on the social

roles they occupy and the value people attach to these social roles. The terms valorising and valorisation refer to the adding of value to something such as an activity or a role occupied by someone and in SRV it is the valorisation of social roles that is at issue. Wolfensberger (2000) provides an overview of SRV and discusses how the schema can be used for designing practical measures for upgrading the perceived value of the roles persons with intellectual disability have and/or extricating persons with intellectual disability from devalued roles.

These writers all enrich the debate concerning the status of people with disabilities. Differences in the meaning and purpose each attaches to normalisation and social role valorisation seems to be related to the emphasis each places on the conceptualisation of the philosophies as they are applied and responded to by services and society. The introduction of the normalisation and social role valorisation philosophies has meant not just a new way of conceptualising and perceiving people with disabilities nor simply a means of modernising services for people but the emergence of a new world view of people with disabilities – a paradigm shift.

However, it seems to this writer that despite being about adding value to what people with disabilities do in their lives, SRV like normalisation, places responsibility with service providers for planning, designing and evaluating how people live their lives. As such they are more in keeping with service-led approaches to care. In contrast to this, contemporary services now place quality care at the level of the individual by adopting a person-centred approach (Sanderson 2003) that has as its overall aim the recognition and enhancement of the person's quality of life.

3.3. Quality of Life

The concepts of normalisation and social role valorisation have, to a large extent, been superseded by a concern for quality of life (QoL) for people with intellectual disability. As Hatton (1997) says, quality of life as if by stealth, has crept up to take the place of normalisation. Seed & Lloyd (1997) suggests that QoL studies have an appeal and utilitarian benefit because they make comparative studies with non-disabled people easier. These writers see QoL as overtaking normalisation as a yardstick for progress in the lives of people with intellectual disabilities.

Brown (1996) suggests that rather than arguing about whether QoL has replaced normalisation, that QoL is a step beyond normalisation. This, of course, is not to suggest that normalisation is no longer a significant concept for how care is defined but rather that developments in care are firmly centred on the individual's lifestyle and his or her satisfaction with that lifestyle. Seed & Lloyd (1997) see social role valorisation as meaning valuing people no matter how disabled, for what they can contribute to the lives of others. They see this as approximating reciprocal relationships, a QoL value that refers to the extent to which there is inter-dependence between people as against dependence on carers or services. It is important to point out here that all humans have value because they are human beings and not because they have capacity or incapacity (United Nations Declaration of Rights of Disabled Persons 1975)

At this juncture it is important to make clear the relevance of discussing quality of life. Many writers see the enhancement of the person's quality of life as an important outcome of service delivery (Goode et al 1994, Felce & Perry 1995, Cummins 1997, Rapley 2003). Some writers go further than this and see the enhancement of quality of

life as the only worthwhile and measurable outcome of service quality (Gardner 1997). Northway and Jenkins (2003) view the concept as important for developing intellectual disability nursing practice because it can act as a sensitising concept for team development and collaborative care planning. In their theoretical paper, Northway & Jenkins argue the benefits of nurses integrating quality of life into their scope of practice, which they can then use as a framework for evaluating nursing care. This writer endorses this view, as nurses are responsible for the quality of their care. Dickens (1990) adds a further endorsement for nurses integrating quality of life into their practice. In his earlier theoretical paper on quality care, Dickens (1990) explained that if enhancement of quality of life for the person is the expected outcome of service provision, then good service quality and quality care is the means of achieving this outcome. In this sense, quality of life and quality care are related.

The term quality of life is neither new nor is it a concept unique to people with intellectual disability. QoL and its assessment first came into research fields during the early 1960s and health-related QoL assessments began a decade later (Flanagan 1982). Interest in QoL began during the 1940s following the WHO definition of health as “a state of complete physical, mental and social well being and not merely the absence of a disease” (World Health Organisation 1948). Health-related QoL has been defined as “the level of well being and satisfaction associated with events or conditions in a person’s life as influenced by disease, accidents or treatments” (Patrick & Erickson 1987). Such a definition addresses the degree of satisfaction from the performance of social roles and activities as well as functional ability of health.

From a search of electronic databases, this writer found a considerable literature on QoL for people with intellectual disability (Landesman 1986, Schalock 1993, Goode

et al 1994, Felce & Perry 1995, Rapley & Beyer 1996, 1997a, 1997b, Cummins 1997, McVilly & Rawlinson 1998, Rapley et al 1998, Brown 1999, Felce & Emerson 2000, Keith 2001). Few publications were found that dealt specifically with QoL and intellectual disability nursing (Sines 1995, Brown & Bramston 1996, Donnelly et al 1997 Barr et al 1999, Northway & Jenkins 2003). Most of the literature on QoL is theoretical and is grounded in attempts at conceptualising the construct and at developing means with which to measure it. For the most part, this literature is centred on three main concerns: 1. Conceptual and definitional issues

2. Dimensions of quality of life

3. Measurement of quality of life

3.3.1 Concept of Quality of Life

From a search of the literature, definitions of QoL appear both elusive (Felce & Perry 1995, Cummins 1997, Rapley 2003), and too numerous (Hughes et al 1995, Hatton 1998). In a review of literature spanning the fields of psychology, social integration and employment from 1970 to 1993, Hughes et al (1995) identified 44 distinct definitions of the concept. From their review, they developed a conceptual framework that resulted in a total of 15 dimensions and each of these included many components (interpersonal relationships, friendships, and social interaction). In a review of empirical studies that included adults with intellectual disability, which assessed at least one of the QoL components from their framework, Hughes et al (1995) identified 1,243 distinct measures that had been used to assess dimensions of QoL.

Zhan (1992) advances what she sees as a multidimensional and context-related definition as “ the degree to which a person’s life experiences are satisfying (p.796) ”

She points out that factors such as culture, environment, age, background and social situation all contribute to a person's perception of meaning and QoL. She also notes the number of related concepts identified in QoL research literature. Zhan observes that happiness and life satisfaction are frequently used interchangeably but sees this as misleading. Happiness is an affective state. Life satisfaction however, is a cognitive evaluation arrived at on the bases of a person's circumstances – a derivation from a comparison of a person's aspiration with their actual achievement.

Taylor & Bogdan (1990) see QoL as meaning satisfaction with one's lot in life. Goode (1990) defines QoL as opportunities to pursue and achieve goals while Keith (1990) believes QoL to mean empowerment, autonomy, personal satisfaction and independence. All these writers agree that evaluation of a person's QoL must recognise individual characteristics and nature endowment. Goode (1990) argues that QoL for persons with intellectual disabilities includes the same dimensions that are seen as important for non-disabled persons.

Goode believes that if QoL is to avoid being an exclusionary term then it must apply to everybody. However, in an earlier paper, Flanagan (1982) said that consideration would have to be given to the dimensions of QoL because of the limitations imposed on a person because of intellectual disability. Flanagan also pointed out that QoL comparisons should only be undertaken with homogenous groups bearing in mind such variables as age, health status and cognitive ability.

Brown et al (1989 p.111) define QoL as "the discrepancy between a person's achieved and unmet needs and desires" The writers report on a series of empirical studies over several years which examined behaviour from a QoL perspective. They identified a number of conditions that compromised the QoL of persons with

intellectual disabilities in their studies. Brown et al (1989) raise issues of concern and put forward suggestions for addressing them. These include ensuring that new staff and trainee professionals have their initial contact with clients in small “normal” home settings as against congregate settings. They also see staff and management training and in particular, staff support, as necessary for staff to be able to enhance the QoL of clients.

Landesman, (1986) in her theoretical paper, suggested that the need to attend to QoL issues is underscored by continuing controversies concerning public policy on deinstitutionalisation, community relocation, early intervention and mainstreaming. Landesman added that an undeniable goal of service agencies for individuals and families affected by intellectual disability is to enhance their QoL. She suggested that attention should be directed towards developing criteria for assessing outcomes of both intervention programmes and life experiences particularly in ways that recognise personal values, preferences and individual differences. In her paper she challenged the American Association for the Mentally Retarded to address the following issues:

- What does QoL mean?
- What does the concept encompass?
- How can the concepts QoL and personal life satisfaction be operationally defined?
- What strategies are likely to be effective in monitoring the QoL of individuals and groups?
- What sets of environmental variables are most likely to enhance the QoL for different types of individuals at different times in their lives?

Most writers agree that both objective and subjective elements are necessary and both must feature in measures of QoL and its evaluation (Felce & Perry 1995, Cummins 1997, Hatton 1998, Rapley 2003). In a critique of the concept of QoL, Cheung Chung

et al (1997) say that eight hundred dimensions of QoL have been identified in the literature and attempts have been made to measure them. In their theoretical paper, the authors examine QoL using some philosophical thoughts particularly from Wittgenstein (1889-1951). These writers cite Wittgenstein's philosophy, which states that even if a definition or measure of QoL could be agreed, we may be in no position to understand its metaphysical structure. From their philosophical analyses, Cheung Chung et al (1997) say that whether or not we understand the concept QoL depends on our knowing how to use words. So without recourse to empirical investigation, researchers already understand what QoL is because they discuss it in their daily lives and research writings.

The authors point out that both the concept and any measures of it are arbitrary and researchers in health care should remain critical of it. They conclude that from such critical appraisal will come new insights but not perfect understanding. Through critical attitudes researchers will arrive at better ways of understanding and using concepts, which is necessary for research developments.

3.3.2 Dimensions of Quality of Life

Perry & Felce (1995, p.60) define QoL as "an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values". They see QoL as the interaction between the circumstances or mode of a person's life, their satisfaction with its various facets and their personal goals and values. From their definition, they point to how researchers have operationalised sub-dimensions such as homelife, work,

material well-being, health, development, choice, activity and emotional well being as dimensions that contribute to overall quality.

In a theoretical paper by Borthwick-Duffy (1992), she presents three perspectives on QoL:

1. QoL as the quality of one's life conditions.
2. QoL defined as one's satisfaction with life conditions.
3. QoL defined as a combination of both life conditions and satisfaction with these.

Felce & Perry (1995) agree the usefulness of the Borthwick-Duffy's third perspective but add a fourth. They define QoL as a combination of life conditions and satisfaction plus weighting by scale of importance to the individual.

Cummins (1997) sees QoL consisting of objective and subjective assessment across all life dimensions. How the subjective assessments on separate life dimensions are measured to produce an overall assessment should take account of the importance the individual places on any particular dimension. Similarly, the importance attached to objective life conditions according to Felce & Perry (1995) should also take account of the individual's' scale of values. In short, the significance of either objective or subjective appraisal of any particular dimension should be interpreted only in relation to the importance the individual places on it.

From a review of 15 key literature sources on conceptual models or implementation studies for QoL, Felce & Perry (1995, p.p. 60-62) identify five main dimensions of the construct. These are listed in table 3.1 below.

Physical well being	Material well being	Social well being
Development and activity	Emotional well being	

Table 3.1. List of 5 main dimensions of Quality of life (Felce & Perry (1995))

Based on considerable agreement that QoL is multidimensional, they categorised QoL into these five dimensions. Felce & Perry cite the origin for their categorisation as based on their extensive review of theoretical and empirical (implementation) studies. These dimensions were chosen as they reflected the areas that were repeatedly singled out in the literature and on which there was most agreement. Based on this, their categorisation is theoretical. It forms part of a model that allows for subjective and objective indicators of QoL and for comparisons to be made between different groups. Felce & Perry (1995) argue that the dimensions are distinct, discriminate between the different components of the QoL construct, and are reported in the literature as among the most frequently measured dimensions.

3.3.3 Measurement of Quality of Life

According to Schalock (1996), measurement of quality of life should adopt a multi-methodological perspective. Two important sources of information relating to QoL measurement have come from Raynes (1988) and Cummins (1997). The Annotated Directory of Measures of Environmental Quality (Raynes 1988) is somewhat dated but measures reviewed are in use and many have been revised. This Directory is not exclusively about measures of QoL and includes instruments useful for monitoring and evaluating quality of service. Over 60 measures are reviewed for their purpose, content, administrative and scientific credibility. References sources are provided on each measure reviewed.

The second source is the Bibliography of Quality of Life & Cognate Areas of Study (Cummins 1997). This publication takes a broader approach. As a bibliographic source of information, several hundred references are provided on aspects and dimensions of QoL. Unlike Raynes' (1988) Annotated Directory, the bibliography is not exclusively about quality in intellectual disability, but covers general and health care literature on the subject. Though many references might appear dated all are useful and include important and seminal works on the subject.

Kelly & Walsh (1996) compared QoL for adults with intellectual disability in an institutional setting and in a community setting. Using two groups of 10 adults, they assessed QoL along three dimensions:

1. Level of adaptive functioning
2. Assessment of physical environment and normalised living practices.
3. Resident's satisfaction and personal and psychological well-being.

The researchers used a number of measures but reported no significant improvement in adaptive functioning in either group but residents in community homes were more satisfied with their lives, were more psychologically adjusted and the community environment provided a more normalised environment.

In a review of the literature in the UK for people with intellectual disabilities, Emerson & Hatton (1994) concluded that in many cases, living in a community-based house did not lead to integration or even participation in the life of the community. In many situations, according to Emerson & Hatton (1994), life in community houses was indistinguishable from life in the institution. Living in a community house is a necessary but not sufficient requirement for community participation. Emerson &

Hatton (1994) point to the need for opportunities. These must be identified by staff and creatively used for participation by staff and clients.

Rapley & Beyer (1995) in a small-scale study on daily activity, community participation and QoL examined the extent to which objective measures of service quality was enhanced by the inclusion of a subjective QoL measure. All participants in their study (14) had been former residents of a large residential service in Queensland, Australia. The researchers looked at four areas:

1. Ability levels
2. Involvement in initiating contact with staff.
3. Participation in community life.
4. Quality of life.

From their results, Rapley & Beyer (1995) report that for less able clients, domestic engagement ranged from low to non-existent. Friendships were low and contact with the local community was infrequent with all clients participating in segregated activities organised specifically for people with intellectual disabilities. They also found that staff were in contact with residents for about a third of the observed time and the nature of interactions were not focused on assisting or encouraging clients to become involved in activity. The direct measure of QoL (Schalock & Keith 1993) was seen as very useful. It demonstrated the central role that people's social lives have in determining key dimensions of QoL to the extent for example, that having and meeting friends was correlated with higher QoL scores.

Hughes et al (1996) compared QoL for people with intellectual disabilities and people who were unemployed or retired. Using a sample of 85 adults with intellectual disability and 62 unemployed/retired people matched for age range and sex, the

researchers used the Life Experiences Checklist (LEC) developed by Ager (1990). The LEC was administered to the sample with intellectual disability by staff in community houses, and to the unemployed/retired sample by the researchers. Results on the 10 items in each of the 5 domains (home, leisure, freedom, opportunities, and relationships) showed that those with learning disability scored as well as the unemployed/retired sample. An exception here was in the domain of relationships where the sample with intellectual disability scored less well.

Janssen et al (1999) report on how they developed an instrument for measuring QoL for use in care facilities in Holland. Their study was a comparison between QoL of people living inside residential care facilities and those living in the community. Both groups had either moderate or mild intellectual disability. From a review of the theoretical literature the authors developed a 4-dimensional model of QoL, which looked at:

- 1 A combined approach of objective and subjective perspectives.
- 2 Domains of life i.e. physical well being, and sub-domains i.e. health.
- 3.Goals of life i.e. development, integration, safety.
- 4.Norms in life i.e. personalisation and normalisation.

The “objective” or outsiders version of the instrument has to be answered by the personal carer of the person with intellectual disability and consists of 17 scales. The “subjective” counterpart has to be answered by the person with the intellectual disability, but if unable to do so, their parents/relatives can answer for them. This version consists of 20 scales. Janssen et al (1999) discuss the reliability and validity of the instrument and the high internal consistencies for the scales. Having employed the two parallel versions of the instrument, the authors found the QoL of residents living

in the community to be significantly higher than for those living in residential facilities. They conclude that living in the community is likely to force carers to provide freedom, training and opportunities for integration.

Cummins (1997) has analysed 13 scales that measure QoL with particular reference to their scope and psychometric properties. He argues that a good QoL scale should contain the following criteria:

- Objective and subjective dimensions of QoL should be measured
- Each dimension should be measured through a number of life domains and these domains in aggregate should represent the total QoL construct.
- Measures of domain satisfaction should be weighted by the importance of each domain to the individual.
- Instruments used should have adequate reliability, validity and sensitivity.
- Scales should be equally applicable to non-disabled people thus ensuring normative comparisons of life quality.
- Response mode and choice of answers should reflect psychometric theory and strike a balance between reliability and sensitivity.
- Scales or instruments should be brief, simple to administer and easy to score.
- A pre-test should be used to establish that respondents could comprehend the questions (p. 201).

Based on the above criteria, Cummins (1997) found only two scales that had been sufficiently well developed for use. One was the Quality of Life Questionnaire (QoL.Q. Schalock & Keith 1993) and the other was the Comprehensive Quality of Life Scale (Cummins 1993).

Seed & Lloyd (1997) in discussing a general framework for measuring QoL stress the importance of “connections” which they see as a recurring theme in QoL. They point out that since a deficiency in one dimension of QoL can affect all other dimensions

we should measure QoL with respect to these connections. These “connections” applying to the individual include family, neighbourhood and workplace. Connections are also made at a more macro level with one’s city, country and at an international level. Seed & Lloyd (1997) see more usefulness in connections between dimensions of QoL network than in attempting to define discreet dimensions. For example, they suggest that rather than focusing on “work” as a dimension, the important connections for this would include how work affects home life and vice-versa. They argue that QoL can be measured through values or by studying aspects of people’s lives from which values can be inferred. These writers also take the view that alternatives to scales and questionnaires for measurement of QoL can be used including structured discussions and personal diaries filled out by the person, or a personal carer on his/her behalf.

Finally, despite the importance of QoL, Hatton (1998) despairs about its measurement. He has suggested that because there are so many conceptual problems with QoL and no uniform definition of the construct, attempts to measure it should be abandoned. Hatton has criticised the measurement of QoL on the grounds of it marginalizing and discriminating against people with intellectual disability. He points out that people with intellectual disability are likely to have either poor or no communication skills. As subjective indicators of QoL are combined with objective indicators, comparisons of results from one person or service to another is not possible. In addition, he also points out that because of having poor communication skills, many people are unable to verbalise their views, feelings and preferences.

To summarise the issues surrounding the QoL debate, most of the established literature is theoretical and concerned with conceptual issues and the relationship between objective and subjective aspects of the construct. More recently empirical studies have centred on specific components of QoL, the connections between these and the extent to which a global measure of the construct can be developed. Bearing in mind these considerations, there is general agreement in the intellectual disability field that the enhancement of QoL is not just desirable but is a necessary outcome of service provision. As such, it has become firmly linked to quality care and quality of overall service. QoL can act as a sensitising concept useful for collaborative care planning and can provide a framework for evaluating nursing care.

Despite these benefits, nurses have thus far failed, at least in any practical manner, to integrate the construct into their scope of practice. It is the view of this writer that this position will become untenable in the future. There are two reasons for this view. The first is that nurses are responsible for holistic care (see below) and thinking about care based on QoL seems a practical and logical way for planning to achieve this care. The second is that in order to achieve holistic outcomes of care, nurses require working as part of a multidisciplinary team and as mentioned above, QoL considerations can provide a useful and agreeable framework for collaborative planning and evaluation.

3.4. Service Quality in Intellectual Disability Services

A considerable literature exists on service quality in intellectual disability services and this reflects the interest and concern with the nature of service provision. Literature is divided between theoretical positions and philosophical ideologies on the

one hand, and empirical and implementation studies on the other. Service quality has been an issue over the past few decades and has been operationalised in quality assurance (or other quality initiatives) and evaluation studies. Current concern according to Maes et al (2000) is grounded in QoL and with the pursuit of service quality activities as the outcomes for the enhancement of QoL.

3.4.1 Relationship between Quality of Care and Quality of Life

From the literature reviewed it is clear that the QoL construct has assumed an important place in service provision and emerges as a central aim in residential service organisations. Raynes (1986) draws a distinction between QoL and quality of care. QoL she points out is a reflection of the extent to which a person feels his or her needs are being met whereas quality of care lies in the way services are created and the opportunities provided for service users. James et al (1989) see QoL as referring to what the individual experiences and quality of care refers to what the service offers to the individual.

Dickens (1990) provides a further distinction and sees quality of service as the service environment, including physical structures, resources and management systems. Quality of care is the processes involved in the delivery of care by staff and includes the attitudes and values of staff. QoL is what Dickens (1990) sees as the outcome of combined quality of care and quality of service. He relates the quality of service, care and life, to Donabedian's (1969) framework of structure, process and outcome. These are summarised in table 3.2.

Quality of Service	↔	Structure
Quality of Care	↔	Process
Quality of Life	↔	Outcome

Table 3.2. Summary of the three dimensions of quality and their relationship to Donabedian's (1969) framework of structure, process and outcome quality

3.4.2 The Need for Quality in Intellectual Disability Services

In a discussion of reasons for quality in intellectual disability services, Dickens (1990) identified three fundamental concerns.

First is administrative. This reflects the desire of governments and service organisations for standards of service for legal, financial and managerial purposes.

Second is the expanding literature in the area on quality of care and QoL.

Third is the humanitarian concern for people with intellectual disabilities. Dickens points out that the need for quality services is due to the rise of consumerism in Western societies. Quality has become necessary through the increasing recognition of self-advocacy groups for devalued people and from the validity of views of disabled people.

Joyce & Carle (1988) saw benefits of a quality service from three perspectives:

1. Quality service is important for people in residential services because these people have not traditionally received a quality service.
2. A quality service will increase people's vision of what a service can offer and achieve for people with intellectual disability.

3. A quality service can assist those seeking resources to provide evidence that resources are being well used.

Bradley (1990) advances five compelling reasons for having quality assurance as part of service management and these are summarised in table 3.3.

Reasons for quality assurance programmes in services for people with intellectual disabilities	
1	Because increasing numbers of people with intellectual disability are now being served in the community
2	Because they are a means of communicating high expectations for service delivery
3	Because they can provide feedback to providers that will help them improve services
4	Because they can be used to justify funding and impress upon policy makers the value of services for improving the lifestyles of clients
5	Because they are needed so as to ensure that improvements in service provision are maintained

Table 3.3. Summary of five broad reasons for service management having quality assurance programmes for people with intellectual disability (Bradley 1990. p.4)

To these can be added the need for an equitable service, responsive to the individual and specialised health needs of persons with intellectual disability (Department of Health and Children Quality and Fairness 2001). According to Maes et al (2000), service providers and professionals may consider care provided to be of a high quality to the extent that it contributes to the QoL of those involved.

3.4.3 Quality Care and Human Needs

Whereas quality care is about processes used by staff to provide a service to clients (Dickens 1990), for human services, Ovretveit (1992) sees quality care as being concerned with meeting the needs of clients as outcomes of service interventions. Quality nursing care then, is about identifying and meeting the needs of clients. As if

in support of this position, Mattiasson & Anderson (1997), have argued that identifying and meeting the needs of patients/clients is a determinant for quality nursing care which can therefore be defined as the extent to which needs are actually met. Within the general framework for nursing practice, the ability of nurses to recognise needs in clients is a fundamental requirement of nursing care since according to Holtkamp et al (2001), the practice of nursing is about identifying and meeting needs in patients/clients, whether they are sick or disabled.

As part of her conceptual clarification of the concept of needs and needs-led nursing Stockdale (1989), cited in Rodgers & Knafl (1993, p.169), put forward the following operational definition:

“ Human need is defined as a process of regulating survival, closeness and freedom requirements. These may be partially fulfilled by the individual or a provider to prevent disequilibrium, which is manifested in illness or maladjustment states. The extent that significant needs are restored is dependent on available resources and functional ability of the individual or society to receive the appropriate intervention. Satisfaction of human needs is based on subjective evaluation by the individual”

From this, Stockdale (1989) made the following assumptions about human needs:

- All human beings have needs
- Humans experience needs that have subjective meaning and importance
- Needs change and have varying degrees of urgency and strength
- Needs are not always recognized or acknowledged by the individual
- Significant deprivation of needs will result in physiological and /or psychosocial harm
- Nursing intervention has the potential to improve the well being of the human condition
- Needs theory is applicable to all aspects of nursing practice.

Needs are an element of the model developed from the present study and warrant further discussion. Four established needs theories are summarised below:

1. *Drive theory* – Murray (1938) likened need to drive and identified two types of needs – primary or viscerogenic needs described as basic and include needs for air, food excretion, sentience, and harm-avoidance. Secondary needs he described as dependent on primary needs being fulfilled and included reaction systems and wishes such as nurturance.

2. *Hierarchy of needs theory* - Maslow (1954) in his theory of motivation included a hierarchical structure of basic needs and higher needs. According to Maslow, unsatisfied basic needs such as for food, rest or safety dominate the individual. In contrast, higher needs like esteem and self-fulfilment are less necessary for survival but when present lead to growth, development and fulfilment in the individual.

3. *Existence, relatedness and growth theory* – Alderfer (1972) saw need as a concept subsuming desires and satisfactions or frustrations. Existence needs constituted an individual's exchange of material and energy in order to achieve and maintain equilibrium with regard to material substances. In this theory, relatedness needs means the individual must interact with the environment. Growth needs are what occurs over time and takes place from interacting with the environment.

4. *Nursing human needs theory* - Yura & Walsh (1988) applied the concept of human needs to the nursing process and identified 35 human needs, which they categorized and then developed a nursing human need theory from what they saw as the basic concepts in nursing: person, family, and community.

Maslow (1954, 1970) developed a hierarchy of human needs as part of his theory of human motivation. According to this theory, there are two major groups of human need:

1. *Basic needs* - include food, water and sleep, psychological needs such as security, affection and esteem needs. Basic needs are deficiency needs because if an individual does not meet them, that person will strive to make up the deficiency.

Maslow believed that the needs at one level must be at least partially satisfied before those at the next level become important motivators of action. Maslow saw needs lower in the hierarchy as prepotent over ones that are higher.

2. *Meta-needs* - also referred to as 'being needs' are the higher needs. These are growth needs and include aesthetic, intellectual and self-actualisation needs. According to Maslow (1954, 1970), only when the basic needs are at least partially satisfied, can the individual have the time, energy and motivation to devote to aesthetic and intellectual endeavours. Maslow described his hierarchy of needs theory as taking a holistic view of the person while being dynamic in light of the ever-changing needs of the person.

While theorists and writers on the subject may differ on their explanation of needs, they generally agree that humans have a range and complexity of needs that operate at different levels. Many writers seem to agree on the existence and importance of other needs described as secondary, psychological or higher needs which are not necessary for the individual's survival. However, when met, these needs lead to growth and development in the individual and promote the ability to withstand or avoid physical, mental and social ill health (Peplau 1952, Maslow 1954, 1970, Henderson, 1966, Erickson et al 1983, Minshull et al 1986). Given the importance of holism in nursing and frequent changes in nursing interventions as a result of changing needs in clients, these concepts are especially relevant when providing nursing care to people.

Although there is little empirical evidence for Maslow's hierarchy of needs theory, a criticism being its lack of a scientific methodology (Atkinson 2000), it is well known to nurses in intellectual disability services and to nurses generally. One reason Maslow's theory of human needs is so well known to nurses is because many caring theories and nursing models are based on it and modified in accordance with nursing situations (Henderson 1966, Minshull et al 1986, Roper, Logan and Tierney 1990). McKenna (1997) for example, describes these nursing models as having much to do with human needs theories since many of them are developed from the theoretical formulations of Abraham Maslow (1954) and his work on motivation.

Peplau (1952) saw humans as having primary needs for food, drink and rest and secondary needs such as power, prestige and participation with others. Peplau also believed that for many clients, they might not know what their needs are or be able to communicate them to others. Such a situation is likely to be the case in intellectual disability care since many clients have profound and multiple disabilities.

In developing their theory of modelling and role modelling in nursing, Erickson et al (1983) drew on the work of several theorists from psychology and in particular Maslow. Based on Maslow's theory, Erickson et al argue that unmet basic needs create need deficits in the individual that can lead to initiation or aggravation of physical or mental distress or illness. Needs satisfaction in contrast, leads to assets and resources that promote growth, health and development and help the individual cope with stress.

3.4.4 Summary of Quality Initiatives in Intellectual Disability Services

The foregoing discussion has made clear the differences between quality care and QoL and the need for quality in intellectual disability services. Early initiatives for quality

can be traced to the decade of the sixties and the philosophical ideologies of normalisation and social role valorisation. These ideologies recognised the need for people to have as normal a life pattern as possible and they foreshadowed community care. Despite their importance, a criticism is that they were more about services than people. Nonetheless, these ideologies have been responsible for improvements in service. In particular, policies and initiatives that culminated in the majority of people with intellectual disability living in the community. These early service-led initiatives ushered in a new service paradigm that was to become based on recognition of the rights of people with disabilities and on a concern for their QoL (see chapter one). This is the prevailing paradigm where QoL as the outcome of service means service provision should be based on the needs and wants of clients. In practical terms this means less concern with disability and more on ability, less concern with medical aspects of care and more on the social aspects and, less emphasis on humanitarian needs and more on the rights of people (Mercer 1994, Cocks 1994).

Such a position makes service quality in intellectual disabilities very complex. If QoL (outcome) is what the effectiveness of care is about, then as Dickens (1990) says, quality of service (structures) and quality of care (processes) are the means of achieving this QoL. However, it is the view of this writer that within the parameters of this paradigm, real understanding of quality will evade nurses until they are able to plan and evaluate care based on QoL. This will only be possible if they integrate QoL into their thinking.

3.5. The Registered Mental Handicap Nurse

While the ultimate responsibility for providing quality care is that of management, the delivery of care is by staff, particularly frontline staff. In residential centres in Ireland, frontline care is mainly the responsibility of Registered Mental Handicap Nurses

(RMHN). These nurses work as part of a team alongside and in collaboration with other professionals and untrained care staff. Although a detailed discussion of the role of the nurse is beyond the scope of this review, this section provides an overview of the role of the nurse necessary for understanding the background and context for this study in residential centres. According to Courell (2000), for the past three decades, concern surrounding the role of nurses in intellectual disability has concentrated on tensions and debates emanating from changes in service provision as a result of the paradigm shift in care provision. Alaszewski et al (2001) explain that these changes in the United Kingdom are a direct consequence of nurses now providing care in the community. In this situation, care is provided by the social services and nurses' work within a social model that attempts to foster community integration and a reliance on generic as against specialist services. In the Republic of Ireland however, this is generally not the case for people with severe and complex disabilities where a great many live within residential homes and will continue to do so in the future (Department of Health and Children 2001).

3.5.1 Role of the Registered Mental Handicap Nurse

As a result of this paradigm shift in care, nurses have had to re-evaluate their place in service provision from a position of service lead care to needs lead care (Seal 1998) and to redefine their role in caring for people in the community. In this sense, the role of the RMHN has been evolutionary reflecting the developments in services for people with intellectual disabilities (Department of Health and Children 1997). There are several definitions for the role of the RMHN. The United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC 1987 paragraph 1.13.1) define the role as:

“ To directly and skilfully assist the individual and his or her family, whatever the handicap, in the acquisition, development and maintenance of those skills that, given the necessary ability, would be performed unaided; and to do this in such a way as to enable independence to be gained as rapidly and as fully as possible, in an environment that maintains a quality of life that would be acceptable to fellow citizens of the same age.”

However, while this has been a widely used definition, Courell (2000) points out that *enabling independence to be gained as rapidly and as fully as possible*, is unrealistic and fails to acknowledge the reality that is intellectual disability. He also sees this definition as over emphasising the skills- building role of the RMHN while ignoring their clinical role for health and social/psychological care.

Gates (1997:16-17) in his definition, states that the role of the RMHN is

“To skilfully assess the social and health needs of people with learning disabilities”

This definition emphasises the role of the nurse with regard to health care and maintenance. The Working Group on the Role of the Mental Handicap Nurse (Department of Health and Children 1997) uses a similar definition to that of the UKCC. However they emphasise how the education and training of the RMHN enables him/her to play a key role in the promotion of physical and mental health, the detection of ill health, the care of clients during illness and the identification of conditions that may compromise health. Thus they see the medical/health aspects of care as a very important component of the role. Such a role is further emphasised in the White Paper: Valuing People (Department of Health 2001) which singles out the intellectual disability nurse as being well placed as a health facilitator for people with intellectual disabilities.

Definitions are descriptive and usually express proactive aims for people with intellectual disability and portray them in a positive light and as capable of achieving

a level of independence to their optimum capacity through learning and development. In light of this, definitions of the role of the RMHN see them as having a multiplicity of roles.

Alaszewski et al (2001) have explained changes in the role of nurses as being linked to new terminology, what service users want, and new policies and changes in the location of care. The respondents in their study reported that the provision of care and support for users and carers was a major component of their role. They also said that management; liaising with families and the multi-disciplinary team and, providing education/advice to staff and other professionals were among the most important aspects of their role.

3.5.2 The Registered Mental Handicap Nurse in Residential Care

In Irish services there are policies and initiatives for people with intellectual disabilities to live within their local community (Needs & Abilities 1990). However, more than seven thousand people, almost one third, live in residential centres (NIDD 2003). In addition to the large numbers in residential care, there is an increased demand for more places (NAMHI 2004). These extra places are required for the people on current waiting lists for residential care and for people who need, but are currently not receiving, specialist services (RTE Prime Time 2004). Extra places are also needed to accommodate the increasing numbers of aged adults in the community who now need residential care because their families are no longer able to look after them. To reiterate, the rationale for this study is justified on the bases of the importance of residential care for clients and their families and the fact that it is nurses who provide the professional frontline care for clients (for a fuller discussion of residential care please see chapter one).

The majority of clients are in residential care because they have complex or multiple disabilities or require frequent physical interventions and health care. Many clients also have severe challenging behaviour necessitating continuous specialist care. In addition, some clients are admitted to residential centres for short periods of respite care while others attend residential centres to participate in day services such as adult and vocational training courses (NIDD 2003). In caring for these people the RMHN provides care across the lifespan of the individual and, depending on the functional ability of clients, this involves providing hands-on personal care and assisting clients to carry out their full range of activities of living. Nurses also engage in activities to meet the physical/health needs of clients and in interventions that will facilitate and promote their social development and quality of life (An Bord Altranais (2000).

In a submission to the Working Group on the Role of the Mental Handicap Nurse (Department of Health and Children 1997), the Nurse Teachers Group (1995) saw the role of the RMHN as encompassing the whole spectrum of conditions affecting people with intellectual disability for which the RMHN required a diversity of skills. They saw the need for nurses to be flexible and to be able to alter their role in response to differing client needs and in accordance with the rhythm of the day.

The range and diversity of disabilities that the RMHN encounters in residential care are listed in table 3.4. Table 3.5 lists the areas of care interventions that form part of the role of the RMHN and which are a reflection of those contained in the Syllabus for the Education and Training of the Registered Nurse of the Mentally Handicapped (An Bord Altranais 2000).

Range and diversity of disabilities encountered by the RMHN working in the area of residential care.	
Persons with challenging behaviour	Persons with epilepsy
Persons with cerebral palsy	Persons with autism
Persons with physical illness	Persons with complex/ multiple handicaps
Persons with psychiatric disorders	Persons with sensory handicaps

Table 3.4 List of the range and diversity of disabilities that is encompassed in the role of the RMHN (Nurse Teachers Group 1997)

Areas of Personal Care Interventions for Educational and Social Skills Training	
<i>Assessment, planning, implementation and evaluation of care for:</i>	
Choice and decision making skills	Self-presentation and assertiveness
Self-help and living skills	Education and pre-vocational training
Community participation and integration	Social and interpersonal skills
Sexuality and sex education	Play, leisure and recreation
Communication, speech and language	Activational and occupational skills
Health education and promotion	Physical health care

Table 3.5. list of personal and direct care interventions that are part of the Role of the RMHN working in Residential centres (Nurse Teachers Group 1997).

As can be seen from table 3.4, the RMHN provides personal and direct care to people with wide ranging disabilities all of who have unique and special needs. In practical terms and irrespective of the nature and extent of a person's disability, the role of the RMHN extends to providing care, education and training across the full spectrum of physical and social needs. Table 3.5 lists the areas of intervention. Collectively, these can be described as representing the basic social living skills for people and as skills and abilities necessary for their physical and social development. The Working Group on the Role of the Mental Handicap Nurse (1997) endorsed each of these components and recognised them as within the sphere of competence and scope of practice of nurses working in residential services.

Other important aspects of the role of the RMHN and which Alaszewski et al (2001) also refers to include the management of the home, liaising with families and the multi-disciplinary team and being responsible for the quality of care they provide for their clients. It should be said here that much of the content constituting the role of the RMHN in Irish intellectual disability services is prescriptive. While the role and functions in general reflects what nurses do, they are grounded in the curriculum of nurses' training (An Bord Altranais 2000) and are not empirically tested functions

3.5.3 Studies on the Role of the RMHN

In addition to the studies already discussed, many other studies have been done. Some are about the role of the nurse for persons with intellectual disabilities (Rodgers (1994), Matthews (1996), Baldwin & Birchenall 1993, Kay et al 1995, Dyer & Quine 1998, Ito et al 1999) or specific areas of care e.g. sexuality (Sheerin & Sines 1991, Jennings 2001) and spirituality (Narayanasamy 1999). Some are about models of care (Lee 1990, McKenna 1994, 1997, Sheerin 1999) or aspects of quality care (Sleven et al 1995). Many are on the role of the nurse within the community (Mansell & Harris 1998, Bollard & Jukes 1999). Courell (2001) reviewed the literature on the role of the Registered Mental Handicap Nurse, and looked at the changing role of the nurse, areas of employment, specialist versus equal (generalist) and tensions and debates surrounding the role. However, few of these studies have addressed specific detailed areas or enactments of the role – what exactly the nurse does for and with the client. In an ongoing study by Sheerin (2002), the researcher is looking at specific areas of care that nurses carry out for clients within residential services.

A contentious issue concerning the role of the nurse is their role in health and illness. Courell (2000), for example, sees a dichotomy between nurses having a narrow

medical approach to care while at the same time asserting that they have a broad holistic role. While intellectual disability nurses have been accused of being too medically oriented in their care (Lahiff 1990) writers like Rodgers (1994) and Matthews (1996) have warned that moves to de-medicalise care for people living in the community could lead to RMHNS ignoring the health care needs of people with intellectual disabilities (see chapter four for a fuller discussion on health care quality). When one considers that most clients in residential care have severe and complex disabilities including health care problems, it is hardly surprising that nurses adopt a medical approach to caring. Also noteworthy and to endorse the medical approach by nurses, many of the recently launched internet networking and discussion groups for intellectual disability nurses is replete with treatment and therapy approaches for a diversity of physical and psychiatric conditions in clients (National Network for Learning Disability Nurses, National Electronic Library for Health Learning Disabilities, Health Evidence Bulletins, Intellectual Disability and Allied Libraries).

In an ethnographic study on the attitudes of nurses that determine the quality of care for people with intellectual disabilities, Ming Ho Lau & Mackenzie (1996) looked at quality care from the family's perspective. From their analyses they identified 3 major categories as characterising the attributes of a "good" nurse:

1. Working with the child
2. Commitment to the caring career
3. Connecting with relatives (p.1111).

In this small-scale qualitative study, the researchers used a sample of 13 key family members to ascertain the expectations and perceptions of what constitutes good quality care. In discussing their findings, the researchers concluded that what families expected was not just competence and commitment of nurses but that nurses establish

and maintain a relationship with the child and his or her family. In particular, what families perceived as good quality care was the way nurses made contact with and accepted their child, irrespective of the severity of his or her disability.

In a mixed methods study with nurses, service users and families of service users on the role and contribution of learning disability nurses, Alaszewski et al (2001), found that changes in terminology, values and policies in care provision have all lead to a diversity of new roles for the nurse in this discipline of care. The researchers reported that less than twenty percent of their sample worked in residential care and they identified what they described as major changes in the roles of nurses from providing care within hospital settings to roles including direct provision of care, support, provision of specialist advice and management of a variety of services.

However, the role that nurses had varied across services. The researchers found that while junior nurses and students spent the majority of their time providing direct care, the main workload for more experienced nurses was divided between administration/management (93.5%), user/carer support (85.4%), communicating with families (60.9%), liaison with the multidisciplinary team (79.2%) and, developing personal competencies (47.2%). From their findings, the researchers identified four distinct elements to the nurse's role:

1. Direct care of service users
2. Management and administration
3. Liaison with families and the multi-disciplinary team
4. Education and sharing expertise with the multi-disciplinary team

Not dissimilar to the findings of Ming Ho Lau & Mackenzie's (1996) study, was the findings that service users and families valued the nurse for:

- Providing the medical aspects of care (physical care)
- Being a helper and enabler to the user
- Being a friend and someone to trust
- Being a skilled helper to user and his/her family
- Having a family focus and working with parents or families
- Having a special knowledge and expertise compared to other types of nurses (p.1103).

Respondents reported a number of criticisms concerning their skills and abilities and saw these as deficiencies in their educational preparation as nurses. Qualified nurses reported deficiencies in areas such as management and administration, client care therapy skills and educating students. Student nurses felt their educational course did not adequately prepare them for the full responsibilities of their job. Students identified deficiencies in the areas of clinical skills, meeting the health needs of clients, not having sufficient training in communication skills and not having adequate management and leadership training. The researchers reported that both the employers and family respondents in the study had clear views about skills and abilities required for service provision, and thus what types of learning experiences students required, but said they were rarely consulted or involved in the development or delivery in any course curricula or instruction.

In a study by Duker et al (1991), the researchers found that in a sample consisting of qualified and unqualified nursing staff, qualified nurses spent more time on organisational and administrative duties as compared to unqualified nurses who spent all their time interacting with residents. The researchers also found that the length of duty of frontline staff had a direct bearing on quality of care. The longer the spell of duty, the more custodial care was provided and the less stimulative care was provided.

They also found that increases in staff numbers on duty resulted in staff providing clients with less stimulating activities.

Hile & Walbran (1991) looking at staff-resident interactions found that frontline care staff spent the majority of their time engaged in either supervision of residents or in pursuit of their own leisure activities. For 32% of the time observed, direct care staff engaged in supervision, the least interactive of the various options. Staff engaged in training residents for only 1.8% of the time and residents were engaged in interactive activities with direct-care staff for only 11.7% of the time. In contrast to the findings of Duker et al (1991), Hile & Walbran (1991) found that trained staff engaged residents more often and training occurred 13 times more often when trained staffs were present with untrained staff. A further observation of Hile & Walbran (1991) was that training/engagement of residents occurred more often in a “classroom” type situation rather than in the living area. Hile & Walbran (1991) said that while more staff was required for desirable activities, this was also related to more staff time spent on non-engagement activities such as supervision or administration.

Felce (1994) in a study on costs, quality and staffing suggested that increased staff numbers on duty may not directly benefit quality of care especially if too much is done for residents. He suggests flexibility of staff rotas and points out that quality of care is more likely to be provided by reducing client numbers and not increasing staff numbers, thus supporting the findings of Duker et al (1991). In seeking a compromise between costs and quality of care, Felce (1994) suggests there is no strong evidence that quality of care is linked to staff numbers. These findings seem to be supported by Rose (1998) who found a positive correlation between increased staff-client ratios and personal plans/day activities for clients. However, Rose concluded that this

relationship was accounted for by reducing client numbers and not by increasing staff numbers. In this study, Rose (1998) used two measures of quality, direct observation of staff and diaries of client activities.

3.5.4 Summary of the Role of the RMHN

To summarise the role of the nurse, there is general agreement that irrespective of where the RMHN is working, he/she has a diversity of roles. In residential care the roles encompass the full range of human needs and are spread across all activities of living. Because most clients have severe or profound intellectual disability, identifying and responding to their complex and frequently ill-defined needs requires constant and repetitive interventions from the nurse. Among the multiple or additional disabilities clients may experience are various forms of physical and psychiatric conditions. Interventions for these types of conditions require that physical and psychological interventions feature as important elements of the role of the nurse in addition to that of social care. However, the enactment of any one role is dependent on the specific needs and requirements of a client at a particular time and place and this requires a high degree of flexibility from the nurse.

In residential services, nurses are the main frontline professionals who interface with clients and provide care and services twenty-four hours a day and seven days a week. Yet there is a dearth of information on how involved nurses are in providing quality care or the extent to which they recognise quality of life as an outcome of their care. Despite reports and discussion papers on the role of the nurse and in the context of residential services in Ireland, little is known about what nurses do for clients. Significant gaps exist in the published literature and in conference proceedings about how intellectual disability nurses conceptualise or approach personal outcomes for

clients. In particular, there are gaps in the literature on what nurses perceive quality care to be for clients and the paradigm and ethos within which they provide care. It is unclear from the literature if intellectual disability nurses do or can provide holistic care and if they evaluate the care they provide to clients. There are also gaps in both the published literature and in conference proceedings on the extent of nurses' involvement and participation in overall service provision to clients and their families.

3.6 Conclusion

This chapter reviewed literature dealing with contemporary issues for service provision to people with intellectual disabilities. Literature on service ideologies underpinning care was reviewed along with literature dealing with quality of life as a central aim of services. Literature looking at the relationships between QoL and quality of care was examined and the need for quality in intellectual disability services was discussed. This chapter also reviewed the role and involvement of the registered mental handicap nurse with particular reference to residential services.

The purpose of this part of the review was to illustrate the complex nature of service provision to people with intellectual disability generally. The review draws attention to fundamental concerns within residential services and provides a foundation and rationale for understanding service quality in the area.

Several important conclusions can be drawn from this review.

- Quality of life is a complex construct for which there is no agreed definition. Most writers see QoL as consisting of subjective and objective elements in a person's life and the weighting of importance that any one person attaches to anyone element. Felce and Perry (1995) see the construct as referring to the interaction between the circumstances or mode of a person's life, their

satisfaction with its various facets and their personal goals or values. QoL is now seen as the legitimate outcome of service provision for people with intellectual disabilities and its dimensions are generally agreed to be the same for both disabled and non-disabled people. Conceptual problems exist with the construct and especially with attempts to measure it.

- The current paradigm for service provision to people with intellectual disabilities is centred on personal human rights and quality of life concerns. The implications for nurses is that if they are to progress with holistic care for their clients, they will have to concern themselves with the debate and considerations about quality of life. In practice this will mean nurses will have to integrate the construct to their scope of practice, which can then be applied to their thinking, planning, and evaluation of care.
- Quality care is a means of achieving quality of life as an outcome of service. If this is to be achieved, then care responsive and tailored to individual clients should be needs led and not service-led. Such an approach requires that nurses can identify the needs of individual clients and can utilise the necessary interventions to meet these needs. Depending on their level of ability, clients have multiple, varying and ever changing needs. While it is these differing and unique needs of clients that makes care complex and multifaceted, they have to be identified and met if dimensions of quality of life are to be met.
- The RMHN as the frontline professional provider of care in residential centres provides a range of services across the lifespan of clients and is both accountable and responsible for the quality of the care they provide (An Bord Altranais 1999).

CHAPTER FOUR

APPROACHES TO QUALITY CARE

4.1. Introduction

The preceding chapter reviewed literature dealing with service ideologies, quality of life, the need for quality in intellectual disability services, the purpose of quality and the role of the RMHN in residential services. The aim was to place service quality in context and provide an understanding of the contribution the nurse makes to quality care for clients. This chapter reviews the literature on specific approaches to quality in residential centres. In particular, role and involvement of major stakeholders in the service encounter, the service user and family and, the organisations processes for quality care. Figure 4.1 is a map tracing the theoretical and empirical literature reviewed in this chapter.

Studies on quality and service evaluation in intellectual disability services are numerous and have been conducted from the perspective of academics, managers, practitioners and researchers. Studies have also been undertaken or commissioned by voluntary groups (National Development Group 1980, Russell 1986, NAMHI 1993, 1999), by service users (Whittaker et al 1990), professional organisations (Royal College of Nursing Standards of Care Project 1992) and government departments (UK Department of health 2001, National Disability Authority 2003). Except for the USA, where evaluation programmes have been used for accreditation and regulating services (Sparr & Smith 1990, Gardner 1997), the majority of studies relating to service quality in Europe and Australia are of relatively recent origin and are the result of changes in service ideology over the past two decades (see chapter 3).

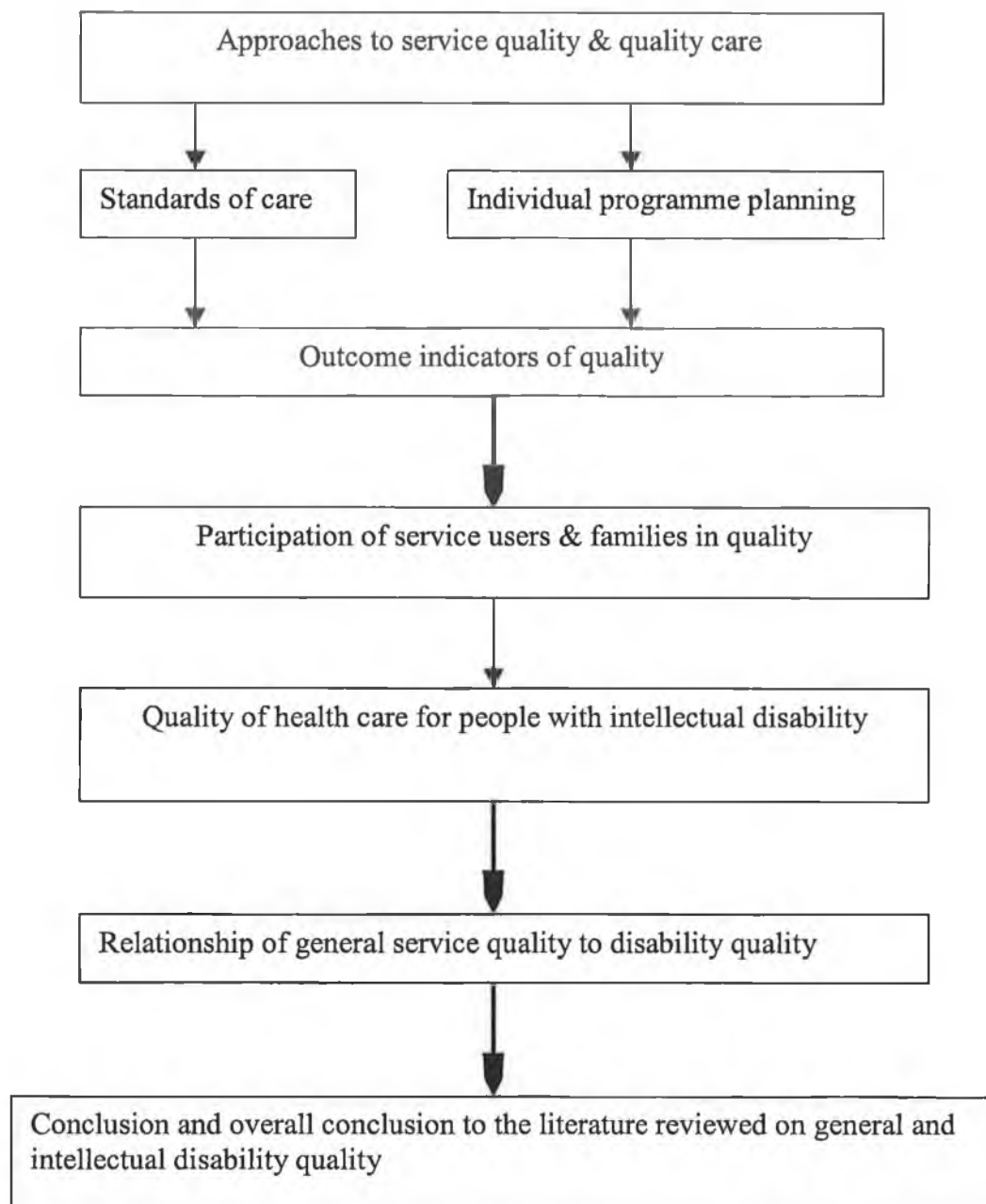


Figure 4.1. Research map tracing the literature reviewed on approaches to quality in intellectual disability services

4.2. Approaches to Quality Care

Various tools and techniques are used to provide quality care. These include systematic and non-systematic approaches. This distinction is important since in the

absence of formal or organisational systems for quality, professionals working in residential centres may adopt techniques at an individual and local level. Common approaches to quality care for persons with intellectual disabilities include quality assurance (Bradley & Bersani et al 1990, Sale 2000), assessing quality through assessment of individual client performance (Stancliffe et al 1999), personal outcome measures (Gardner 1997), and service evaluation (Cass & Kugler 1999, Maes et al 2000). Each of these is discussed below.

In an early paper, Raynes (1986) identified what she described as the three main approaches to measuring quality of care:

1. Assessing services against a set of standards.
2. Assessing services against a set of scales.
3. Assessing services through the assessment of individual client performance.

In her discussion, Raynes (1986) was addressing specific techniques rather than systems. She comments on the overall usefulness of each approach but without discussion on details of application. Scales such as the measures of QoL discussed earlier are useful for comparisons in service provision. Raynes point out that whereas standards are value-based, scales are based on theoretical ideas and are used periodically by researchers. Assessing quality of care through assessment of individual client performance is a more established approach. Using this method, information is pooled from all assessments and used as a measure of overall quality. Raynes (1986) points out that inference drawn from this approach must be guarded since the method does not look directly at the quality of the environment. Despite this caution, Redmond (1993) in his study of medium and large residential centres in the Republic of Ireland found that the majority of centres (90%) reported using

assessment of individual client performance to measure quality of care. None of the twenty-three centres involved in the study used scales and only half had standards.

4.2.1 Standards of Care

Written standards are a necessary part of most quality systems (Katz & Green 1992, Sale 2000) and in intellectual disability services are seen as central to any attempts at service evaluation (Maes 2000, National Disability Authority 2003). In the document 'Standards of Care for People with Learning Disability', the Royal College of Nursing Standards of Care Project (1992) discussed the importance of standards of care for nursing practice based on the Donabedian model. These standards and their underlying rationale are based on the Royal College of Nursing Dynamic Standard Setting System (1990) and were meant as a catalyst for nurses to develop their own local standards.

The Health Services Accreditation (HSA, 1998) has developed sets of service standards for people with intellectual disabilities. The draft standards relate to health needs and are based on four general principles:

1. People with learning disabilities have the same human value as other people.
2. People with learning disabilities have the right to live like others in the community.
3. Services should recognise the individuality of those with a learning disability and provide for them accordingly.
4. Services should aim to minimise the effects of disability and allow individuals to live their lives as normally as possible (p. 14).

The HSA (1998) standards are set out as principles grounded in the five accomplishments of O'Brien (1987, p. 179). These principles were not advanced as dimensions of QoL but as what O'Brien saw as a basic set of factors that can contribute to QoL for people with disability. These are summarised in table 4.1.

- | |
|--|
| <ol style="list-style-type: none"> 1. Community Presence: concerns the places where the person visits or spends time and includes where he/she lives, works and pursues their leisure activities. 2. Community Participation: refers to the relationships that a person has with people who have a valued status in our society and who are not paid to be with that person as a care worker. 3. Rights and Autonomy: this concerns the exercise of choice so that the person is seen as an individual who has his or her preferences with the right to make choices. 4. Competencies and Contributions: means opportunities for the person to be seen as someone who has things to give to other people, not just someone who receives, and as someone with potential to increase their skills. 5. Status and Reputation
Means being seen as an individual with a good reputation and worthy of respect |
|--|

Table 4.1. A summary of O'Brien's Five Accomplishments (O'Brien 1987, p. 179).

These sets of standards are at an early stage of development. They are either procedural or qualitative and are not expressed as measurable outcomes. However, the HSA (1998) suggest approaches to monitoring and feedback based on audit, with both internal and external evaluation.

Money & Collins (1999) developed a framework for measuring satisfaction for all people with learning disabilities and ground the dimensions of satisfaction in O'Brien's Five Accomplishments (O'Brien 1987). The framework uses survey questions as a tool for measuring satisfaction at an individual and service level and to gather information for quality of care. Information can be collected from verbally able people, people with limited communication skills and people with no formal language or communication skills. Questions are open-ended and different question formats are used depending on people's communication skills (Stenfert Kroese et al 1998). Question responses are recorded as positive, neutral or negative and results recorded as quantitative and qualitative scores. Signs and symbols are used to elicit responses e.g. picture cards. Prior to use, attempts are made to assess the client's level of understanding of questions. For people unable to communicate, two staff members that know the person well are asked to respond for the person. This approach

increases the reliability of responses and reduces subjectivity. This is a service tool rather than a research tool and is being refined and developed but no information is provided on validity or reliability of the measure.

The American Association on Mental Retardation (AAMR, 1998) have published two comprehensive guides on service quality. One is a Consumer's Guide to help and direct consumers and their families on how to look for quality. The other companion document is a Provider's Guide to assist and direct provider organisations on how and where to provide quality. Both are useful guides and build on the continuing service quality developments of the AAMR. Examples of good quality are provided and suggestions made on implementation approaches. Useful WEB sites are also provided to assist organisations develop quality programmes. These guides are not standards documents, but they do emphasise the importance of standards being set for personal outcomes. They also provide checklists that organisations may use to assess the extent to which they are providing a quality service.

The National Association for the Intellectually Disabled of Ireland (NAMHI) launched their Standards of Care Document in May 1999. This was developed in response to what the Association saw as the needs and expectations of people with disabilities and their families. It is underpinned by the recent reports on the Commission on the Status of People with Disabilities, "A Strategy for Equality" (1996), and the Health Strategy Document, "Shaping a Healthier Future" (1994). Both these Reports stress the principles of Equity, Quality of Service and Accountability. In brief, the document covers eight areas of service provision from which 23 general standards are derived. Issues such as health care, safety, protection from abuse, and

physical conditions are addressed along with standards relating to advocacy, assessment and individual programme planning for clients and their families.

More recently in Ireland, the National Disability Authority (NDA 2003) has published its final draft of national standards for disability services. Under their statutory responsibilities to the Minister for Justice, Equality and Law Reform the NDA is required to oversee the implementation of these standards across all services for people with disabilities. Standards are person-centred and organisation-centred. There are 116 standard criteria covering:

1. Residential services
2. Respite services
3. Day services
4. Training services
5. Home support services

Unlike the Standards of Care Document introduced by the NAMH (1999) that were aspirational in nature, the standards launched by the NDA (2003) will be obligatory for service providers. The standards are grounded in government policy for health and disability services. In particular, the government's National Health Strategy, Quality and Fairness (2001) and its key principles of people-centredness, equity, accountability and quality. Each of the standards was derived through wide consultation with service users and providers and reflects the NDA Strategic Plan. The aim of the national standards is to ensure that disability services in Ireland can contribute to an improvement in the quality of life of the recipients of services. As outlined in the NDA Act (1999, 8 d), the NDA has a statutory role for monitoring the implementation of the national standards in all services for people with disabilities and for commissioning external audits of the standards on a three yearly basis.

Following assessment, each centre will be issued with an action plan that will form the basis for their continuous quality improvement strategy. The standards were piloted in 20 services and have recently been evaluated by an evaluation team lead by Professor Roy McConkey from the University of Ulster. Recommendations concern the refinement of standards with some becoming mandatory. They also include the need for guidelines on the role of service users and their families and the need to draw upon the expertise of staff working with people as the internal assessors of these standards.

Maes et al (2000) advance 13 quality standards they call criteria for use in residential care. The researchers used the Delphi technique and a survey questionnaire with various stakeholders to refine and operationalise the criteria, which are listed in table 4.2 below. The criteria are based on five broad principles that underlie the current paradigm of care for people with intellectual disabilities. The five principles are:

1. *Inclusion* – participation in the community and engagement in normal activities.
2. *Support* – appropriate to the needs of the person and including social support
3. *Self-determination and empowerment* – being able to make choices
4. *Education and development* – stimulating activities as well as treatment interventions
5. *Planned and methodical action* – goals and supports based on reflection and well-considered decision-making to assure quality of care is provided

As can be seen from the table, the criteria are similar to the service accomplishments of O'Brien (1987) and support most components or dimensions of quality of life.

Criterion	Description
Individuality	Clients recognised as individuals and care based on personal needs and potential
Involvement	Clients must be involved in the care process
Freedom of choice	Clients preferences are taken into account and clients are assisted to make their wishes known
Respect	Clients treated as equals and their dignity and privacy is respected
Atmosphere	Clients feel safe and accommodation tuned to clients individuality
Relationships	Clients are treated with concern and trust and care workers feel responsible for clients
Development	Clients are assisted to achieve their potential in various developmental domains (dimensions)
Independence and support	Clients are helped in their activities and encouraged to carry out activities themselves
Structure and flexibility	Clients have consistency and structure in their lives depending on the client's individuality and on context
Methodical action	Clients care must have objectives and be systematically evaluated and corrected
Integration	Clients must be facilitated to participate in the social life of the community
Perspective	Clients are assisted to make plans for their future
Participation of important third parties	There must be an exchange of information and consultation with important third parties with regard to care and service provided to clients

Table 4.2. Summary of the 13 criteria for quality evaluation in residential care (Maes et al 2000, p.548)

In summary here, Maes' (2000) standard criteria are people – centred and are similar to but not as detailed or as numerous as those of the NDA (2003) which also encompass organisational-centred standard criteria for service evaluation.

4.2.2 Individual Programme Plans

Individual programmes are seen as essential for the delivery of highly personalised and responsive care to clients with intellectual disability (NAMHI 1999, Quality & Fairness 2001, NDA 2003). According to Garrigan (1987), individual programme plans (IPPs) are an essential component of quality assurance in service delivery to people with intellectual disability and Jenkins et al (1988) see them as necessary for

both personal and service needs of the client. The process of IPPs encompasses the identification of personal needs and wants of a client which are then discussed with those people, including the client, who have a contribution to make to the achievement of these. Kaplan & Kauffman (1992) see the IPPs as a road map for the individual's future. The IPPs sets out who will do what and when. IPPs also assign responsibility and accountability for what is to be done and provides the basis for reviewing development as well as charting personal achievements of the client (Carnby 1997).

Wright & Moffatt (1992) point out however, that IPPs frequently fall far short of their intended use with frontline staff regarding them as a chore and an added workload. Cummins et al (1996) has reviewed the use of IPPs for quality care. They examined 163 IPPs and found that just 39% of IPPs were up to date, just 14 % offered any criterion for evaluation of performance objectives and the average number of skill building objectives was less than 3 per plan. From their findings, Cummins et al (1996) reported a very low number of skill- building objectives and a high number of activity objectives. From the literature they reviewed and the IPPs they examined, Cummins et al (1996) conclude that if IPPs are to realise their quality assurance potential, staff training in plan preparation as well as issues of accountability must be addressed.

On the frequency of IPPs, Redmond (1995) found from his descriptive study of all nurses, care staff and student nurses on duty over two consecutive days, that 70 % of nurses (n = 69) reported holding IPPs for residents but the majority of residents only had an IPP annually or less often. Care staff (n = 97) as permanent members of the living-area team, were involved in less than 10% of IPPs. Student nurses (n = 40)

were involved in less than 5% of IPPs. Based on these findings, recommendations were made to management for additional staff training and in particular that issues of responsibility and accountability for conducting IPPs be addressed.

Dangan & Sturmeay (1994) say that claims for individual planning as supporting best practice have rarely been validated empirically nor has the relationship between implementation and outcomes been evaluated. Stancliffe et al (1999) suggest that many of the problems associated with the use of individual planning in residential settings are due to frequent changes in staff and to limited training. They see inconsistency in implementation, failure to specify appropriate outcome objectives, and the involvement of multiple staff members as compromising the attainment of individual goals.

In their research study into the effectiveness and quality of individual planning in residential settings, Stancliffe et al (1999) found little evidence for their effectiveness and report that much of what is known about the effectiveness of individual planning is contradictory. They point out that that in many research studies comparisons were not made between clients with and without individual plans and that consequently they fail to show that having a plan made any difference to achieving outcome goals. Stancliffe et al (1999) employed what they called quality indicators to assess the effectiveness of individual planning arguing that goals with features that satisfy specific quality indicators would be more effective than goals without these features. They rated the individual plans of 123 clients against 23 separate quality indicators divided into five areas. These were functionality, community focus, technical adequacy, teaching methods, and data collection. There was a period of 12-months

between pre-test and post-test so as to provide sufficient time for objectives to be implemented. From their results they report no evidence existing for the expectations that the presence or quality of individual plan objectives contributes to the increase in behaviours, skills or participation of clients and they found no evidence to support the view that individual plans are important in maintaining such outcomes.

Stancliffe et al (1999) suggest reasons why individual planning was found ineffective which include the poor quality of written plans. Poorly written objectives that fail to identify best practice quality indicators are unlikely to be effective. Another possible reason was the marked lack of correspondence they found between stated objectives on an individual plan and the day-to-day practices within the residential settings.

4.2.3 Outcome Indicators of Quality

A problem with many early standards was that they were either too general or aspirational or were developed for a limited number of service interventions (Gardener 1997). Often designed for structures and processes only, standards were frequently set for achieving some minimal level of care or service. Many of the standards advanced by the National Association for the Intellectually Disabled of Ireland (1999) could be described as examples of basic standards given that they are about human rights and access to services. In contrast, the national standards now being introduced by the NDA (2004) are also about outcomes that recognise personal needs and wants of people.

Current concern with quality is based on outcomes (Janssen & Vreeke 1995, Department of Health Valuing People 2001, Pillenger 2003). This of course means outcomes of service provision but more particularly, personal outcomes, as determined by the individual with intellectual disability (Gardner 1997).

According to Felce (1996), service policies with respect to needs-led social care and effectiveness-led health care, suggest a growing tendency to accept outcome as the ultimate evidence of a service's validity. Felce (1996) points out that quality-related information is frequently collected by and about services. This usually concerns service inputs (staffing, resources and budgets), service specifications (size of setting and design), or service processes (individual plans and assessments). In contrast, little information has been collected on outcome: the impact of service processes on the quality of life of the service user. For example, the reasons for having service quality advanced by Joyce and Carle (1988) and Bradley (1990) discussed above, referred to service provision but did not mention outcomes.

Felce (1996) sees outcome as an essential ingredient of quality assurance and puts forward a framework for thinking about it. According to Felce, QoL is now seen as the ultimate outcome. In support of this, Felce (1996) suggests that the initial pre-occupation with skill change as a principal outcome is now being substituted with a willingness to explore other aspects relevant to, and determined by, service users.

Qureshi (1996 p.40) defines outcome as the "impact, effect or consequence of a service or policy " She points out that to review the impacts on people receiving services must pose basic questions about objectives, that is, what is it that services are trying to achieve and to what extent do ideas about this differ between different interested groups? She points out that since both technical and value issues are important in addressing questions about outcomes, concerns about user involvement, advocacy and self-advocacy raise conflicts among the various stakeholders about the relative importance of different outcomes.

Qureshi sees two types of outcomes; the first goes no further than measuring service changes. These service-level outcomes however, say nothing about the personal impact on a person's life. The second she sees as user-based outcomes and she refers to these as final outcomes and these are similar to what Gardner et al (1997) call personal outcomes. Qureshi puts forward three necessary steps for collecting information on outcomes and these are summarised in table 4.3.

First	Understand what aspects of a person's life situation are intended to be affected e.g. physical well being
Second	Collect evidence that the outcome is being achieved e.g. measure selected areas so that the outcome/s is detectable
Third	Interpret results of intended outcome/s and examine alternative explanations for changes that must be ruled out

Table 4.3. Summary of three basic steps for collecting information on outcomes

Qureshi (1996) sees outcome measurement as important at every level of service evaluation but to be effective it must be based on some form of comparison. Levels of outcome evaluation include service policy, nature and types of services provided, and specific interventions with service users. She also advances a number of ways research literature can be of use to professionals and managers. Research can assist in the process of identifying important areas of outcomes to explore, for example, research can help to answer the question: which outcomes have been identified as important in evaluating services? Research can also provide data for comparison purposes and suggest when methods other than quantitative measurement may be more appropriate.

Janssen & Vreeke (1995) have reviewed outcome indicators and divide these into four general categories:

1. Achieving a certain level of QoL for people with an intellectual disability.

2. Improving the practical and social functioning of people with intellectual disability.
3. Ensuring social integration.
4. Ensuring that clients (and their families) are satisfied with the care provided.

In linking QoL (outcomes) to quality of care (processes), Janssen & Vreeke (1995) discuss each category and argue that current outcome (QoL) instruments are insensitive for measuring quality of care. For example, on functioning, the extent to which a person with an intellectual disability is able to show his/her wants, develops or shows abnormal behaviour can all be determined by instruments that measure QoL. These instruments however fail to provide direct information on the quality of care provided. Janssen & Vreeke (1995) also point out that since people with severe intellectual disabilities score lower than those with milder intellectual disabilities, the instruments used require refinement if they are to be considered valid and reliable indicators of quality of care. They emphasise the importance of using instruments that measure the process of care in addition to instruments that measure QoL, the outcome of care.

Newton et al (1996) report on how focusing on values and lifestyle outcomes is being used in the State of Oregon in the USA to improve the quality of residential services for people with developmental disabilities. They stress the importance of values for their continuous quality improvement programmes. Their approach involves teaching service providers how to gather timely and accurate information about the quality of their service processes and outcomes and then teaching them how to use this information in team meetings to make decisions and take actions to improve processes and outcomes. Newton et al discuss the lifestyle outcomes of physical integration, social integration and independence and the importance of preference as a valued

outcome. Their system is described as a bottom-up approach and consists of 10 core standards and 42 non-core standards. Assessment is conducted by The Oregon Technical Assistance Corporation and by frontline staff. In order to show evidence that a service provider is implementing the outcomes with fidelity, a programme must meet one 100 percent of the core standards and at least 80 percent of the non-core standards.

In the USA, the Council on Quality and Leadership in Supports for People with Disabilities (1997), hereafter referred to as the Council, has been actively involved in developing personal outcome measures for the past decade. Personal outcomes as defined by the Council, are what people expect from the service, and the supports they receive. They refer to the major expectations that people have in their lives. In 1989 the Council had over 800 process standards in place. Commencing in 1991, the Council undertook research by interviewing people with various types of disabilities in order to elicit priority outcomes in their lives.

Following this, the term personal outcome appeared for the first time in the 1993 edition of the Outcome Based Performance Measures. The current edition (1997) is based on over 2,000 personal interviews with people who have disabilities. These Outcome Based Performance Measures form the foundation for the Council's national accreditation programmes, organisational assessment workshops, the Quality Consortium and the numerous consultation activities throughout the world. The Council underpins their Outcome Based Performance Measures with a distinction between traditional and personal outcome approaches to quality. These are summarised in table 4.4

Traditional Outcome Approaches	Personal Outcome Approaches
Starts with professional assessment	Starts with person's self-assessment
Goals based on service needs	Goals based on personal desires
Personal choice only considered in context of programme goals & activities.	Personal choice is considered within the context of life & social realities.
Service & training are the preferred & expected methods of support.	Service, training & other supports are offered to the person for consideration.
Success is measured through programme activities.	Success is measured through personal achievement.

Table 4.4. A summary of difference between traditional & personal outcome approaches to quality (Council 1997).

In summary, the personal outcome measure consists of two separate but related components. First are the 25 personal outcomes for the person. These are divided between 7 measures and reflect the needs and wants of the client. Second are the 21 organisational measures for the organisation's management. These represent the key factors that support and contribute to the organisation's capacity to assist people to achieve their personal outcomes.

Gardner et al (1997) see personal outcomes as providing self-advocates with greater control over their lives and of affording them real decision-making opportunities. They recognise that interacting with people to identify their definition of outcomes and establishing whether the outcome is or is not present is time-consuming. Nonetheless, they argue the point that compared to reading programme documentation and checking off compliance with organisational process standards, personal outcomes are more in keeping with meeting the needs and wants of clients. On the skills required for interviewing and learning about service-user's personal outcomes, Gardner et al (1997) see these as acquired by meeting and interacting with people.

The process of orientation and training for interviewers takes place over several accreditation reviews during which new reviewers observe, participate and then lead the interview.

4.3. Participation of Service Users and Families in Quality

Although this study is focused on nurses, in any overall general consideration of service quality, the views of service users and their families must be taken on board. In a study on how family and informal supporters appraise service quality, Grant et al (1994) examined the relationship between variables involved in a structure-process-outcome evaluation model. Respondents were asked questions on their satisfaction with structures (service & organisational systems); processes (needs, expectations & preferences); and outcomes (personal outcomes for families, service package). In their discussion of findings, Grant et al found that different outcomes were affected by different clusters of factors that were tied up with elements of the service process. They identified the families' wish for frontline staff to empathise more with service users and provide individual plans and keyworkers for service users. They also identified the need for an individual service package to meet the needs of families.

Implicit in service quality is the recognition that the focus of service agencies must be on the needs of the service user and his/her family (Emerson & Hatton 1994, National Development Team 1998, NDA 2003). Without this recognition there is no need for quality. As Zeithaml (1990) says, without the service user, there is no need for a service. Atkinson (1988) said that any study or attempts to alter the lifestyles of people with intellectual disabilities should make every effort to obtain the views and opinions of service users as consumers.

McKenzie et al (1999) for example, criticise many studies looking at likes, dislikes and satisfaction. Such studies, they suggest, provide information to shape local service provision but don't necessarily address the importance of the various factors to the individual or the extent to which structures and processes meet their needs. McKenzie et al used semi-structured interviews to elicit the importance of 16 service items to a random sample of 56 adults from residential and community services. Service items included access to professionals; involvement in individual care plans; having a say in personal future plans and having a job or other meaningful activity. The researchers found eighty five percent of participants rated all 16-service items as important to them. A notable exception was access to a doctor where participants with a lower level IQ rated access as unimportant. The researchers suggest this might be due to individuals' experience of doctors in a negative sense e.g. taking blood. McKenzie et al (1999) see their study as useful but point out the limitations which include the small number of participants and the fact that they came from a limited geographical area. Another important limitation is the exclusion of individuals with more severe learning disabilities since it is possible that such individuals might differ markedly from more able individuals.

Gregory et al (2001) in their cross-sectional study looked at variations in levels of satisfaction between clients in village-type communities (24 hour residential supports, n: 45) and clients in community-based residential settings (small dispersed, domestic-style housing, n: 51). Semi-structured interviews were used to collect data across seven domains: home, activities, social/recreational activities, support, friendships, /relationships, choices and risks. Interviewees in village communities expressed greater satisfaction with friendships/relationships than did interviewees living in

community- based residential houses but they found no statistically significant differences between the two groups across the other six domains. They also found a wide range of variables relating to personal characteristics of interviewees and support services, which were associated with variations in levels of expressed satisfaction. These findings are not dissimilar to the findings of Emerson and Hatton (1994) and Rapley and Beyer (1995) who found that living in domestic homes in the community does not necessarily lead to friendships and participation for clients.

Obtaining the views of service users with intellectual disabilities is problematic since many users have poor communication skills, low cognitive ability and in many cases may present with serious behavioural problems or multiple disabilities (Felce & Perry 1995).

Whittaker et al (1990) employed a number of novel approaches including the use of picture cards to elicit responses from service users. This research project was also significant since co-researchers in the project were themselves service users.

Literature has been emerging on methodological problems for obtaining and responding to the views of people with intellectual disabilities. In their paper on the definition and measurement of quality of life, Felce & Perry (1995) have discussed a number of issues, which raise problems for researchers and practitioners when attempting to obtain information from clients. They have appealed for ongoing research in the area. Stenfort Kroese et al (1998) have reviewed the literature on consumers as service evaluators. Methods suggested and used for obtaining service users views include combining open-ended and forced-choice questions with unstructured interviews. Use of appropriate language is important so as to aid comprehension, attention and expression of responses.

Sigelman et al (1982) suggested unstructured interviews and said this approach could reduce acquiescence, the tendency to agree with the viewpoint of others, and recency effects, recalling those words said most recently. Cummins (1993) suggested using pictures with faces expressing emotions as the basis of Likert-scales to aid responses (this is similar to the technique employed by Whittaker et al 1990). Cummins (1993) advocates a pilot test before hand to ascertain if respondents can understand and use the abstract reasoning needed to use a Likert-type scale reliably.

Studies reviewed by Stenfort Kroese et al (1998) indicate that:

- Open-ended questions are more likely to yield valid and reliable service user reports than forced-choice questions.
- Questions such as yes/no and either/or question format can also be useful but should be used in conjunction with open-ended questions in order to test for reliability and validity.
- Visual presentations (picture cards) facilitate communication and reduce acquiescence and recency effects.
- Interpersonal dynamics between interviewer and respondent must be further investigated as questions and answers can be distorted by subtle processes during the interview and produce misrepresentation of service user views.

Stenfort Kroese et al (1998) suggest three further issues for consideration in addition to interview methodology. *First* is the need to establish if the person interviewed has a positive self-image and the assertiveness skills necessary to fulfil the role of a consumer. In this regard, the researchers advocate informing the service user of their rights as service users. *Second* is the need to assess the competence and experience of

the service user to make decisions. In this regard, it is important to allow and encourage the service user to express all their preferences.

Third is the requirement that the interviewer make a clear statement of the purpose of the evaluation. Here it is important that service users will be provided with feedback and they need to be informed of service developments that result from the evaluation. In this way, according to Stenfort Kroese et al, the service user will be given a clear message that their views and opinions will be listened to and treated seriously.

4.4. Quality of Health Care for People with Intellectual Disabilities

The present study is not specifically concerned with healthcare but it is important to acknowledge its importance here. In residential centres for example, many clients will have severe/complex disabilities resulting in health-related problems requiring healthcare and physical nursing care (Ganesh et al 1994, Marshall et al 2003). As a reflection of this, intellectual disability nurses are trained in healthcare interventions. There are at least two other reasons why healthcare is important. One is that most people with intellectual disabilities have greater health needs than the rest of the population (Department of Health 2001) and in many cases special kinds of health needs (Powrie 2003). Two is that physical well-being is one of the dimensions of quality of life for people (Felce & Perry 1995, Walsh & Kastner 1999) and thus healthcare is an important outcome of service provision for people.

Walsh & Kastner (1999) suggest that quality of health care for people with intellectual disabilities can be defined from different perspectives. It may be defined as technical care with the emphasis on both the efficiency and effectiveness of clinical interventions. It may also be defined from the perspective of the client's views in

terms of patient satisfaction with the emphasis on the extent to which the client is satisfied with the health care provided and its outcomes. Either way, quality of health care is complex and consists of many subjective and objective variables.

Pulcini & Howard (1997) adopted Donabedian's framework for their analysis of health care models for adults with intellectual disability. This consists of the three domains of structure, process and outcome with a fourth domain of satisfaction that, taken together, are meant to address the coverage of health care. The domains of structure and process according to Walsh & Kastner (1999) are external to the individual and are largely concerned with systems while the domain of outcome is directly related to the individual at a personal level. Satisfaction is also related to the individual at a personal level and Donabedian (1992) sees patient satisfaction as constituting a special type of health care outcome. Pulcini & Howard (1997) focused on structure the first component of Donabedian's framework and examined three models for the domains of access, comprehensiveness and cost. The main contention of the writers was that the way models of health care are structured, may lead to improved processes and to more responsive outcomes of health care for adults with intellectual disability.

It should be pointed out at this juncture that most of the contemporary literature on healthcare seems to come from the consequences of people being relocated to the community where generic services are used (Walsh & Kastner 1999). In contrast, in residential centres, general and specialist healthcare tends to be routinely provided and responsive to clients needs. A probable reason for this is that since most clients have healthcare needs associated with their disability, doctors (or local GPs), nurses

and other health professionals like physiotherapists are in constant contact with clients that need them. This said, several studies located within the community point to unmet health needs in people with severe intellectual disability.

Meehan et al (1995) for example, have pointed out that people with intellectual disabilities are subject to the same diseases and illnesses as people without disabilities but are more prone to certain health problems. In particular, being underweight or obese, having visual and hearing impairment, dental caries and hypothyroidism.

Marshall et al (2003) in their study found similar health problems in health check screening of 562 children and adults. They also found little consideration was given to health promotion for people with intellectual disability.

Aldridge et al (2000) found body weights of subjects to be polarized at the extremes of overweight or underweight. They found that most of the underweight children were profoundly disabled, frail and with dysphagia (difficulty in swallowing). Aldridge et al see these findings as reinforcing the importance of feeding techniques by nurses, patience in feeding and greater attention to adequate nutritional intake for clients.

Thompson & Pickering (2001) in their study of the political and social context of care in the United Kingdom also found people with intellectual disability to have many unmet health care needs. These authors advanced a strategy for identifying and providing responsive holistic healthcare involving changes in the role of the nurse.

In particular, that of advanced practice and clinical nurse specialist roles where highly trained nurses could respond to the health needs of clients.

Finally here, Pillenger (2003) in a study commissioned by the NDA on health services for people with disabilities in Ireland, has highlighted the need for health service mapping by health boards. In her study about people with all types of disabilities, she draws attention to the fact that they are marginalised when it comes to accessing and utilising generic health services. In particular, she raises concerns about the continued use of the medical model of dependence as against a social model of independence. She also sees variations in provision of health services across health boards and the lack of choice and control available to disabled people as examples of further marginalisation. Pillenger (2003: 15) also observes that it is “only when substantial care needs exist or where there is an absence of family or informal care support, that services are provided... there are many people who are outside of the ‘care chain’ for whom no services are provided.” Based on this observation it is not unreasonable to suggest that if people in residential centres had less severe and pervasive disabilities that necessitated less urgency or demand for health/physical care, they, like other people with disabilities in the community might not be receiving the coverage of healthcare they currently get.

In summary, people with intellectual disabilities have greater healthcare needs than non-disabled people. Despite this, many people living in the mainstream community have unidentified and unmet healthcare needs. A criticism of healthcare under a medical model is that it marginalizes disabled people because it fosters dependency. In view of the fact that most people in residential centres have severe/ complex disabilities that demand urgent attention, healthcare provision is likely to be satisfactory. A reason for this is that residential centres employ healthcare professionals and thus care may be based on a medical as against a social model.

4.5 Quality Systems

A quality system refers to the roles, responsibilities, processes, policies and procedures an organisation has in place for ensuring that people carry out quality management (Evans & Lindsay 2002). Examples include quality assurance and total quality management. Managing and controlling for quality usually adopts a framework of events that follow a cyclical process the basis of which is to define expectations, compare these with observed reality and, in response, bring about a change in practice (Redfern & Norman 1996). Such a framework is described as a quality cycle (Sale 2000).

With the emphasis now being placed on quality management as distinct from quality assurance, Ovretveit (1992) describes the cycle as a management cycle because it is a part of the service strategy for planning, implementing and evaluating the management of quality and he sees it as having application to all types of services. At the minimum, the cycle usually refers to the basic processes used to guide and direct the management of quality. The cycle has a built-in feedback loop and usually commences with selecting the quality features of the service, setting standards, measuring performance against the standards, analysing the performance and taking action based on performance.

Quality cycles may contain various levels of detail like the one shown for illustrative purposes in figure 4.2. As can be seen, it emphasises values for quality, the types of standards and criteria to be included and the approaches and types of actions to be taken based on performance.

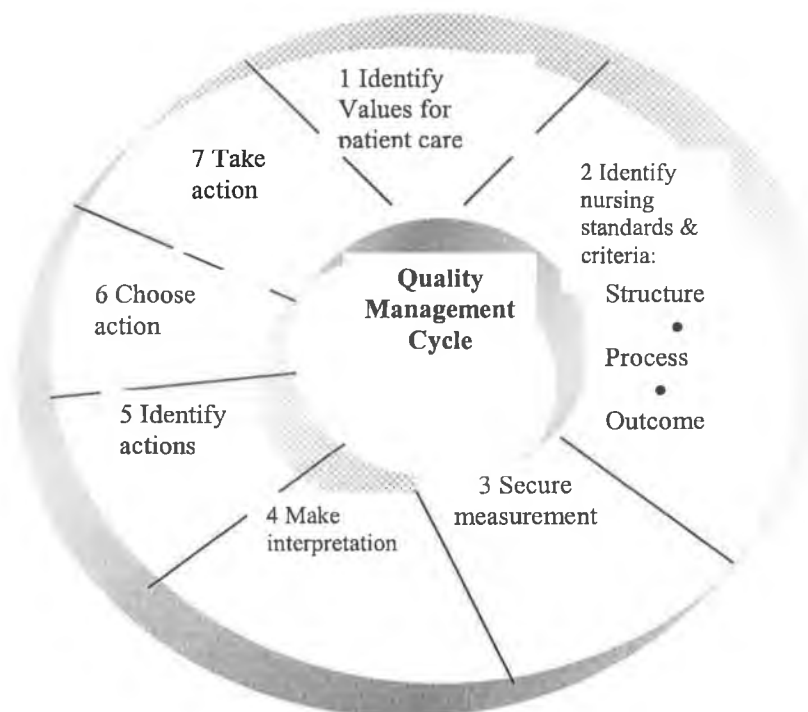


Figure 4.2 Components of a quality management cycle applied to nursing (Sale 2000. p.42)

According to Ovretveit (1992) many services do not utilise a quality management cycle because they do not have a quality system in place. The cycle seems to be based on the Deming (1986) quality improvement cycle of plan, do, check and act (PDCA). Within intellectual disability services, this writer sees two important applications of the cycle: one, it is a framework for planning and implementing quality processes and two; it is a useful framework for evaluating service provision. In addition, because the cycle is similar to the steps in the nursing process, the principles are already familiar to nurses.

In the context of health care generally, Ovretveit (1992) sees quality systems having three people-dimensions: client quality, professional quality and, management quality. Client quality has to do with what clients want from a service and how their needs are met. Professional quality has to do with how well the service meets needs as defined

by professionals and carries out processes believed necessary to meet the needs of clients. Management quality has to do with the efficient and productive use of resources within the limits set by higher authorities.

To these three people-dimensions this researcher suggests a fourth, parental/family. The reason for adding this extra dimension is because as mentioned in chapter one and repeated in chapter three, the service encounter in intellectual disability is complex and asymmetrical. It involves the nurse, the client, the client's family or advocate and the service organisation. Parents/families have an important role and contribution to service quality. At an individual level and through participation in groups like parents and friends associations, families may seek to improve services by raising awareness, providing extra resources and acting as pressure groups to promote better services.

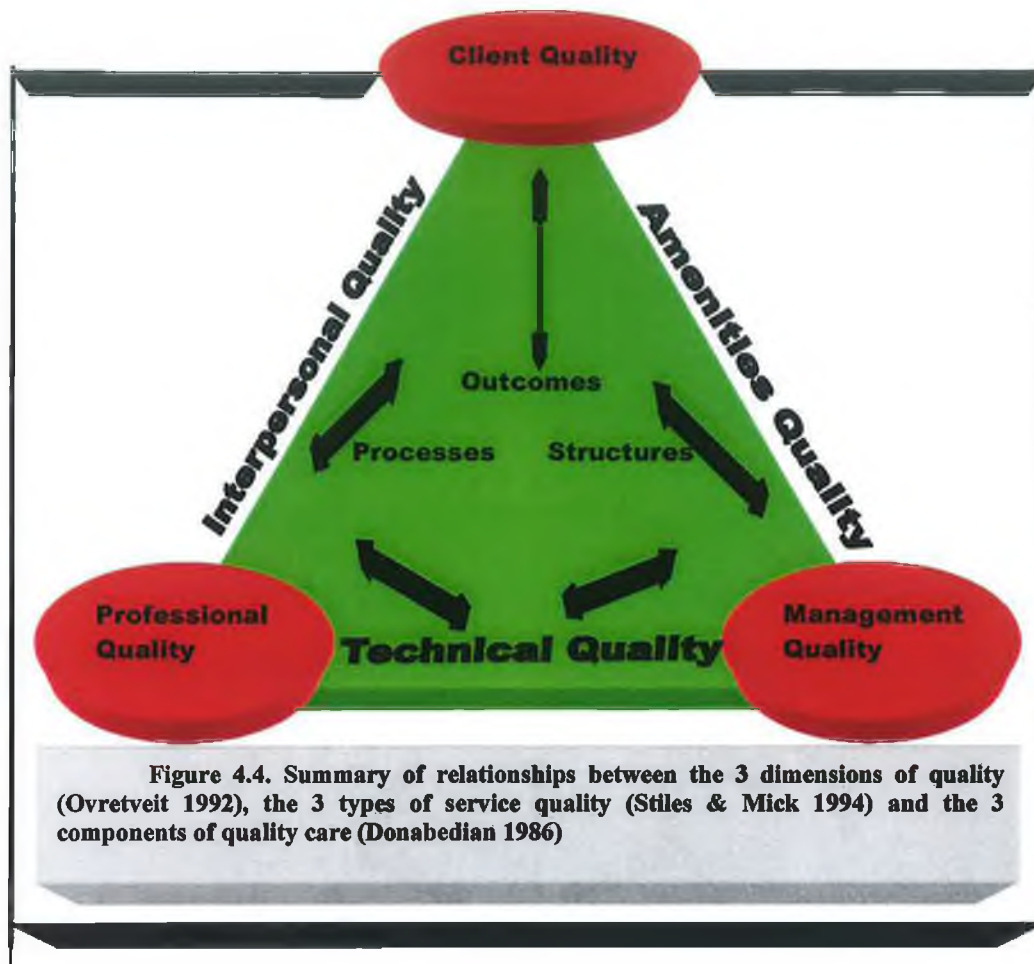
They also have a role to play in monitoring service quality and initiating organisational change (Russell 1986, NAMHI 1999). Thus, this researcher feels that to exclude parents/family from the dimensions of quality is to ignore their important contribution. For illustrative purposes, figure 4.3 below shows the relationship between the four people-dimensions of the quality management cycle.



Figure 4.3. Summary of the three people-dimensions of quality management adapted from Ovretveit (1992) with the addition of a fourth dimension of parents/ family for application to intellectual disability services.

Quality assurance, has been well established in nursing services (Kitson 1989, Sale 2000) and in intellectual disability services (Bersani & Bradley 1990, Albin 1992) and was originally based on accreditation or licensure of service agencies with the aim of ensuring and evaluating quality of care. However, as a systems approach to quality it is now becoming obsolete and is being replaced with an emphasis on quality management. More than a decade ago Katz & Greene (1992) suggested that the term was inaccurate and misleading because in fact quality cannot be 'assured' only managed or improved. Zeithaml et al (1990) also saw quality assurance as flawed and criticised programmes for emphasising programme processes at the expense of

addressing outcomes. Figure 4.4 shows the relationships between the dimensions, types and components of service quality.



An additional problem with quality assurance according to Schalock (1993), is the fact that service quality is not evaluated on outcomes alone and the only determinant of service quality that matters is that expected and perceived by the service user. Schalock (1993 p.205) advances the need for a reformulation of quality assurance by:

- Focusing on quality enhancement as against quality assurance.
- Adopting a paradigm shift to focus on strengths and capacities of the individual, integrated services and the empowerment of the person.

- Person-centred planning and partnerships with families, professionals and communities.

The replacement of 'assurance' with 'management' (or improvement) is nonetheless a relatively new way of thinking and many writers still refer to quality assurance (Marquis & Huston 2000, Sale 2000). Torres (1992) considered quality assurance as a form of internal programme evaluation with the benefits being that:

1. It becomes part of management's information processing system and avoids duplicity of monitoring/evaluating activities.
2. As a decision-making model it draws on the systems perspective, which is in keeping with the need to relate the programme's mission to care processes and quality outcomes.
3. The focus becomes directed at monitoring and self-improvement.
4. Internal programme evaluation attempts to be thorough and credible to all parties.
5. It facilitates awareness of the contextual variables of the organisation and the perspectives of stakeholders in the organisation.

Despite these criticisms, many services utilise a quality assurance systems approach. Dale (1990) for example, provided an account of how a hospital for people with intellectual disabilities introduced a quality assurance system linked to audit of care. The project team developed standards for three areas of support services, lifestyle and special needs and independent assessors from outside the service conduct the audit. Although the audit consists of 28 standards (with 300 criteria) the structures, processes and outcomes of the system are about service requirements for the client as against client personal outcomes obtained from the client

In an implementation study by Smith (1995), he describes how an organisation initiated its quality system through ISO 9000 accreditation and then used this as the basis for developing its total quality management system. The writer discusses how

the organisation adopted the Life Plan Process which is somewhat similar to the Individual Programme Plan but which requires a minimum standard of achievement from assessment stage to evaluation of outcome. Smith (1995) summarised the benefits of the ISO9000/TQM to the organisation, clients and staff as:

- *Organisation* – developing a mission, vision & the integration of business goals.
- *Client* - assessment, participation, life planning & satisfaction with outcomes.
- *Staff* – recognition, good practice, standards and participation in decisions.

This system encompassed all areas of the service and focused on client development. However, outcomes centred more on what the service wanted for the clients as against what clients needed and wanted as personal outcomes for themselves.

Capie (1995, 1996) described the service evaluation approach used in New Zealand. SAMS (Standards and Monitoring Services) is a consumer-based evaluation system and involves a team of trained evaluators evaluating a service organisation. The approach to evaluation was originally centred on the environment of residential services but was developed to focus on total lifestyles of residents. The system consists of six key standards and incorporates a two-tier evaluation approach:

1. *Key Point Monitoring* done at 6 monthly intervals by a team of consumers who look at the areas of Environment, Options & Activities and Management & Staff.
2. *PREM-Procedure for Evaluating & Monitoring*, involves evaluating the total lifestyle of a random sample of service users based on interviews and observation.

This is a quality assurance system specifically related to residential services. It focuses on clients and the evaluation approach involves asking clients about their personal outcomes as reflected in their expectations and perceptions of their lifestyle.

Despite the rhetoric of quality and the importance of service evaluation to both service user and service provider, only a few studies have been done in Ireland. Kelleher et al (1990) in a descriptive exploratory study evaluated the quality of service in 96 community-based residences. Areas looked at included the location and physical amenities, type of staff employed by agencies and the lifestyle of residents in the houses.

In a study of all residential centres in the Republic of Ireland, Redmond (1993) found that of 23 centres surveyed, 22 centres reported having some form of quality initiative in place. 30% had a total quality management system and 68% reported quality-related activities such as IPPs. Only 1 centre had no quality activities in place. Of the 15 non-TQM centres, quality activities were initiated by staff rather than by management and appeared to be the prerogative of professionals.

4.6 Critical Factors Impacting on Service Quality and Gaps in the Literature

From the literature reviewed, a number of critical factors have emerged as necessary in intellectual disability services. These factors are not exhaustive but are repeatedly singled out for attention and are seen as necessary in human services. Some are derived from the general literature but most are from the intellectual disabilities area. It is the view of this writer that since nurses are at the interface of service quality in residential centres, each of the factors has implications and requirements for nurses and management. As a summary of the literature surrounding the research problem, the seven critical factors provide a platform for identifying gaps in the literature and for deriving the research questions for the present study:

1. *To be affective, quality care must be holistic, provided across all dimensions of a person's life and responsive to the individual's needs (Raynes 1986, Health Services Accreditation 1998, NAMHI 1999, NDA 2003).* Despite this, a gap exists in the literature as little is known about the dimensions of care nurses see as important or evaluate in residential centres or whether their care is based on any analyses of needs.

2. *Service quality requires that organisational processes be in place to facilitate assessment, planning, intervention and evaluation of care (Health Services Accreditation 1998, NAMHI 1999, Irish Health System Accreditation Scheme 2000).* However, within the context of Irish residential services, no literature was found dealing with nurses' involvement in organisational care processes e.g. standards of care, service evaluation.

3. *In human services, quality is dependent on the employees and in particular their training, participation and decision making in the service (Morrison & Rahim 1993, Kondo 1997, Dahlgard et al 1998, Gates 2003).* Although literature exists on the training/education of nurses, none was found that dealt with nurses' participation or decision-making in residential services.

4. *Meeting the needs of clients is contingent upon teams and teamwork (Deming 1986, Thiagarajan & Zaire 1997, NAMHI 1999, Evans & Lindsay 2002).* While teams in intellectual disability services are of central importance to care delivery (NDA 2003), no literature was found that dealt with nurses' level of involvement or participation in teams' in the context of residential services.

4. *Quality care is reflected in the beliefs and values about people with intellectual disability and thus the service ideology or model of care used to frame the service delivery (Mercer 1992, Burton & Sanderson 1998, Northway & Jenkins 2003).*

Despite this, no literature was found that examined if nurses in Irish residential centres used a particular model to underpin or guide their care of clients.

5. *Organisational service quality is dependent upon management's support and recognition of staff and how they value staff for their contribution to the service (Ovretveit 1992, Beckford 1998, Evans & Lindsay 2002).* Within the context of residential services, no literature was found on either management support for nurses or nurses' perceptions of management support.

7. *Quality care is necessary for enhancing quality of life for people with intellectual disabilities (Schalock 1993, Felce & Perry 1995, Gardner 1997, Maes et al 2000, Northway & Jenkins 2003).* There is no evidence that the intellectual disability nurses in this study value the importance of QoL for clients. Although the present study does not investigate QoL it is an important outcome of service quality and quality care for clients.

4.7 Rationale for the Statistical Analysis for the Main Survey of Nurses

The data analysis for the present study is discussed in the methodology chapter. This section explains the rationale for the type of statistical analysis used by the researcher for the descriptive survey of nurses in residential centres. The survey is aimed at answering the following five research questions that have been derived from the critical factors discussed above:

1. What if any, are the differences between dimensions of care that nurses see as important for nursing and dimensions that nurses see as important for client care?
2. How do the dimensions of care that are the focus of nurses' interventions compare with the dimensions of care nurses evaluate most often?
3. In what ways are nurses' involved in organizational care processes used for planning and delivering care to clients in residential centres?
4. What organizational management practices do nurses identify as facilitating and inhibiting their ability to provide quality care to clients?
5. How does participation and involvement in organizational decision-making relate to nurses provision of quality care for clients?

Data relating to the variables in each of these questions was collected from the survey questionnaire, a copy of which can be seen in appendix 11. As can be seen from the questionnaire, the variables are mostly categorical so that the level of statistical measurement is essentially nominal with some questions requiring an ordinal level of response and measurement. Because the level of measurement is for the most part nominal and to facilitate description, the survey requires a more qualitative response as distinct from a quantitative response resulting in numerical data. For this survey analysis, both univariate descriptive statistics and inferential statistics will be used.

Descriptive statistics are a group of statistics used to organise and summarise numerical data from a population or sample. Inferential statistics permit inferences about whether relationships in a sample are likely to occur in a larger population of concern. The rationale for their use in the dominant survey is to ascertain if there are any statistically significant differences or relationships between the variables being investigated. The Wilcoxon signed ranks test and the Chi – square test are two non-parametric tests that will be used in this study. These are both described in chapter six.

4.8 Summary of General and Intellectual Disability Service Quality

The literature reviewed from the general and the intellectual disability service sectors indicates there is much in common between them. Both aim for a responsive consumer-driven service linked to needs and wants of the consumer/client. Both recognise the need for monitoring, measurement and feedback and thus the need for standards, evaluation and responses. However, while the two sectors share similar general aims and approaches to quality management, there are differences between them and these are summarised in table 4.5. This summary is based on the typology of technical, interpersonal and amenities quality (Stiles & Mick 1994) when looked at from the perspective of the structure, process and outcome framework of Donabedian (1986).

Dimensions of Quality	Components of quality		
	Structure	Process	Outcome
Technical	<p>IDQ: Specialist professional staff, emphasis on teamwork, Resources & equipment to provide specialist care & skill-mix of staff. Services are necessary & clients may have little choice about services</p> <p>GSQ: Depending on service type may have specialist staff & may rely on teamwork but technical service tends to be individual as against multiple. Services may not be necessary but optional</p>	<p>IDQ: Pure human services, provide constant care across the lifespan of clients. Care is holistic & responsive to all the personal needs and wants of clients. Clients may not know their needs or be able to communicate these.</p> <p>GSQ: processes often associated with a product, & are usually specific, limited to a particular service & episodic. Often optional with a choice available</p>	<p>IDQ: Client outcomes related to fulfilment of personal needs/ wants & Professional outcomes related to processes of care Management outcomes related to efficiency & effectiveness of service.</p> <p>GSQ: Depends on service type. Profit & number of service users. Fitness for purpose. Maybe related to expertise of staff & to low risks for the firm</p>
Interpersonal	<p>IDQ: Competent staff responsive to needs of clients. Empathic, patient & understanding & accepting staff. Good communications with staff,</p> <p>GSQ: Competent, pleasant & responsive staff who are able to understand & ascertain clients needs & provide service to their specifications</p>	<p>IDQ: Bonding with client in family-like atmosphere, 'Connecting' with clients, empathic relationship, promoting clients needs. Service relationships</p> <p>GSQ: relationship depends on service type, often short-term & superficial for purpose of service delivery Service encounters</p>	<p>IDQ: Warm, friendly & supportive relationships. Staff acknowledgement of clients individuality, client Satisfaction with care & activities for development</p> <p>GSQ: Cordial & helpful staff, client satisfaction with service, willingness to use the service again,</p>
Amenities	<p>IDQ: Complex array of structures - housing, and appropriately equipped specialist & therapy units & training & educational facilities</p> <p>GSQ: Offices or 'call-in' facilities that provide pleasant, non-threatening surroundings & instils confidence for service delivery</p>	<p>IDQ: Comfortable normative accommodation, Access to work, leisure & community amenities, Access to all specialist services</p> <p>GSQ: Depends on service type, pleasant comfortable surroundings, and access to helpful reception personnel</p>	<p>IDQ: Clients live, play & work in as normative an environment as possible. Clients & families feel satisfied with amenities</p> <p>GSQ: Client's view amenities as fitness for purpose & value for money & as per their expectations</p>

Table 4.5. Summary of comparison and differences between general (GSQ) and intellectual disability service quality (IDQ) Adapted from the frameworks of Stiles & Mick (1994) and Donabedian (1986).

Compared to general services quality, intellectual disability quality involves structures that are extensive and pervade all aspects of the disabled person's life (e.g. housing, employment). Processes are uniquely human and involve activities by a range of people whose concern is the safety, growth and development of the individual.

In intellectual disability, the interface of quality is dependent on service relationships between several stakeholders within a tripartite approach to care. In general services the interface is less complex and intense and the emphasis is on the service encounter.

Outcomes are concerned with enhancement of quality of life for the person, may constantly change and may not always be achieved. In short, quality care in high contact human services, especially residential services, is complex, multi-dimensional and very intangible and the level of care required by clients is usually very personal, holistic, constant and provided across their lifespan.

As discussed in chapter one, the importance of findings from this study are that they will inform nursing practice, nursing management and nursing education about issues and influences affecting nurses provision of quality care in residential centres. Findings will also contribute to the professions understanding about nurses' involvement in service quality and to the larger debate on service quality generally.

4.9 Conclusion

It is clear that quality initiatives in intellectual disability range from uni-professional or informal approaches, to organisational-wide systems such as total quality management. Most of the literature on the subject stems from service ideologies that have evolved over the past few decades, particularly normalisation (later developed as social role valorisation) and the more recent concern for quality of life for people with

intellectual disabilities. The literature suggests that these ideologies influence and, in turn, are themselves influenced by service developments such as de-institutionalisation and community care policies and practices. In turn, these developments have led to recognition of the importance of needs-led care and service evaluation for service users and their families.

Approaches to quality of care with reference to outcomes and personal outcomes were reviewed along with literature relating to client and family service relationships. Research has tended to concern itself with quality as a by-product or means of achieving QoL. This is not to imply that such studies are unimportant or less relevant, Seed & Lloyd (1997) for example, see service evaluation and the responsiveness to service users views as providing an important link between QoL values and quality of care. These and similar studies on quality/QoL illustrate major issues of concern for service providers, professionals and service users.

Healthcare for people with disabilities was reviewed briefly. Health is an important dimension of quality of life and people with disabilities have greater healthcare needs than non-disabled people. This is particularly likely to be the case in residential centres where many clients will have severe/complex disabilities requiring almost constant healthcare/nursing interventions.

It is clear that the principles and aims of service quality in intellectual disability are similar to those in the general service quality arena. However, quality and service evaluation in intellectual disability services is more complex when one considers that the prime objective is centred on assessing, measuring and improving quality of life.

The processes of quality assurance seemed easy when the major change facing the evaluator was to ensure that people had a minimal level of service and were secure from harm. Recent years however, have raised expectations on the part of service providers, families, advocates and service users. Now the demands for safety and security must be balanced with demands for good quality practice and a good quality of life.

A number of critical factors for quality were highlighted and gaps or deficiencies in the literature were identified. The rationale for the statistical analysis of the dominant survey of nurses in residential centres was outlined. Finally, in the last section of the chapter, the similarities and differences between general service quality and intellectual disability quality were summarised.

4.10 General Conclusion to Chapters Two, Three and Four

This review has drawn attention to many of the issues and concerns for service quality and quality of care. Literature was reviewed from two separate but related areas. Such an approach is important since much of what is understood about quality in human services either has its origins in general service quality, or has been influenced by the theoretical and empirical research carried out there.

Quality initiatives taking place in general services, especially service encounters and service relationships, have a profound effect on how service quality is conceptualised. In intellectual disability, the interface of quality is dependent on service relationships. These exist throughout the lifespan of the client and are multidimensional in nature because of the constantly changing needs and wants of clients. These relationships are

also complex since at the very least, they involve a dynamic multi-user partnership between clients, their families; professional care providers and service organisations.

Most of the published studies and reports of the past few decades have centred on outcomes of overall service provision to the service user and this has found expression in the literature on quality of life. Whereas quality of life is of central importance it is not the same as quality of care or quality of service. Gaps in the literature relate to theory and practice in residential care and the extent of nurses' involvement in quality. It is noteworthy that non-nurses within the context of community services publish most of the literature in the area of quality. Much of this literature is theoretical and gaps that exist may indicate either a dichotomy between this theory and the practice setting. Alternatively, there may be a lag between nurses knowing about these theoretical considerations and their readiness to integrate them into their practice. Practical gaps in the literature relate to the dearth of applied or implementation studies found dealing with nursing care in residential services.

However, methodological and implementation issues are now firmly on the agenda for service providers, professionals and service users as is demonstrated by the reports and conferences at national and international level. The application of quality measurement in the area of long-term personal social services presents challenges of a conceptual and methodological nature and the development of systems supportive of sustained and meaningful responsiveness requires that such systems fit their particular service.

CHAPTER FIVE

THEORETICAL PERSPECTIVE AND SYNTHETIZED MODEL

5.1. Introduction

This chapter is divided into two sections. Section A presents a theoretical perspective for the present study. Section B advances a model and typology developed from a synthesis of the literature reviewed on service quality in chapters two, three and four.

5.2. Section A: Theoretical Perspective

Deductive, quantitative research uses a theoretical framework or theoretical perspective as a foundation for its inquiry with the results of the study then used to support or refute the particular theory used (Creswell 1994). This section presents the theoretical perspective for the study. This is based on assessing the extent to which the medical and humanistic service models are used to underpin nursing care for people with intellectual disabilities in residential centres.

5.2.1 Use of Theory in Research

LoBiondo-Wood & Haber (2002, p.501) define theory as “A set of interrelated concepts, definitions and propositions that present a systematic view of phenomena for the purpose of explaining and making predictions about those phenomena.” Research is related to theory because it is the process by which theory is substantiated, modified or rejected. Theories attempt interpretation of phenomena but research provides the evidence for them and a means of generating new ones (Parahoo 1997).

Fawcett (1999) views theory as being associated with three specific forms of research:

Descriptive theory - basic theory that involves naming and classifying characteristics

of a phenomenon and which is tested by descriptive research techniques. Fawcett sees descriptive research as answering questions about the characteristics and prevalence of a phenomenon and the way in which a phenomenon is experienced.

Explanatory theory – specifies relationships between characteristics of a phenomenon and explains why a phenomenon exists. Fawcett points out that this type of theory should be investigated using correlational research techniques.

Predictive theory – predicts relationships between characteristics of a phenomenon or differences between groups and should be studied by experimental techniques.

Research can test existing theories or develop new ones. In theory testing, the process uses deductive reasoning, which draws upon the general picture and moves to the specific area of research or practice. In theory development, the process uses inductive reasoning, which draws upon the specific research findings and moves to the general picture (LoBiondo-Wood & Haber 2002).

The present research is a descriptive study and attempts to describe and answer questions about the characteristics of phenomena. Theory testing research is mainly in the positivistic tradition and this is the paradigm in which this present study is carried out. Parahoo (1997) has observed that theoretical framework, conceptual framework and conceptual model are terms sometimes used interchangeably in nursing research. He suggests that a theoretical framework is the term best suited to a study underpinned by a single theory. A theoretical framework according to Burns and Grove (1999) is an explicit and brief explanation of a theory or portions of a theory to be tested in a study and refers to the conceptual underpinnings of a study.

In this study, the researcher is adopting a theoretical perspective, which provides a way of regarding facts and of judging their relative significance in a particular situation (Creswell 1994).

5.3. Conceptual Models and Theory

Fawcett (1995) distinguishes the differences between conceptual models and theory. She sees a conceptual model as a more abstract general system of concepts and propositions while a theory, in contrast, deals with one or more relatively specific concrete concepts and propositions. Conceptual models are general guides that must be specified further by relevant and logically congruent theories before action can occur. Fawcett then, sees theory as being based on conceptual models because the concepts that makes up a model can generate theory when they are tested by research.

In nursing and disability practice however, while models may be used to generate theory, these models for practice are usually founded on pre-existing theories.

Elsewhere, King and Fawcett (1997) explain that a conceptual model is the network of related concepts that can be used to explain broad nursing phenomena whereas the theory is the narrative explanation that accompanies the conceptual model.

In his discussion on the subject, McKenna (1997) sees the difference between theory and model as one of abstraction, explication and application. He defines a model as:

‘ A mental or diagrammatic representation of care which is systematically constructed and which assists practitioners in organizing their thinking about what they do, and in the transfer of their thinking into practice for the benefit of the client and the profession.’ (1994. p16).

Pearson et al (1996) in their discussion about the value of nursing models, say that agreement on the use of a particular model of care has important advantages for the quality of care provided and these are listed below.

1. Consistency of care is more likely to take place with a shared model of care.
2. Agreed beliefs and values will result in less conflict within the team
3. The team will be better able to make sense of the logic and rationale for care.
4. Better direction will be provided since the team will understand goals of care.
5. Provide a guide to decision-making and model can be used to check decisions.
6. A model will provide a guide for the criteria on selecting new team members

5.4. Paradigms in Intellectual Disability Services

From the social role valorization (normalization) movement (Nirje 1985, Wolfensberger 1972, 2000) and the rhetoric on ideologies and approaches to caring for persons with intellectual disabilities (Felce & Perry 1995, Mercer 1992, Burton & Sanderson 1998) various new service models and frameworks for care and service delivery have emerged. The term paradigm may be used to refer to these different ideologies and traditions.

Kuhn (1970) was the first person to use the term paradigm. In his seminal work, the *Structure of Scientific Revolutions*, Kuhn argued that science is a social enterprise undertaken by a scientific community who develop the paradigms that guide their scientific activities. Gummesson (2000) views a paradigm as a person's value judgments, perspectives, norms and ideologies. He points out how periods of existing or normal science are overtaken as paradigm shifts when the established norms, ideologies and values are challenged. In research, Gummesson refers to paradigm as the researcher's perceptions of what he/she should be doing and how he/she should be doing it.

Some writers see paradigms as having the same meaning as conceptual models (Fawcett 1993) but other writers see paradigms as referring to broader and more general worldviews. Mercer (1992) for example, explains a scientific paradigm as:

“The fundamental worldview that members of a given scientific community share and that tells them what entities exist in nature and how these entities behave. It includes the beliefs, values, and techniques shared by members of a given scientific community and systematically transmitted to new recruits through standard textbooks, case illustrations, and apprenticeships” (p.16).

In sum, Mercer (1992) sees a paradigm as consisting of the assumptions a scientific community makes about the nature of reality and the nature of society, assumptions that may not always be explicitly stated but are passed on as “tacit” knowledge to each new generation of scientists.

Paradigms are based on theories or contain theories. As such, the term has a more general and broader scope than does theory. Several writers have discussed paradigms and paradigm changes in the area of intellectual disability practice. Cocks (1994) in his argument for a paradigm shift in service provision, uses the term to identify and analyse different and competing philosophies in human services.

According to Burton and Sanderson (1998 p.47) distinctions are made in the natural sciences between:

- a) Pre-paradigmatic science where workers or schools, work within different paradigms;
- b) ‘Normal science’ where the whole of a discipline works within one paradigm and its boundaries and;
- c) Periods of crisis or scientific revolutions’ where a new paradigm emerges and defines parameters for a new period of science

Distinctions like these may be seen in the way in which Burton and Sanderson (1998) explain the paradigm changes in intellectual disability as evolutionary. These ranged from early notions supporting theoretical and social administrative frameworks that

legitimised segregation and under-resourcing (e.g. eugenics theory). Following this came an emphasis on pathology and deficiency (e.g. biological theories). Progressing to the present situation with widespread legitimation for notions of shared humanity, inclusion, civil rights and the need for additional supports (e.g. humanistic and discrimination theories).

Mercer (1992) traces the paradigms that have underpinned intellectual disability care. She points to how prior to the 1960s, the dominant single paradigm on which service provision was delivered was the functionalist – objectivist paradigm embodied in the medical model and a derivative of this, the psychomedical model. Mercer suggests that although alternative paradigms have been advanced by the scientific community, the traditional paradigm – the medical model - has continued to be used to guide research and practice. Both the medical and psychomedical models are discussed below.

With developments like normalization and social role valorization during the decades of the sixties and eighties, and their implications for services (processes and structures), new paradigms have emerged. More recent developments like the rhetoric on quality of life in the nineties with its emphasis on the client (outcomes), the field of intellectual disability has moved from being a single dominant paradigm to one of multiple paradigms.

In her discussion on changing paradigms in the field of intellectual disabilities, Mercer refers to the work of Kuhn (1970) to interpret changes in service provision. In particular, she draws on the two dimensions that Burrell and Morgan (1979) used to

describe fundamental assumptions about their typology of four scientific paradigms:

The extreme objectivist view and the extreme subjectivist view.

1. *The extreme objectivist view* sees reality as external to the individual and as hard and measurable with common universal meaning. Human nature is deterministic and shaped by heredity and environment.

2. *The extreme subjectivist view* of reality sees cognition as the means through which all experience is interpreted. It does not deny objects and behaviours external to the individual but stresses that individuals create meaning through interaction and consensus about objects, behaviours and beliefs. Because service models are derived from scientific paradigms, each of the four fundamental paradigms from Burrell and Morgan's typology are discussed below.

1. Functionalist –objectivist paradigm is based on an assumption of objective reality, homogeneity and integration within society. For the functionalist -objectivist, the only source of knowledge about the world is through positivistic, empirical research with the only acceptable proof of facts or existence of phenomena derived through the human senses, which can be verified and replicated. Mercer (1994) sees this paradigm as the most widely employed in social science and as the oldest in disability services. It assumes disability exists in the individual, can be measured, diagnosed and treated. Within research, the preferred methodology is experimentation and in practices like care/treatment and education, it is standardized assessment, categorization and standard teaching that are employed. Mercer (1994) and Burton & Sanderson (1998) see the medical and psychomedical models grounded in this paradigm (please see below).

2. Objectivists-conflict paradigm also assumes the presence of objective reality. However, unlike the functionalist-objectivist paradigm with its emphasis on homogeneity and integration in society, this paradigm is based on differences, that are heterogeneity and non-integration within society. This paradigm is also widely used in the social sciences. According to Mercer (1994) it was only first introduced in the arena of disabilities generally during the civil rights era in America. The introduction of the paradigm at this particular period was in response to disabled people and their families exercising a voice to rebel against exclusion and discrimination in their lives.

3. Interpretive paradigm is in direct contrast to the functionalist-objectivist and objectivist -conflict paradigms above. Assumptions of this paradigm are that reality is subjective and relies on the interpretation the individual puts on it. According to Burrell & Morgan (1979) in this paradigm individuals focus on mechanisms by which they create consensus in their relationships and dealings with others. The interpretive paradigm has been important in social science since the introduction of symbolic interactionism by Mead in the 1920s. According to Mercer, the paradigm was only introduced to the field of disabilities in the 1960s in response to societal recognition of intellectually disabled people having meaningful roles and rights to self-expression.

4. Interpretive conflict paradigm also emphasises the existence and meaning of subjective reality for the individual. However, unlike the interpretive paradigm this paradigm is grounded not in consensus so that society may hold together but rather in the existence of conflict between individuals. According to Mercer, this paradigm has not been used within the field of disabilities.

5.5 Service Models in Intellectual Disabilities

From the above summary of Burrell & Morgan's scientific paradigms, Mercer (1992) was able to locate what she sees as the theoretical models in intellectual disabilities services. These models are listed in table 5.5.1.

1. Medical model	2. Psychomedical model	3. Social system model
4. Cultural pluralism model	5. Conflict model	6. Cognitive model
7. Humanistic model		

Table 5.5.1. List of theoretical models in intellectual disability services (Adapted from Mercer 1992).

Mercer (1992), suggests these models emerged at particular points in time either as a response to anti-discrimination laws in the United States of America; or reactions to new conceptualisations about people with intellectual disabilities, or as a response to the needs of vested groups of people concerned about the status and needs of disabled people in society.

Figure 5.5.1 below summarises the location of each of the theoretically derived service models in terms of Burrell & Morgan's (1979) four basic paradigms and in terms of their degree of association with the objective or subjective dimensions of reality. Of significance here is the observation of Mercer that the emergence of all these models means that the intellectual disabilities field, which was once based on a single paradigm (functionalist-objectivist), has now become multiparadigmatic.

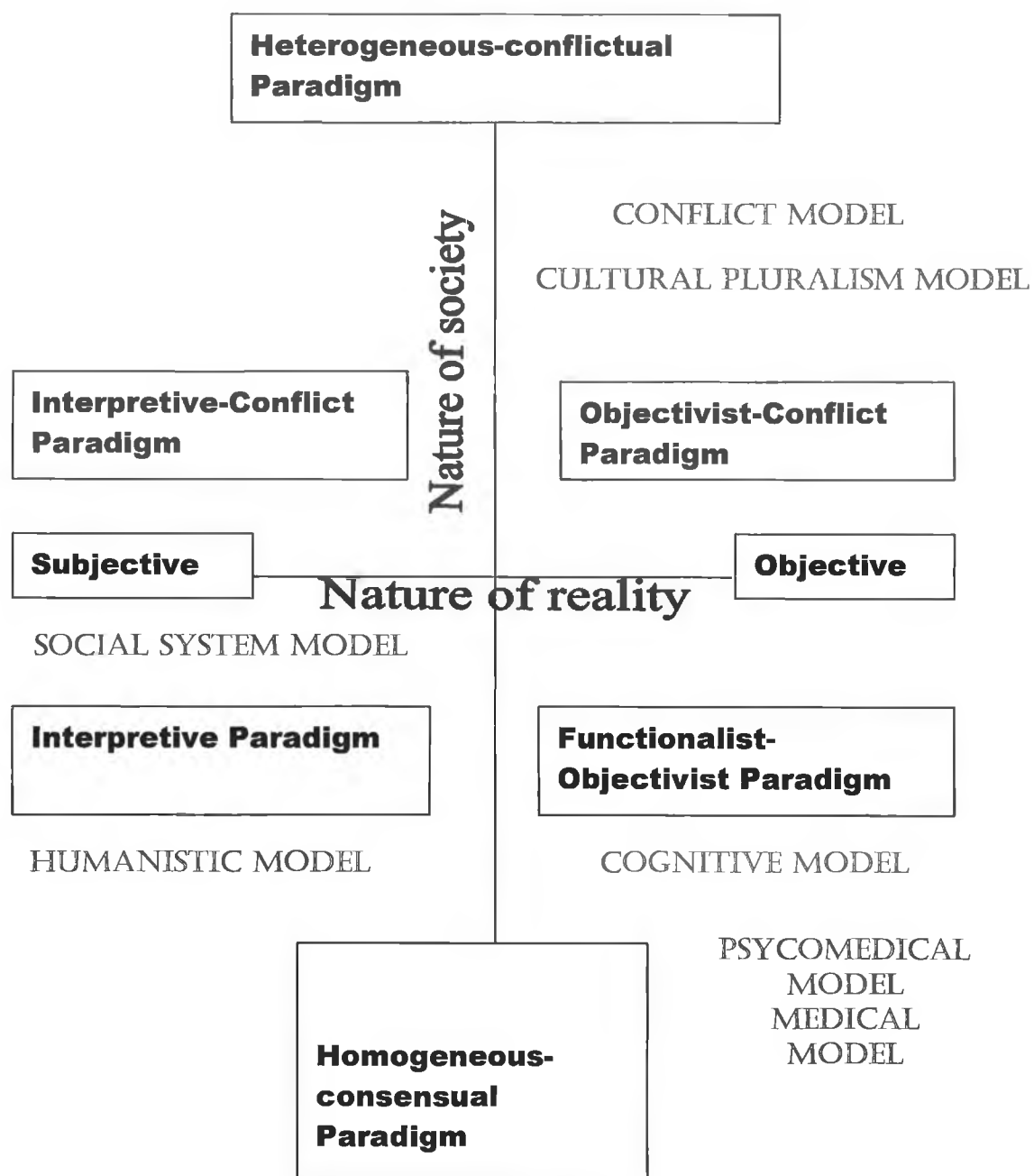


Figure 5.5.1. Summary of the four fundamental scientific paradigms and the location of service models within the paradigms (Mercer 1992)

Lying within the subjectivist area of the interpretive and homogenous-consensual paradigms (left lower quadrant of figure 5.5.1), are the humanistic and social system models. As the humanistic model is part of the theoretical perspective for the study it is discussed in some detail below.

The Social system model sees intellectual disability as a social construction that evolves from social interactions where people evaluate each other's behaviour in relation to norms and in terms of what constitutes normal or intelligent behaviour. Within the interpretive paradigm, intellectual disability is viewed as an achieved social position for the individual, albeit a devalued and marginalised one (Mercer 1992). According to this perspective, an individual may be intellectually disabled in one culture but not in another since intellectual disability is viewed as a social enactment.

Lying in the objectivist area are several models. Within the areas of the heterogeneous-conflictual paradigm and the objectivist-conflict paradigm (right upper quadrant of figure 5.5.1) are the conflict and the cultural pluralism models.

The Conflict model acknowledges the objective reality of intellectual disability as a disability. However, it sees society not as homogenous and consensual but as social structures in conflict from racial, linguistic and social class divisions. This model sees a continuous struggle between groups. The dominant groups make their values and beliefs the norm for society. They determine the curriculum, language and content of tests and thus preserve their social and economic dominance (Mercer 1992). From this perspective, people from non-dominant groups like those with intellectual disability, are disadvantaged and marginalized from educational and social opportunities.

The Cultural pluralism model also takes an objectivist view of intellectual disability and recognises the heterogeneous nature of society. It differs from the psychomedical model with its reliance on intelligence tests (see below) by proposing modifications to

that model. Instead of using intelligence tests scores as diagnostic of intellectual disability, it advances other measures that should be taken into account. For example, if children have academic difficulties in school, but are performing well in non-academic environments, this should be taken as evidence that they are not intellectually disabled. A second modification to differentiate people who are intellectually disabled from those that only appear to be, especially in cultural minorities, is to use multiple frameworks for interpreting test scores. An example of this would be to compare an individual's performance with that of other individual's from similar linguistic, educational and cultural backgrounds (Mercer 1992).

Within the objectivist area between the functionalist-objectivist and the homogenous-consensual paradigms (right lower quadrant of figure 5.5.1) are the medical and psychomedical models. These form the theoretical perspective for the study and are discussed below in detail.

The Cognitive model attributes learning difficulties to faulty learning strategies in the individual as against some biologically based disability. It emphasises motivation and assumes learning will take place when the learner becomes actively involved. The role of teaching is to facilitate the individual's motivation and to teach more efficient ways of learning. This model is not tied to statistical definitions of normal but it views cognitive skills, learning strategies and learning problems as objective realities. Whereas the standardised intelligence and achievement tests of the psychomedical model provide information about end results of learning, the cognitive model is concerned with how individuals process information and learn from instruction.

The Psychiatric model is not considered by Mercer but is discussed in brief here as many people with intellectual disabilities have mental health problems. Intellectual disability care has its historical roots in psychiatry which itself stems from the older medical model of care. While a biomedical construction of mental distress is still the focus in mental health services, (Fletcher & Stephenson 2001), new approaches to treatment and care are based on a more biopsychosocial model. This represents an eclectic approach and reflects the view that many psychological and emotional disorders are influenced by psychological and sociological factors as well as biological factors (Peplau 1952). The biopsychosocial approach has given rise to psychotherapy, psycho education, medication management and family care (Fletcher & Stevenson 2001).

These approaches and therapies mean that within the modern mental health organisation, professionals from different backgrounds work as part of a team to deliver their therapeutic interventions in accordance with the needs and requirements of their patients. None of these approaches however are mutually exclusive since the complexity of many mental health conditions frequently requires the collaborative interventions of several different professionals.

Of more recent origin is the multidimensional model known as the Tidal Model developed by Barker (2000). This model which emphasises the uniqueness of the contribution of nursing care focuses on a number of areas including the need for the person to be understood in terms of the meaning his illness has for him, his need for physical and emotional security during his illness and the type and level of supports he needs from a range of professionals and service agencies.

5.6 Theoretical Perspective for the Study

From the service models identified by Mercer (1992), three are discussed here. These particular models are highlighted partly because other writers have discussed them as practice traditions in the field, and in part because this writer sees them as particularly relevant in residential services. The three models are the humanistic or developmental, the medical and the psychomedical. Each of these has its underlying assumptions about the nature of disability and therefore its particular emphasis on the type of services required by the person. In reality of course, any one conceptual model of care is unlikely to guide thinking and practice on its own. As McKenna (1997) in his discussion on nursing models points out, there is considerable overlap between models and it would be a mistake to view them as mutually exclusive. The fact that people with disabilities have differing needs requiring different services and interventions means it is unlikely that any one specific model ever guides thinking and practice on its own.

5.6.1 The Humanistic Model

This takes a subjectivist view of reality. The underlying theory of this model is the philosophy of humanistic existentialism, a philosophical term that can be traced to the Danish philosopher Kierkegaard. Humanism as a system of thought originated during the middle ages and placed the centrality of human beings above science or religion (Bevis 1989). As a system of thought, it emphasises the value, beauty, and significance of being human and the importance of human ideals and quality of life. The philosophy of existentialism holds that each person is unique and that the whole of a human being is more than, and different than, the sum of his parts.

Among the basic tenets is that humans are thinking beings who are free to make choices and who are accountable for these choices (Bullock et al 1977, Bevis 1989). Existential psychology according to Bullock et al (1977) sees each individual as constantly making choices that cumulatively determine the type of person they become. Carl Rogers (1902 - 1987) and Abraham Maslow (1908 - 1970), the main proponents of humanistic psychology, saw psychology as being concerned with the individual's attempts to discover a satisfying sense of personal identity and meaning to life. In summary, the origins of this model can be found in the normalization / social role valorization movement (O'Brien 1987, Wolfensberger 1972, 2000) and in the concern for quality of life for people with intellectual disabilities (Felce & Perry 1995, Cummins 1997, Schalock 1997).

According to Mercer (1992), the humanistic model is subjective in its assumptions about reality and unlike the objectivist medical model, it emphasises the uniqueness of each person and their integrity within a social world. In this sense it is a social model. It is similar to what McKenna (1997) refers to as the developmental paradigm where the individual is constantly undergoing growth in their cognitive, psychological, social and spiritual development and where the role of the nurse lies in fostering such development. A basic tenet of the humanistic model is that it focuses on people's individualities and not their similarities and it rejects objectivist thinking which places people (and their disabilities) into categories (Mercer 1992). The humanistic model emphasises holism, individualistic care and development in the individual through assisted and personalized learning of new knowledge, skills and attitudes in order that they may optimize their independence and personal

competence. As such, this model then, is useful for sensitizing conceptualizations and values about quality of life for people.

Applied to the individual nurse, a humanistic nursing approach requires an existential involvement of the nurse, that is, an active presence with the whole of the nurse's being. In their theory of humanistic nursing, Patterson and Zderad (1988) see humanistic nursing as an expression, a living out of the nurse's commitment to another human being. Nursing is seen, as an existential engagement aimed at nurturing another human's potential. Patterson and Zderad see humanistic nursing as, existentially speaking, being concerned with man, his subjective self and his choices. In their theory, the care that the nurse provides is seen as being an intersubjective transaction that provides the platform for client and nurse to experience the process of making responsible choices. Humanistic nursing is not just about doing but also about being, where the nurse is open to the reality of a situation in the existential sense. The essence of this theory is that if nursing is to be humanistic the process must involve the nurse as an experiencing, valuing, reflecting, conceptualizing human being alert to opportunities for the client to exercise his freedom of choices within the limits of safe and sound practice. Viewed existentially, each nursing encounter is unique and is colored and formed by the individual participants (Patterson and Zderad 1988). Thus the nurse must consider how the client experiences his lived world and how nurturance is communicated and affected through nursing activities.

5.6.2 The Medical Model

The earliest and the oldest model in use in disability came from medicine because according to Mercer (1992), the scientific community classified as disabilities only

those conditions with evident biological components which manifested as specific anomalies like sensory disability (e.g. blindness, deafness) or physical disability (e.g. cerebral palsy). Markwick et al (2003) agree with this view and describe the medical model as more of a custodial model that is used predominantly in residential institutions. The medical model is not an explicit conceptual model in the sense of being represented diagrammatically as theory derived from concepts and propositions. This is not to say that medicine and medical care is not based on theories since these have always existed and can be traced back to Hippocrates, Aristotle and Galen (Mc Kenna 1997) and to historically more recent and supportive scientific theories like biochemistry and genetics. Rather, what is put forward as the medical model refers to a scientific rationale based on theories and which are expressed as processes and procedures that are followed in providing medical care (Aggleton & Chalmers 2000).

The medical model views the individual as a complex set of anatomical components and physiological systems. The emphasis is on the biological needs of the individual with anatomical, physiological and biochemical malfunction seen as the cause of ill health. The model stresses structure and function of body parts as against the uniqueness and integrity of the individual. As such, it is a model of reductionism as against holism (Aggleton & Chalmers 2000). Within the model, much of the individual's social behaviour and psychological processes are seen as originating in physiological or biochemical systems and many of the individual's psychological and physical health problems are seen as malfunctions of these systems. Aggleton and Chalmers (2000) see the reductionist- biological approach of the medical model proceeding through a number of discreet steps and these are summarised in table 5.6.1 below.

STEP	ACTIVITY	CENTRED ON
Assessment	Signs, symptoms and diagnosis	May be patient or doctor centered
Planning	Planning to restore bodily function	Most often doctor centered
Intervention	Treatment/therapy	Doctor centered
Evaluation	Prognosis	Doctor centered
Nurses Role	Carrying out doctors instructions	Nurses may be seen as doctors assistant

Table 5.6.1. Summary of steps usually adopted in the medical model

Mercer (1992) takes the view that the medical model sees the facticity of the objective reality of symptoms of a disabling condition in the individual. The assumptions that the disability has been caused by factors such as genetic disorders, disease processes or trauma may well be accurate as many conditions resulting in disability can either be lessened in severity or completely cured once identified and medically treated.

According to Gates and Wilberforce (2003), because of its reductionist approach, the medical model may not always have served the best interests of people with intellectual disabilities. However, they see the model as contributing to the scientific community's understanding of biological and genetic dimensions of intellectual disability and thus the contribution of medicine to the lives of people with intellectual disability remains valid. It is worth noting from the discussion on healthcare in the literature section that since most clients in residential centres have healthcare needs, it is possible these could remain undetected in the absence of the medical model.

5.6.3 The Psychomedical Model

In summary, the psychomedical model is an extension of the medical model. The model is based on a statistical definition of 'normal' that is then superimposed on the medical model. According to Mercer (1992) the origin of the psychomedical model

resides in the theory of intelligence and intelligence testing. This theory assumes that intelligence tests measure intelligence, a trait that was seen as heritable for the individual and stable during the person's life as it is based on a biological substrate. Like the medical model, the psychomedical model is objective and relies on what it sees as hard scientific facts – that low scores on intelligence tests can be used within the medical model as a symptom of intellectual disability. The next section provides further discussion and a critique of the psychomedical model. The three models and their underlying assumptions about people with intellectual disabilities are summarised in table 5.6.2.

Model	Assumptions and Emphasis for Service Delivery and Practice
Humanistic	This model emphasises the uniqueness of the individual, their personal interests and needs and focuses on their individualities and not their similarities. This model views the person as capable of growth and development (Mercer 1992, McKenna 1997). A model focusing on a subjective /interpretive view of individuals
Medical	The oldest disability model with the emphasis on the disability and dependency since it views the person as requiring predominantly medical or physical interventions in their day-to-day life (Mercer 1992, McKenna 1994, 1997). A model focusing on an objective/positivistic view of individuals
Psychomedical	An extension of the medical model where a statistical definition of normal is superimposed on the medical model, it is associated with intelligence and IQ tests and assumes intelligence is a heritable trait and stable throughout the life of the individual because it is based on a biological substrate (Mercer 1992). A model focusing on an objective/positivistic view of individuals

Table 5.6.2. Summary of three conceptual models and their assumptions about disability care (Mercer 1992, McKenna 1994,1997).

5.6.4 Reasons for Selecting the Medical and Humanistic Models

Part of the purpose of this study is to assess the use or influence of the medical and humanistic models in intellectual disability nursing in residential centres. This will be achieved by assessing the dimensions or areas of care nurses see as important for

nursing; the dimensions of care nurses identify as being important to clients and, the dimensions or areas of client care that nurses evaluate. Specific reasons for selecting these two models are outlined below.

The Medical Model has been selected for two main reasons.

One, the study is based within institutional settings where clients are likely to have severe, multiple, and complex physical disabilities and along with a range of other needs, are likely to have physical and health related needs.

Two, in Mercer's review of changing paradigms in intellectual disability, she sees a re-emergence of the medical model as the primary and predominant model in the field. Mercer's premise for this belief is founded on three main observations:

1. Demise of the psychomedical model. Intelligence tests that were until recently believed to measure differences between intelligence and achievement are now acknowledged by diagnosticians and researchers not to do so (Jensen 1989). With this premise out of the way, according to Mercer (1992), the psychomedical model collapses since intelligence and intelligence testing will no longer be defensible as the means of diagnosing and classifying people with intellectual disabilities. This said, it must be said here that intellectual disability is neither defined nor diagnosed by intelligence tests alone but includes functional and adaptive skills as well (see definition of intellectual disability on page 12). However, with less emphasis on intelligence and intelligence testing, assessment has now become a truly multidimensional approach (Mercer 1992).

2. *Re-classification of intellectual disability in the USA.* Mercer believes that if intelligence and achievement tests measure the same dimensions of performance, it is not possible to distinguish between low achievers and intellectually disabled. As a consequence of this and the successful litigation proceedings initiated by families of persons labeled with intellectual disability, there has been a need for re-classification of categories of intellectual disability.

3. *Individuals with moderate, severe and profound intellectual disabilities* will be unaffected by new classifications. People in these categories have always been recognized (without benefit of intelligence testing), as intellectually disabled. Mercer argues that with the gradual demise of the psychomedical model with its reliance on intelligence testing and the use of multidimensional and multidisciplinary assessments, intellectual disability will increasingly become a condition grounded in biological origins and will be conceptualized within the medical model. In the context of the present study, it is predominantly people with severe, multiple and complex disabilities, many with dual diagnosis, who reside in residential centres. These are the people nurses work with and care for and are the people whose needs Mercer (1992) argues, have always been identified within the medical model of care.

The Humanistic Model has been selected because:

First, in contrast to the medical model, it comes from a paradigm that emphasises the individuality, integrity and uniqueness of the individual. With many parents and professionals valuing the ideals of acceptance, inclusion and normative living for people with disabilities, this model is a social one and its assumptions constitute the rhetoric in intellectual disability services (O'Brien 1987, Wolfensberger 2000).

Second, unlike the medical model with its reductionist and dependency view of people, the humanistic model views people holistically and as independent choice-making beings. In terms of service provision, it is a social model that finds expression in efforts to relocate people to community living; support structures for education, employment and relationships, and a willingness to recognize and foster quality of life for people. Writing about this model more than a decade ago, Mercer (1992) took the view that it would take a considerable amount of time before the policy implications of the model would be known.

Finally, as Burton and Sanderson (1998) point out, different models can co-exist and where competing models exist, one over-riding model may be applied with other models feeding into it. McKenna (1997) believes that bearing in mind the complexity of human needs, in the presence of competing models, some degree of overlap will exist between them.

5.7. Conclusion to Section A

This section presented a theoretical perspective for the research study. This is based on the medical and humanistic models and the way in which these underpin and influence the care nurses provide to people in residential centres. The use and rationale for theory in research was outlined and the relationship of theory to conceptual models was discussed. Service ideologies and traditions were discussed and the term paradigm was defined. Paradigm was used to explain these ideologies and traditions as the worldview that members of the scientific community in the intellectual disability field share and which underpin thinking and professional practice in the field.

Burrell and Morgan's (1979) basic scientific paradigms were discussed and the theoretical models identified by Mercer (1992) as originating in these paradigms were outlined. Three specific service models and their assumptions about people with intellectual disabilities were critiqued in light of their significance and application to the field of intellectual disabilities. The medical and humanistic models and their assumptions and implications for caring for people with intellectual disabilities were outlined and the rationale and justification for selecting these models as the theoretical perspective for the study were discussed.

SECTION B

SYNTHETIZED MODEL AND TYPOLOGY OF NEEDS-BASED QUALITY

5.8. Introduction

This section presents a model and typology based on dimensions of human needs and their relationship to dimensions of quality of life. The model is descriptive and is derived from a synthesis of the literature reviewed in chapters two, three and four. Following the analysis of findings in chapter eight, results will be used to confirm and further develop this as an integrated conceptual model of needs based quality care.

5.9. Levels of Model Abstraction

Chapman (1985) provides a description of how conceptual models can explain the relationships of concepts for specific phenomena as either one, two, or three-dimensional:

A one-dimensional model is at the most abstract level and consists of a verbal explanation about relationships between concepts. While these relationships can be considered and manipulated mentally, they cannot actually be observed in practice.

A two-dimensional model is less abstract and illustrates relationships between concepts by means of pictures, diagrams or graphics. The model advanced in this study consists of a series of related diagrams and explanations and is thus a two-dimensional model. Such a representation is in keeping with most other models developed by nurses. According to McKenna (1997) most nursing models began as one-dimensional and were later constructed as two-dimensional.

A three-dimensional model is the least abstract of all and shows the relationships between parts in a physical format. Such a model is meant to provide the most understanding and detail. An example of a three-dimensional model is a physical model of an architect's building design.

5.10. Conceptual Model of Needs and Outcomes

Of the critical factors identified from the literature on service quality, three emerge as fundamental for intellectual disability and are repeatedly emphasised in the literature:

Processes for service quality must be needs based to be responsive and holistic.

Outcomes for service quality must be based on the enhancement of quality of life.

Processes and outcomes impact on each other and must be considered as connections.

5.10.1 Needs of Clients and Dimensions of Quality of Life

The needs of clients (dimensions of care) require specific care processes and in the context of their use here, meeting needs is viewed as process -elements of care. These process-elements are related to outcomes. Specifically, to quality of life outcomes where each set of process-elements can be seen to relate to each of the five broad dimensions advanced by Felce & Perry (1995). To remind the reader, enhancement of the quality of life of patients/ clients is a central aim in nursing (Draper 1997).

It is a fundamental outcome of service provision and the rationale for quality initiatives in services for persons with intellectual disability (Rose 1998). Quality of life may be the outcome of service provision but the dimensions of care- the needs of the client- are representative of the process elements of care for clients.

Dimensions of quality of life can be described as the conditions and circumstances of a person's life and include their objective, subjective and weighting components (Borthwick-Duffy 1992, Felce & Perry 1995). These dimensions are not hierarchical but it is reasonable to suggest that for the individual, achieving and sustaining a level of satisfaction in these dimensions is dependent on basic and higher needs being met. A further distinction between the needs and dimensions of quality of life is that some of the latter may be more important to the individual than others. Most people for example, would want and need dimensions like physical well being, to exist at an optimum level in their lives. Some people might view (or weigh) certain dimensions as less important to them and will tolerate their existence at a lower level in their lives.

The model and typology is explained through three separate but related stages:

First, are the basic and higher order needs that all people have as advanced by Maslow (1950, 1970) and their relationship to quality of life dimensions as advanced by Felce & Perry (1995).

Figure 5.10.1 schematically illustrates the relationship between specific needs and specific dimensions of quality of life. Two-way arrows signify that meeting needs affect and are affected by the dimensions of quality of life.

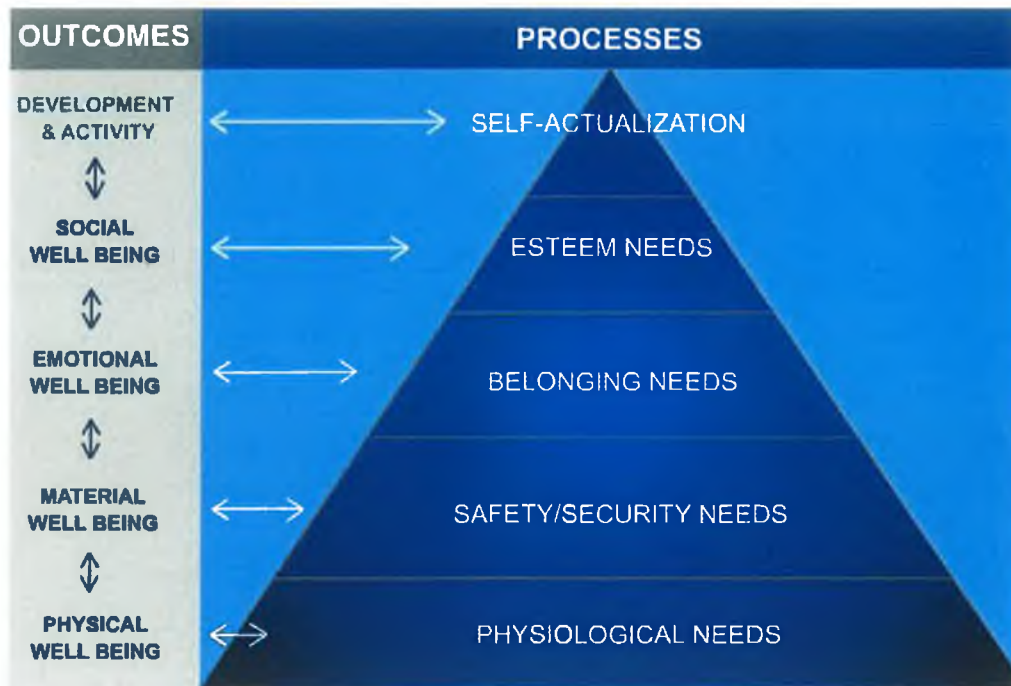


Figure 5.10.1. Shows the relationships between Maslow's Hierarchy of Needs as processes of Care and Felce and Perry's dimensions of Quality of Life as outcomes of care. (Adapted from Maslow 1970 and Felce & Perry 1995).

5.10.2 Dimensions of Needs "connections" with dimensions of Quality of Life

Second is that the relationship of specific needs with specific dimensions of quality of life are not meant to over-simplify relationships between the processes and outcomes. In reality, the ways specific needs might relate to specific outcomes is neither linear nor solely dependent on one group of met needs leading to a specific outcome. Instead, relationships are complex with satisfaction or deficits in some needs impacting on more than one outcome. They are advanced here as a means of understanding the ways different needs might connect with different dimensions of quality of life.

Seed and Lloyd (1997) take the view that for descriptive and measurement purposes, dimensions of quality of life are usually discussed as discrete aspects of a person's life. However, because of the complex inter-relationships between dimensions, for example, social well being and physical well being, if a change occurs in one of these dimensions it is likely to have an impact on the other. An example of this would be if a person becomes ill or disabled, their physical well being is likely to affect their activities and leisure (social well being). Seed & Lloyd see writers making "connections" between care and service interventions and their effects on quality of life but criticize them for their failure or omission to consider ways in which any one dimension of quality of life may affect and be affected by other dimensions. Instead of dimensions being discrete and separate, Seed and Lloyd view them as continuous with their inter-relationships being the "connections" between them.

In addition, these "connections" according to Seed and Lloyd, occur at the micro level between the individual, his/her family, work, and community and thus at the nurse/client interface. Figure 5.10.2 illustrates schematically, the inter-relationships and connections between the needs of clients, the process elements for meeting these needs and the specific outcome elements of quality of life. Two-way arrows indicate the inter-connections between the elements and between the different dimensions of quality of life that influence and are influenced by each other.

This researcher advances these as conceptualizations for understanding and thinking about caring for persons with intellectual disability and as a means for generating hypothesis for further research

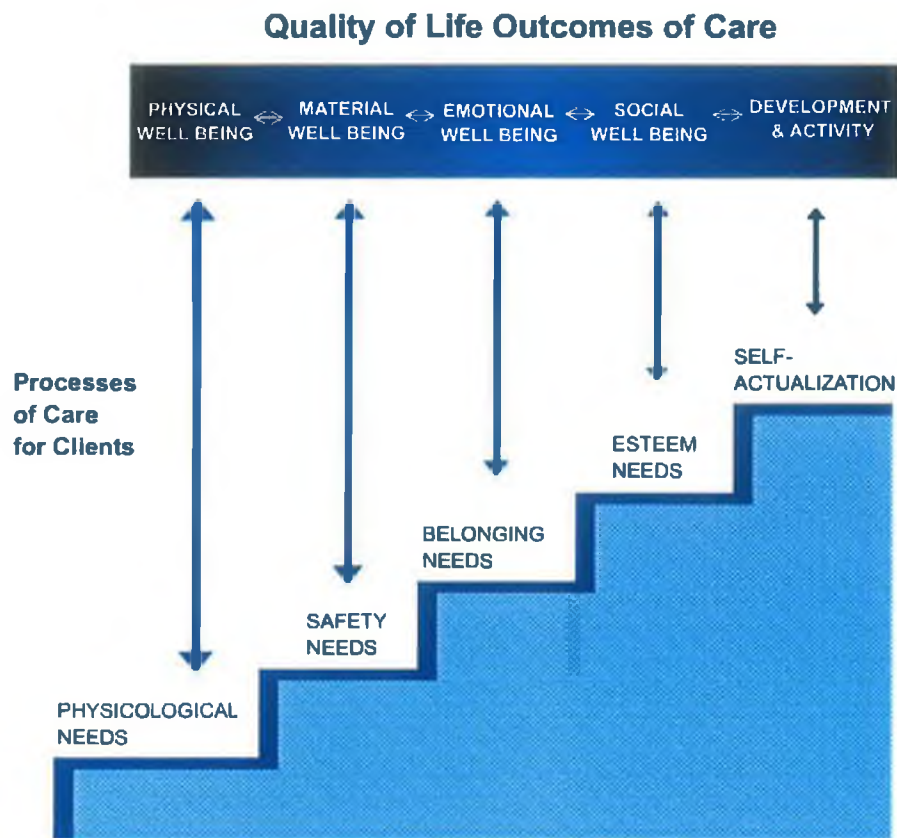


Figure 5.10.2 shows the relationship between dimensions of quality of life outcomes and needs of clients as dimensions of care. Two-way arrows indicate how each quality of life outcome influences and is influenced by processes of care to meet each level of need. Source: Redmond 2004. (Adapted from Maslow 1970 and Felce & Perry 1995).

5.10.3 Typology of Service Quality for Intellectual Disability Services

Third is that from the synthesis of needs of clients (dimensions of care) with dimensions of quality of life (outcomes of care), it is now possible to construct a typology. This uses a similar framework to that advanced by Stiles and Mick (1994). (See chapter two, pp.62-63). However, whereas their framework is organisational – led, the model advanced by this researcher is client-led. To achieve this, the variables for organisational quality used by Stiles and Mick have been substituted with those for client quality. Figure 5.10.3 shows the typology as a matrix of the five broad needs

or dimensions of care based on Maslow's (1954) needs theory placed on the vertical axis. Felce & Perry's (1995) five broad dimensions of quality of life as the outcomes of care are placed on the horizontal axis. This typology will be useful for thinking about and planning care. The application of the typology will be discussed following the analysis of findings in chapter eight.

HIERARCHY OF NEEDS DIMENSIONS (Maslow 1954)	QUALITY OF LIFE DIMENSIONS (Felce & Perry 1995)				
	PHYSICAL WELL BEING	MATERIAL WELL BEING	SOCIAL WELL BEING	DEVELOPMENT & ACTIVITY	EMOTIONAL WELL BEING
PHYSIOLOGICAL					
SAFETY & SECURITY					
LOVE & BELONGING					
SELF ESTEEM					
SELF ACTUALISATION					

Figure 5.10.3 Typology for service quality showing relationship between the five broad needs dimensions of care as exemplified through Maslow's (1954) needs theory and the five broad dimensions of quality of life as exemplified thorough Felce & Perry's (1995) dimensions of quality of life (Redmond 2004).

5.11 Conclusion to Section B

This section presented a model and typology of needs based quality from a synthesis of the literature reviewed in the area. The model shows the relationships between dimensions of needs and dimensions of quality of life as the outcomes of these needs. An important element of the model is the processes for achieving specific needs and outcomes and the recognition of the inter-connections between all the dimensions. Following the analysis of findings in chapter eight, the model will be confirmed. In

light of this, it will be developed further as an integrated conceptual model of needs based quality care.

The typology of needs-led quality care is advanced as an adjunct to the model. It will be useful to nurses and other professionals when considering relationships between needs of clients and dimensions of quality of life as outcomes of meeting these needs. It will provide a useful means for thinking and planning care. In particular, it will be useful for pointing to areas where professionals may need to concentrate their attention because it will show gaps in care provision. Findings will be filled-in from the present study following the analysis of findings.

CHAPTER SIX

METHODOLOGY

6.1 Introduction

Literature reviewed in the preceding chapters and the conceptual model synthesized from this literature show that in intellectual disability services, an overarching concern is with processes for meeting the needs of clients and the way these impact on quality of life as outcomes of service provision. This chapter explains the purpose of the research study on quality service for persons with intellectual disability in residential services and describes the methodology and design for the study.

6.2 Purpose of the Research Study

To describe nurses' perceptions of service quality by investigating dimensions of care they see as important; the management processes they see as facilitating quality and, their level of participation and involvement in decision-making in residential centres.

Develop a model and typology from the theoretical literature in the area and confirm and develop this as an integrated conceptual model in light of findings from the present study.

To use the findings to indicate the extent to which nurses in residential centres use a particular service model to underpin their nursing care of clients.

6.3 Sample Population and Sample Selection for the Study

Samples and sample selection is discussed in detail under each of the three empirical investigations conducted as part of the study. In summary here, the study consisted of two phases with the results of the first phase used to inform and plan the second phase.

6.4 Research Questions

From the summary of literature reviewed, seven factors emerged as being critical and necessary for quality in intellectual disability services (please see pages 140-142). In discussing these factors, gaps were found relating to intellectual disability nursing care and organisational management where little or no knowledge or information was available. The present study seeks to provide understanding and closure of these gaps by answering the following research questions:

1. What if any, are the differences between dimensions of care that nurses see as important for nursing and dimensions that nurses see as important for client care?
2. How do the dimensions of care that are the focus of nurses' interventions compare with the dimensions of care nurses evaluate most often?
3. To what extent are nurses involved in organizational care processes used for planning and delivering care to clients in residential centres?
4. What organizational management practices do nurses identify as facilitating and inhibiting their ability to provide quality care to clients?
5. How does participation and involvement in organizational decision-making relate to nurses provision of quality care for clients?

6.5 Limitations of the study

The study is limited to a sample of nurses employed in clinical practice at either staff nurse or charge nurse level since these are the grades of nurses who provide hands on care and thus form the population from which the sample has been drawn. While the results will generalize to the population of nurses working in residential services, such generalizations will not apply to nurses in the areas of community or day services.

A further limitation of the study is its descriptive design, with the methods of data collection confined to surveying nurses working in residential care.

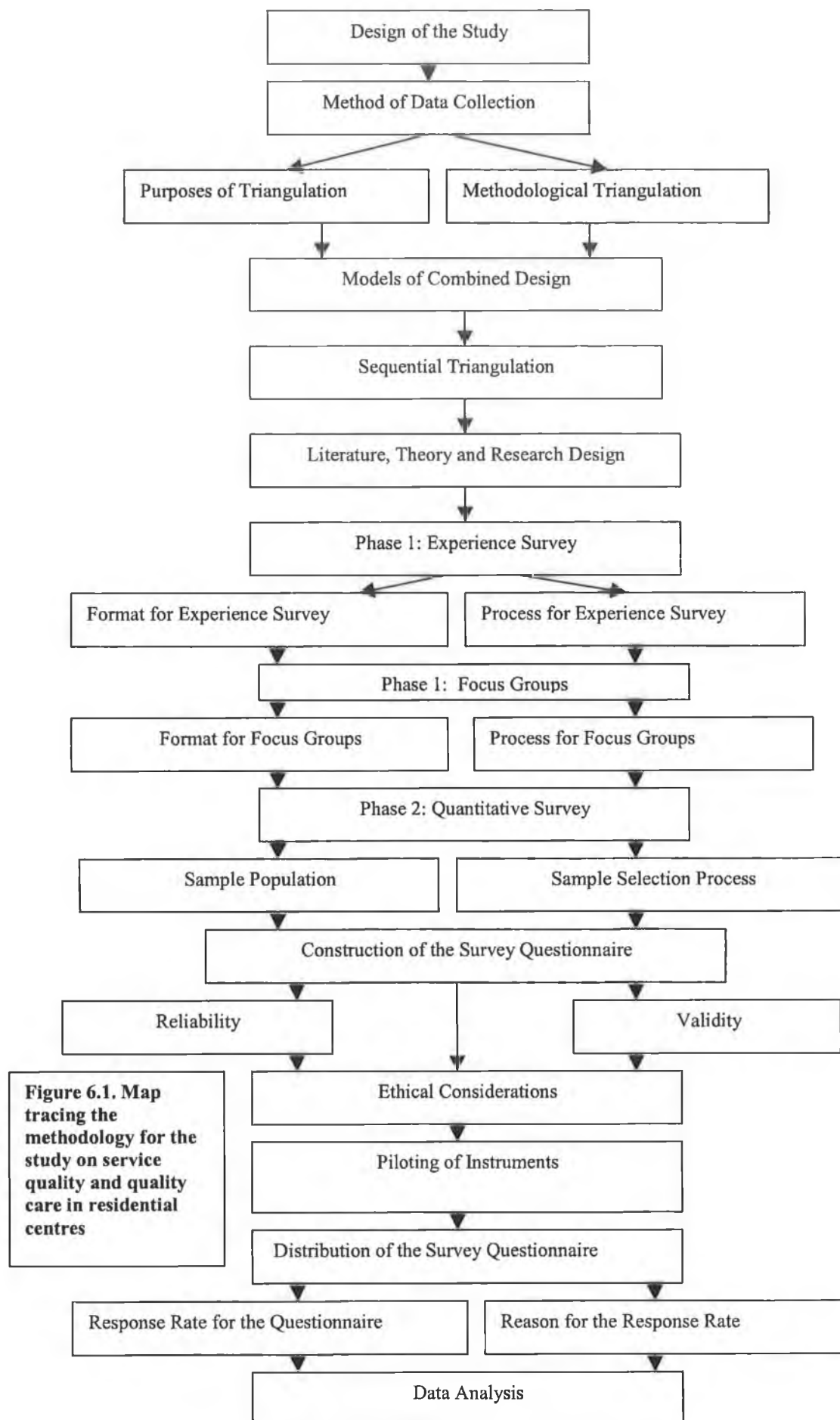
6.6 Design of the Study

This research study is grounded in the quantitative paradigm. It is descriptive and uses a two-phase dominant- less- dominant design. The dominant phase is a quantitative survey. The less-dominant phase consisted of an experience survey of experts in the area and two qualitative focus groups with nurses in clinical practice. The reason for the less- dominant phase was to help construct the survey questionnaire for the dominant phase and to elaborate on the results of the survey (Creswell 1994).

6.7 Method of data collection

To answer the research questions, it was decided to use a combined design through the process of triangulation. The reason for such an approach was to add depth and richness to the data and facilitate verification of information. In research, triangulation has been described as a combination of two or more theories, data sources, methods, or investigators in one study of a single phenomenon (Denzin 1989).

Figure 6.1 below is a map tracing the outline of the methodology for this study on Quality Service and Quality Care for Persons with Intellectual Disability living in Residential Centres in the Republic of Ireland.



6.7.1. Purposes of triangulation: Confirmation & Completeness

Two basic purposes of triangulation are identified in the literature. Confirmation refers to the confirmation of data on a variable (Jick 1979, Fielding & Fielding 1986, Denzin 1989). Fielding & Fielding (1986) for example, say the important feature of triangulation is not just the combination of data, but also the attempt to relate them in a way that will counteract threats to validity, which may be found in one single method.

Webb et al (1981 p35) point out that “once a proposition has been confirmed by two or more independent measurement processes, the uncertainty of its interpretation is greatly reduced. The most persuasive evidence comes through a triangulation of measurement processes.” This position is consistent with Denzin (1989) who takes the view that the fundamental outcome of triangulation is to confirm the researcher’s results and conclusions.

Completeness is a second basic purpose of triangulation. Jick (1979) describes a completing purpose in addition to a confirmation purpose where a more complete, holistic and contextual portrayal of the data is captured. Fielding & Fielding (1986) point out that combining of multiple methods (or theories) in a single study adds to the researcher’s depth and breadth of understanding. They also link the term triangulation to the goal of completeness. In addition to these two basic purposes of triangulation, Greene et al (1989) suggest others:

Developmental – where the first method is used to help inform the second method;

Expansion – where the mixed methods add scope and breadth to the study; and

Initiation – where contradictions between methods may result in new perspectives.

Denzin (1989) has described four basic types of triangulation:

1. Data triangulation with three subtypes- time, space and person.
2. Investigator triangulation involves the use of multiple investigators instead of just a single investigator.
3. Theory triangulation employs the use of multiple rather than single perspectives for the same objects.
4. Methodological triangulation may entail either a within method approach or a between method approaches.

6.7.2 Methodological Triangulation

Denzin (1989) regards this approach as a more satisfactory form of method triangulation where dissimilar methods are used to illuminate the same class of phenomenon. He points out that the rationale of this approach is that the flaws of one method are often the strength of another and by combining methods; researchers can achieve the best of each while overcoming their unique deficiencies. Denzin (1989) also adds that the researcher using different methods should not expect findings generated by different methods to merge into a coherent picture. Rather, each method will yield a different picture and slice of reality and this is what methodological triangulation allows to happen.

6.8 Models of Combined Designs

From a review of the major paradigms of research, quantitative and qualitative, Creswell (1994 p177) puts forward three models of triangulation design:

1. *Two-phase design*. In this model the researcher proposes a qualitative phase for the study and a separate quantitative phase. Creswell points out that this design keeps each paradigm separate and allows the researcher to present each phase separately. A disadvantage is that the reader may fail to see the connection between the two phases.

2. *Mixed –methodology design*. Represents the highest degree of mixing of paradigms. This approach according to Creswell (1994) requires complete mixing of the paradigms throughout the entire research process. It also requires working forth and back between inductive and deductive thinking in the research and adds considerable complexity to a design.

3. *Dominant-less dominant design*. Creswell (1994) argues that this model allows the researcher to conduct the study within a single dominant paradigm with one small component of the total study drawn from the alternative paradigm. Creswell (1994) sees the advantage of this design as presenting a consistent paradigm throughout the study while gathering limited information to probe one aspect of the study in detail. A disadvantage Creswell sees is that purists of either qualitative or quantitative paradigms may find models of combined design unacceptable since the central assumptions of the study would not link or match the qualitative or quantitative data collection procedure.

6.9 Sequential Triangulation

The design of the present study employs sequential triangulation where two phases of the research are conducted with the results of the first phase used for planning the second (Creswell 1994). . Sequential triangulation was used for the purpose of exploring and generating the constructs and variables required for the development and construction of the dominant quantitative survey of nurses. Construction of the survey questionnaire was achieved through three sequential stages.

First, theoretical and empirical literature from the area was reviewed as secondary research for the study and theoretical and practice-based issues relevant to the research problem were identified.

Second, issues identified in the literature were used to develop a survey questionnaire for a small-scale experience survey (Selltiz 1965). This survey was conducted through personal interviews with experts in service quality in learning disability services. The survey was used to explore the area, (especially in the sense of what was happening in the context of Irish services), identify constructs, clarify issues raised in the literature, and provide information and topics for the next stage (please see appendix 2).

Third, issues identified from both the literature and the small-scale experience survey with experts were used to develop an interview guide for two experiential focus groups with nurses working in clinical practice (please see appendix 6).

6.10 Literature, Theory and Research Design

Creswell (1994) points out that both literature and theory should be consistent with the paradigm being used by the researcher. The researcher takes this approach and uses the theoretical literature to drive the dominant paradigm, the quantitative survey.

6.11 Phase 1: Experience Survey

The first stage of the less-dominant phase was a small-scale experience survey conducted through personal interviews with members of the Task Group on Quality set up in 1997 by the Federation of Voluntary Bodies for the Mentally Handicapped. Underpinning the work of the Task Group at the time were government reports including 'A Strategy for

Equality: Report of the Commission on the Status of People with Disabilities' (1996) and 'Enhancing the Partnership: Report of the Working Group on the Implementation of the Health Strategy in Relation to Persons with a Mental Handicap (1997).' The Task Group membership consisted of nine individuals all of whom had background knowledge and experience of quality in intellectual disability services. The reason for the survey of Task Group Members was to explore their experiences and observations of nurses in the context of service quality, identify constructs and variables for the main survey questionnaire and plan for the focus group interviews with nurses.

According to Selltitz et al (1965), social practitioners in particular areas have a reservoir of experience that can be invaluable in helping a researcher become aware of important influences operating in particular situations. The authors point out that in the formulative and discovery functions of an experience survey it is necessary to allow respondents to raise issues not previously considered by the researcher. Selltitz et al also emphasise that since the aim of an experience survey is to gain insight into the relationship between variables and to seek provocative ideas and useful insights from respondents, it is important to ensure a representation of different types of experience.

With these considerations in mind, interviewees for this study were important because:

1. Each person had experience, knowledge and valuable views about service quality.
2. Each person represented a different professional discipline ranging from psychology and education to nursing and management.
3. Each person had a management responsibility and all occupied different levels of management in their services.
4. Each person had a service responsibility and commitment to quality in their service.

5. Each person represented a different service organisation for the mentally handicapped.
6. All organizations were geographically dispersed throughout the country.

In summary, it was felt that individually and collectively, Task Group Members would provide valuable insight and information on a broad spectrum of issues relating to quality of care and service quality by frontline nursing staff working in services.

Of the 9 members of the Task Group, one was the researcher and one member declined to participate. The remaining 7 members all consented to be interviewed. The member who declined to take part said she felt she had nothing to contribute as she had already discussed her views on quality during the fortnightly meetings of the group, which took place over a period of one year as they investigated quality initiatives in Irish centres.

6.11.1 Format for the Experience Survey

All interviewees were initially contacted by telephone and reasons for the interview were explained. Following this, arrangements were made for each interview and confirmatory and thank you letters were sent to each person (please see appendix 1). Interviewees were seen either in their own service organisation or a nearby venue of their choosing. All interviews for the experience survey were in-depth and lasted approximately two hours. Interviewees were assured of confidentiality of information and anonymity for their organisation.

6.11.2 Process for the Experience Survey

As the experience survey was conducted through personal interviews with the respondents, the researcher utilized the guidelines provided by Polit & Hungler (1995) and Hussey and Hussey (1997) for conducting interviews. Questions for the experience survey were developed, from the critical factors and gaps identified in the literature and from the contemporary developments in the service generally. The questionnaire, a copy of which can be seen in appendix 2, consisted of 19 questions. Prior to its administration, the researcher discussed the questionnaire with his supervisor and with colleagues.

The interviews were not tape-recorded. The reason for not using a tape recorder was in part because some of the respondents felt they would talk more freely without being recorded and in part because it was easy to explain, clarify, recheck and record respondents experiences and comments as the interview proceeded. In keeping with the aims of an experience survey, interviewees were asked to provide comments and additional information beyond those questions from the survey questionnaire. At the conclusion of each interview, the researcher checked respondents' answers to the questions on the questionnaire. Appendix 3 presents a summary of findings from the experience survey.

6.12 Phase 1: Focus Groups

The second stage of the less-dominant phase involved two experiential focus groups that were used developmentally. A focus group is a form of group interview that capitalizes on communications between research participants for the purpose of generating data (Kitzinger 1995). It consists of a group of individuals who are selected and assembled by

the researcher to discuss from personal experience, the topic that is the subject of research. According to Powell & Single (1996), as a research technique, a focus group uses guided, interactional discussion, in order to generate the rich details of complex experiences and reasoning behind an individual's attitudes, beliefs, perceptions and actions. They argue that focus groups are particularly useful when current knowledge about a subject is inadequate and elaboration is important, and when the subject under investigation is complex and concurrent use of additional data is necessary for validity.

Powell & Single see focus groups as useful prior to quantitative studies when a researcher wishes to explore or assess the views and knowledge particular groups hold about a topic and to generate issues for the construction of a relevant and valid questionnaire. Vaughan et al (1996) concur with this view and add that focus groups can assist with the identification of categories and constructs that researchers might not otherwise have considered. Krueger (1988) and Morgan (1993), also view the data produced by focus groups as particularly useful for generating issues and content for questions in the construction of survey questionnaires.

The reasons for employing focus groups as part of this research study was twofold:

1. To explore the topic of quality care with groups of nurses representative of those from the sample population. This was considered important since the concept of quality is elusive and that of service quality is complex.
2. To develop and clarify variables for the question items in the construction of the survey questionnaire to be used with the large sample of nurses in the main study.

6.12.1 Format for the Focus Groups

Focus groups have been widely used in marketing but are also used extensively in nursing research (McElroy 1995, Smith et al 1995, Powell et al 1996, Sheerin 2002). In the present study, focus groups were used to explore the participants' thoughts, feelings, perceptions and experiences of quality care and thus their purpose was experiential. Fern (2001), asserts that experiential focus groups are appropriate when the researcher has no interest in generalizing beyond the population of interest and where the shared beliefs, opinions, attitudes and perceptions- and not necessarily their underlying dimensions- are the focus of inquiry. According to Fern, experiential focus groups are concerned with the sameness and not the difference between participants and thus participants should be homogenous with respect to characteristics of interest in the particular population.

Experiential focus groups deal only with information known to the participants; this form of focus group emphasizes intersubjectivity between participants. Fern (2001) sees the sharing of common experiences happening when there is cohesion in the group and a collectivist value orientation is present. Fern also sees experiential focus groups as being especially useful when a researcher is interested in triangulation and confirmation of information, which in this study is used for the construction of the survey questionnaire.

The members in each of the two focus groups were chosen because they shared key characteristics relevant to the research. To ensure the focus groups contained the full range of possible observations, theoretical sampling was used (Powell & Single 1996). This was achieved by drawing on the theoretical literature on service quality and health care quality; the curriculum of training of nurses; and the researcher's knowledge of practice settings in residential service organizations in Ireland.

Nurses taking part in the focus groups did not know or work with each other and all came from geographically dispersed organisations. In each group, members were relatively homogenous since they all worked in clinical practice and in residential settings and all had similar qualifications. There was an interval of two weeks between the two focus group meetings and both were conducted in the same venue and each lasted two hours. Participants were contacted by telephone initially and were asked if they would like to join a group of nurses to talk about topics important to their practice. They were not informed of the specific purpose of the group discussions so as to avoid bias (Krueger 1988, Morgan 1993). Following agreement, participants were sent a formal letter seeking their consent and advising them they could withdraw at any time. Information was sent about directions, times and the location of the venue. Copies of letter seeking permission to conduct the focus groups in the researcher's place of work, and letter of invitation to the focus group can be seen in appendices 4 and 5 respectively.

6.12.2 Process for the Focus Groups

Planning and preparation for the focus group meetings took place over several weeks and followed the guidelines and rules for focus groups as provided by Krueger (1998). In order to listen and observe the dynamics of the group, participants sat in a semicircle where they could easily see each other and each had their name displayed on their chair for easy recognition. Discussion was facilitated and coordinated by a moderator whose role was to introduce the purpose of the meeting and provide the ground rules for the discussion. The moderator asked the questions, facilitated and encouraged participants to talk and provided prompts only if necessary. The moderator also probed the participants' comments for deeper meaning or clarification when required.

The researcher's role during the meetings was to observe participants and their interaction with each other, especially the intensity of how they felt about an issue. The researcher took notes and was responsible for tape recording the discussion. Prior to the meetings, the researcher and moderator (a colleague of the researcher) worked together to prepare for the meetings. The first focus group consisted of 9 nurses of whom 2 were male and 7 were female. The second focus group consisted of 5 nurses of whom 4 were female and 1 was male.

The schedule of questions for the focus groups consisted of 12 open-ended questions. The first two questions were introductory questions to establish rapport and focus thinking; the next nine questions were the key questions. A copy of the schedule of questions can be seen in appendix 6. Just before the conclusion of the meeting, the moderator provided a summary of the group discussion and the points raised. Following the summary, a final question was asked to find out if participants had any additional comments to make before closure of the meeting.

6.13 Phase 2: Quantitative Study

For the dominant quantitative phase of the research it was decided to use a survey. Denzin (1989, p.139) defines a survey as a "methodological technique that requires the systematic collection of data from populations or samples through the use of the interview or the self-administered questionnaire." Surveys are investigations where self-report data are collected from a sample where the purpose is to describe a population on some variable or variables of concern to the investigator (Nieswiadomy 1998). According to Babbie (1990), the purpose of a survey is to generalize information collected from a

sample of a population to the whole population so as to make inferences about characteristics, attitudes or behaviour of that population.

The purpose of this survey was to collect information from a sample of a population of nurses working in residential centres in order to generalize to the whole of that population in the Republic of Ireland. The reason for choosing a survey was because of the large population of nurses involved, the fact that they were a relatively homogenous population with reference to important key characteristics, and the fact that they were geographically dispersed. Three methods were considered for the survey.

First, personal interviews: these are important for as Judd et al (1991) say; they can provide the best source of data quality. The interviewer is able to establish rapport and motivate the respondent and can correct misunderstandings. The interviewer can also probe inadequate answers and clarify questions. Judd et al draw attention to disadvantages that include interviewer bias and the high cost involved, especially in time. Because the survey was anonymous and since a large representative sample of nurses was required, this approach was rejected.

Second, telephone interviews: these were considered since as Judd et al (1991) point out, their advantage is speed and convenience and they can permit a high response rate. A disadvantage with this approach is that some respondents might not be contactable by telephone. Another disadvantage is that there were too many questions on the questionnaire for a telephone survey. Because of these disadvantages, the fact that the researcher had no access to the identity of respondents, the need for anonymity and, the large sample involved, this method was also rejected.

Third, written questionnaires. Judd et al (1991) see the advantages of questionnaires as being their low cost, the avoidance of interviewer bias and the fact that they place less pressure on respondents for an immediate response. Other advantages according to Nieswiadomy (1998) is that questionnaires are:

1. A quick means of obtaining data from a large number of respondents
2. Among the easiest instruments to test for reliability and validity
3. Less time consuming than interviews
4. Suitable for obtaining data from respondents in wide-spread geographical areas
5. Necessary for allowing respondents to remain anonymous and thus collect more honest answers

The major disadvantage according to Judd et al is the low response rate. Other disadvantages are poorer data quality affecting accuracy and completeness of questions and the loss of opportunity to correct misunderstandings or clarify questions for the respondents. Despite these disadvantages, a written questionnaire was chosen as the research instrument. Judd et al (1991) suggest written questionnaires are appropriate when seeking information on facts, opinions and perceptions from homogenous groups. The population of nurses involved in this study is relatively homogenous since they have similar professional training and work in similar settings.

6.13.1 Sample Population for the Dominant Quantitative Survey

The population was all the registered mental handicap nurses working in residential centres in the Republic of Ireland. At the time of collecting the data there were a total of 4,200 nurses of whom the vast majority was employed in residential services (An Bord Altranais 1999). In view of the large numbers of nurses, a sample was drawn for

inclusion in the dominant quantitative phase of the study. To generalize the findings to the total population of nurses in residential care, a representative sample of sufficient size was necessary in order to reduce the standard error of the sample size while increasing the level of accuracy of the sample findings to the population (Nachmias & Nachmias 1996). Sample size is important but according to Nieswiadomy (1998), of more importance is how representative the sample is. The sample in this study is homogenous with respect to the variables being investigated.

In order to generalize the findings and given that the researcher had access to the full list of the population of nurses, probability sampling was employed using a simple random sample design. The size of the sample was determined by means of the Sample Size Calculator (Creative Research Systems 2001). From the 4,200 nurses on the register and for a confidence level set at 95%, a sample size of 353 nurses was required for the survey. An actual sample of 460 nurses from residential services was selected for the study.

6.13.2 Sample Selection Process

An Bord Altranais (Irish Nursing Board) undertook the process and procedure for accessing the population of nurses at the request of, and in collaboration with, the researcher. This was achieved through a random selection of nurses from the computer data banks of An Bord Altranais. From the 4,200 nurses on the register, a random sample of 460 working in residential centres was selected as the population of interest. Only nurses meeting the inclusion criteria, that is, working in residential care and practicing at staff nurse or ward sister level, were selected.

The sample of 460 nurses constituted 11% of the population of practicing nurses since only nurses on the register can be employed as nurses. Prior to the random selection for piloting the questionnaire and for the main study, the researcher delivered all questionnaires, cover letters and stamped addressed envelopes for the posting and return of questionnaires to the computer department of An Bord Altranais. Since only the computer operator knew the names of nurses in the sample, the procedure involved this person inserting the names of nurses on the cover letter, coding questionnaires, putting all documentation in envelopes, and addressing and posting the envelopes.

6.14 Construction of the Survey Questionnaire

The questionnaire went through several stages of development with the findings from the sequentially used literature review, experience survey and experiential focus groups of phase 1 being used to construct and develop the items for the main survey questionnaire. Additional important contributions to constructing the questionnaire included information the researcher gained from networking with many individuals and organizations involved. The questionnaire consisted of 56 items divided into 4 separate sections: biographical details, organisational details, organisational quality details, and nursing quality details.

Nieswiadomy (1998) sees the length of a questionnaire as likely to influence the willingness of respondents to participate in a research study. Oppenheim (1992) agrees with this but points out that the length of a questionnaire, the number of pages and time required to complete it, have all been investigated but that results are inconclusive. However, both writers point out that despite the length of a questionnaire, if the topic is

of intrinsic interest to respondents and if they feel their views will influence policy; they will be more motivated to complete it. Appendix 11 is a copy of the questionnaire.

6.14.1 Section A. Biographical Details

Section A, questions 1-7, collected biographical details about the respondents' gender, qualifications, work title and further training needs. All questions were fixed-response and were considered important by the researcher as they provided basic information about the respondents' professional background.

6.14.2 Section B. Organisational Details

Section B, questions 8-16, collected organizational details and consisted of 9 fixed-response questions. Six of these questions (8 – 13) were about the size of centres, numbers of residents in the home, numbers of nurses in the home, level of adaptive functioning of residents, and whether there were mixed sexes living in the home. Each of these areas has been identified in the literature as important variables impacting on the quality of service for people in residential care (Borthwick-Duffy 1992, Lakin et al 1992, NAMHI. 1999), and these questions were based substantially on the theoretical and empirical literature in the area.

The last three questions in this section: *How is your centre administered?* (Q14), *Does your centre have an active parents and friends association?* (Q15) and, *Does your centre have a nurse training school?* (Q16), were based partly on the experience of the researcher and partly on the literature. For example, residential centres are divided between voluntary and health board centres where each is funded and administered

differently and in some cases staff training and numbers are different. Literature has drawn attention to the influence of parents associations in promoting service quality (NAMHI 1999). A general aim of nurse training schools is to provide the highest standards of care for clients (An Bord Altranais Syllabus of Training 2000). Finding out if these were present in centres was considered important.

6.14.3 Section C. Organisational Service Quality Details

Section C, questions 17-26, contained 9 fixed-response questions and collected details about aspects of service quality in centres. The organization's mission, philosophy, and type of quality initiatives have all been identified as important (Beckford 1998, Evans & Lindsay 2002). The value and contribution of teams and teamwork are seen as necessary for quality initiatives (Kehoe 1996, Beckford 1998,) and in intellectual disability services, the multidisciplinary team is seen as central for services to clients (NAMHI 1999, Gates 2003).

Questions about the organisational mission (Q17), organisational philosophy (Q18), quality accreditation and quality systems (23-26) were all derived from the literature on service quality. Questions that asked about the multidisciplinary team (Q19-20), if nurses were consulted about service provision (Q21), and if families of clients were consulted about service provision (Q22) were developed from the findings of the experience survey and the focus groups.

6.14.4 Section D. Nursing Quality Care Details

Section D, questions 27-56, collected details about the dimensions of care nurses see as important and information on organisational processes used for quality care, type of client behaviours that indicate quality care, and approaches nurses adopt to evaluating their care. This section also collected information on the level of nurses' participation and involvement in decision making in centres and the management practices they see as facilitators and barriers to nurses providing quality care to clients.

This last section consisted of 30 items divided into 5 rating questions using Likert-type scales, 10 rank-ordered questions, and 15 fixed-response questions. This section contained the largest number of questions and addressed the substantive areas for answering the research questions. To achieve this, question items were distributed across six specific areas so as to collect information on the concepts and constructs of importance to the study:

1. *Knowledge and perception of quality care:*

Three questions were asked to collect information about respondents' knowledge of quality care (Q27), their perception of quality care in their centre (Q28) and facilities available for clients in their centres (Q29).

Question 27 was asked because the literature has drawn attention to the importance of employee awareness and training for quality in their job (Deming 1990, Parsley & Barnes 1995, Goodale et al 1997, Evans & Lindsay 2002).

Questions 28 and 29 developed from the experience survey with the experts on quality (see questions 2 and 3) and from the focus groups with nurses (see question 8). The questions asked respondents to rate their perception of quality in centres (Q28) to rate the facilities available to clients (Q29) and were primarily about awareness of quality.

2. Dimensions of care and client indicators of quality care:

Three questions were asked to find out the dimensions of care needs that nurses considered most important for clients (Q30), dimensions of care needs that receive most attention from nurses (Q31) and, the client behaviours that might indicate that a client was receiving good quality care (Q32). These questions were developed from all three sequential investigations.

Particularly in light of changes in approaches to caring for persons with learning disabilities, the theoretical literature on intellectual disabilities has drawn attention to models and frameworks for care along with their underlying assumptions about service provision (Mercer 1992, Wolfensberger 2001). In addition, literature on applied research has addressed specific approaches to client care from the perspective of service agencies and from professional interventions (Stancliffe et al 1999, Maes et al 2000, Alaszewski et al 2001, Northway & Jenkins 2003). The literature was used to develop the experience survey which asked respondents about activities nurses engage in with clients; what client behaviours might indicate quality care, and if nurses recognise situations that indicate quality care for clients (see questions 6,7 & 8).

Focus group questions were developed from issues in the literature and findings from the experience survey and asked participants to discuss two related questions. The first was on aspects of care that receive attention by nurses, and the second was on aspects of care nurses saw as important for clients (see questions 4 & 5). The outcomes from questions 4 and 5 as well as those from questions 6,7, and 8 from the experience survey were used to develop the three questions on dimensions and indicators of quality care.

3. Organisational care processes for providing quality care

Fourteen questions were asked to collect information about care processes seen in the literature as being directly or indirectly associated with quality care in organisations.

(See questions 19, 20, 22 & 33-43). The care processes addressed were: the multi-disciplinary team, standards of care, models and care plans, individual programme planning, and client and family involvement in care provision. Essentially, organisational care processes relate to the assessment, planning, implementation, and evaluation of care and are usually initiated and maintained at both the organisational and professional level of care. Evaluation is important in nursing and any form of service quality. This was investigated by means of a different set of questions (please see 6 below).

Multi-disciplinary teams are seen as necessary for planning, delivery and evaluation of care for clients and their families (NAMHI 1999, McCray 2003). While nurses are responsible for the day-to-day care of clients it is usually the multi-disciplinary team in consultation with the client and his or her family, which acts as the professional decision-making group. From the experience survey, all seven experts said the provision of quality care was dependent on multi-disciplinary teamwork (see question 4). All seven experts said that in some centers nurses might not be accepted as an equal member of the multi-disciplinary team (see question 5). From these considerations, two questions were asked about multi-disciplinary teams in centres. Question 19 asked respondents if service provision to residents was based on a multidisciplinary approach in their centres and question 20 asked respondents if nurses were members of the multi-disciplinary team in their center.

Standards of care are seen as central to quality initiatives in human services (NAMHI 1999, Sale 2000, NDA 2003). In the experience survey, all the experts said standards were important but must apply to all areas and not just physical care and they must be audited (see question 14). From the focus groups, over two thirds of participants in both groups saw having and meeting standards of care as a way of knowing quality care was being provided to clients (see question 7). From these considerations, two questions were included in the main survey questionnaire. Question 33 asked respondents if care in their centre was based on written standards and question 34 was a four-part question asking if standards were written for structure, process, outcome and personal outcomes of care. This last question was important as the applied literature now emphasises outcomes and the relationship between process and outcome standards of quality care (Gardner et al 1997). Many clients with severe or profound intellectual disabilities have very limited communication abilities with which to express needs and wants. Question 37 was asked to find out from which particular staff member is information most sought about the needs and wants of clients unable to communicate.

Models of care and care plans are terms familiar to all nurses. Non-nursing models are broad service models that underpin the paradigm of care to clients and their families. They include the medical and humanistic models that form the theoretical perspective for the present study. Nursing models in contrast, are specific to nursing and like most models have their concepts and underlying assumptions grounded in theory (Deloughery 1998). Asking about nurses' use of a model of care is important for as McKenna (1997) said, when understood and applied correctly, a model can serve as a rationale to underpin the assessment, planning, implementation and evaluation of care.

Nursing care plans are linked to the nursing process and are a means for nurses to structure their thinking in discussing and recording their planning, implementation and evaluation of care (Mason 1999). Nursing care plans provide for an important means of communication within the MDT as well as between nurses. When used appropriately they constitute a written record of individualized holistic care for clients (Mason 1999).

From the experience survey, all 7 experts said having a model of care for service provision was important but the type of model depended on individual centres and their mission as well as the client groups and their needs (see question 17). Based on the literature and responses to the experience survey, two questions were developed for inclusion in the survey questionnaire. One on using a model of care (Q35) and one on the use of care plans (Q36).

Individual programme planning has been recognised as an important process for addressing the personalized needs of individual clients. In its Standards of Care Document (1999 Standard 7.3), the National Association for the Mentally Handicapped of Ireland identifies individual programme plans as a key component for care delivery and the intellectual disability literature sees them as an essential component of quality assurance (Cummins et al 1996, Stancliffe et al 1999, NDA 2003). From the experience survey, all 7 experts considered individual programme planning along with staff and multidisciplinary meetings as important for quality (see appendix 2, question 16).

Four specific questions on individual programme plans were included in the survey questionnaire (see questions 38-41). These were designed to address issues raised in the literature concerning the frequency of meetings, types of objectives, and the people who attend the meetings (Stancliffe et al 1999).

Families of clients in residential centres are stakeholders and a resource for service provision to clients. Involvement and consultation with families of clients, particularly on matters affecting their member receiving a service, has been identified as both their right (Capie 1993, Grant et al 1994) as well as being a necessary component of quality assurance (NAMHI 1999, NDA 2003). From the experience survey, all 7 experts considered contact as necessary and important. Based on the considered importance of family consultation, three questions were included on the survey questionnaire. These questions collected information about consultation with families of clients (Q22), the frequency of consultation with families of clients (Q42) and, who initiates the contact with families (Q43).

4. Participation and involvement in decision-making:

The general service quality literature emphasises that if employees are to be motivated to commit to quality, they must perceive that their participation in the service is high and that they are involved in organisational decision making (Bowen & Lawler 1992, Beckford 1998, Evans & Lindsay 2002). According to Bowen and Lawler (1992) worker participation and involvement in decision-making is necessary for organisational quality. From the experience survey, all 7 experts said nurses' participation in organisational processes and their involvement in decision-making was necessary for service quality (see question 11). Five questions were included in the survey questionnaire. These collected information on decision-making (Q44), participation (Q45) making suggestions to management (Q46), forum for nurses (Q47) and, further education (Q48).

5. Management practices affecting nurses provision of quality care:

Employee commitment, motivation and leadership for quality have all received much attention in the literature. The literature on motivation (Maslow 1970, 1998, Herzberg 1977), leadership (Gardner 1990) and commitment to quality (Deming 1986, Beckford 1998) emphasise the importance of the worker feeling valued, supported and empowered by management to provide a high quality service to clients. From the Experience Survey, all 7 experts said a participative leadership style was necessary for quality. All 7 said quality could not be achieved with a bureaucratic management style, management must tell staff exactly what is expected of them, and management must have an open communication with staff (see question 10).

From Focus Group One, 5 of the 9 participants felt valuing staff was most important and 6 of the 9 felt management needed to acknowledge the skills and abilities of nurses. 6 of the 9 said bureaucracy was the biggest barrier, 6 of the 9 said too little communication was a major barrier, and 4 of the 9 participants said management's mistrust of nurses was the biggest barrier.

From Focus Group Two, 4 of the 5 said it was important that management gave more autonomy and responsibility for care to nurses. 3 of the 5 participants said bureaucracy and poor communication was biggest barrier, 2 of the 5 said constraints on budgeting and 3 of the 5 said not allowing staff to take responsibility for client care were the biggest barriers to quality client care (see questions 9 and 10). Based on these considerations, two questions on management practices were included in the survey questionnaire. Question 49 asked respondents to number the management practices that they perceived

facilitated nurses providing quality care. Question 50 asked respondents to number the management practices that they perceived were barriers to nurses providing quality care.

6. *Evaluation of structures, processes and outcomes of care:*

Evaluation is the process of determining the extent to which goals or objectives have been achieved and in quality care it refers to that assessment activity used for determining the meaning and importance of data collected (Katz & Green 1992). Evaluation is important in the areas of nursing care (Swansburg & Swansburg 1999), quality management (Kemp & Richardson 1995, Sale 2000) and learning disability services (Seed & Lloyd 1997, Holm & Perl 2001, Northway & Jenkins 2003).

From the Experience Survey, all 7 experts said nursing evaluation was predominantly in the areas of physical and behavioural care. 5 of the 7 said formal evaluation of client care was achieved through IPP and clinic meetings. All 7 said the most complete (holistic) evaluation of client care was through a multidisciplinary team approach (see question 15). Based on the literature and the findings from the experience survey, the last six questions on the survey questionnaire were included to find out if respondents evaluated their care. Question 51 asked respondents about methods they used to monitor their care. The other questions were specific to evaluation and collected information on resources evaluated (Q52), processes evaluated (Q53) and client personal outcomes evaluated (Q54). The last two questions asked respondents if they evaluated nursing care (Q55) and the areas they evaluated most often (Q56).

6.15 Reliability

Reliability refers to the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure and it is a prerequisite for validity. To measure the stability of the main survey questionnaire, the researcher conducted test-retest reliability estimates with six nurses working in clinical practice (3 staff nurses and 3 ward sisters). There was an interval of ten days between each of the questionnaire completion times and a correlation coefficient of .79 was obtained for the test-retest.

The majority of the questions on the main survey questionnaire were dichotomous items as distinct from scaled items and their format did not lend itself to a reliability estimate of internal consistency. Other steps taken to improve reliability included having a range of variation on the question items and providing a longer questionnaire with more individual items that provided a higher reliability than shorter questionnaires (Judd et al 1991). The respondents were given clear instructions for completing the questionnaire thus helping to avoid random errors and simple mistakes which lead to unreliability (Judd et al 1991).

6.16 Validity

Parahoo (1997) suggests that content and construct validity can be assessed by submitting the survey instruments to a panel of experts in the area. In this study, the experience survey questionnaire (phase 1), the schedule of questions for the focus group (phase 1), and the dominant survey questionnaire (phase 2), were all given to a panel of experts. The same experts were involved in reviewing the instruments, which occurred sequentially over a period of many months. Prior to this and for each instrument to be tested, the researcher had two colleagues review and comment on draft questions, their

wording and ordering on the three instruments. The experts consisted of six experienced nurses- three staff nurses and three ward sisters/charge nurses from the researchers own organization and two non-nurse experts in service quality from two different organizations. The six nurse experts reviewed the schedule of questions for the focus group interviews and the survey questionnaire (phases 1 and 2 respectively). The two non-nurse experts reviewed the semi-structured questions for the experience survey (phase 1) and the survey questionnaire (phase 2).

The reason for this was that the six nurses were deemed to possess practical nursing knowledge and experience concerning the usefulness and appropriateness of content for the nursing-related questions for the focus groups and the survey. However, it was thought unlikely they would have the breadth of knowledge useful for the interview schedule for the experience survey with the experts on quality. The two non-nurse experts were selected because they had the experience of theoretical and management aspects concerning the implementation of quality initiatives and strategies for their evaluation.

In an attempt to collect additional information about the content and construct validity of the survey questionnaire, the researcher asked six parents of children/adults in residential care to review and comment on the survey questionnaire. They were asked to comment with particular regard to the ease of understanding of the questions and whether or not in their view (bearing in mind the purpose of the survey), other or more useful questions about quality of care should be included in the questionnaire. This was carried out anonymously through the National Association of the Mentally Handicapped in Ireland.

Since parents of children/adults in residential care are likely to have a vested interest in how their offspring are cared for, the rationale for asking them to review the questionnaire was to see if, in their opinion, important areas were omitted from the questionnaire. A copy of the letter to parents can be found in appendix 8.

None of these people were involved in either the pilot study or the main survey. In addition to this, the researcher's supervisor reviewed the questionnaire and a statistician was consulted about the type and level of analysis for the survey questionnaire. The six nurses and two colleagues saw content validity for the focus group questions as very high. Content validity of the questions on the survey questionnaire was also high but one item was seen as inappropriate. This concerned a question asking respondents their age range. This question was deemed irrelevant and was excluded from the questionnaire. Other comments concerned the wording of a number of questions which were described as being 'jargonized.' These questions were amended before piloting the questionnaire. Of the six parents sent a copy of the questionnaire, four responded with comments. Unfortunately, comments were not made about questions themselves but about the usefulness of asking nurses about the quality of care they provide to people with mental handicap and about what they see as important in providing good care.

Construct validity was more difficult to assess than was content validity. This was not specifically tested for the experience survey interviews since it was understood the experts had considerable insight, theoretical knowledge and experience of service quality.

The constructs discussed at the focus group interviews were explored and clarified through the interactive discussions. Construct validity for the survey questionnaire was assessed using the 'known-groups technique' (Lo Biondo-Wood & Haber, 1995). This involved a comparison of the two non-nurse experts who were known to be familiar with the constructs with the six nurse experts who were not known to be familiar with the constructs. This method was successful in discriminating the knowledge and understanding between the two groups. However, many of the variables and constructs referred to in the questionnaire were already familiar to the six nurse-experts since they are part of the knowledge base of nurses.

6.17 Ethical Considerations

Throughout the separate phases of the study, the researcher has endeavored to maintain the highest ethical standards. Information was collected from professionals about their perceptions, opinions and approaches to providing quality care for people with intellectual disability. The study did not involve questions concerning individual clients or collecting data from clients or their families. To ensure best ethical standards a checklist developed by Kervin (1992, p.38) was used and involved the researcher asking the following questions:

1. Is the research process likely to harm participants or those about whom information is collected?
2. Will findings of the research cause harm to those not involved in the research?
3. Is the researcher violating accepted research practice in conducting the research, analyzing data or drawing conclusions?
4. Will the researcher be violating community standards of conduct?

Informed consent was sought and obtained from participants prior to conducting the experience survey during phase 1 and again, prior to the focus groups in phase 1. For phase 2, the dominant quantitative survey, a cover letter was addressed to respondents to inform them of the purposes of the study and to ask for their cooperation in completing the questionnaire. In this latter case, consent was taken as given by virtue of respondents returning their completed questionnaires. Participants in the experience survey and focus group interviews were informed that they could withdraw at any time if they so wished.

Confidentiality of information about participants and their organizations was assured, as the information provided by them was only available to the researcher. The researcher did not require the names or identities of organizations where participants are employed.

Anonymity for the participants in the experience survey and focus group interviews was problematic. For the experience survey, all the participants knew each other although all were interviewed separately. With the focus groups, anonymity between participants was clearly not possible nor was it an issue since participants agreed to take part in a group activity the nature of which stresses the importance of people interacting.

In keeping with the guidelines for good practice in interviews, the importance of confidentiality was stressed with all participants. Anonymity for those taking part in the quantitative survey was assured since only the person who compiled the sample and dispatched the questionnaires knew addresses and place of work of respondents.

6.18 Pilot Studies

Piloting instruments, materials or measuring equipment before embarking on a study is crucial to the validity, reliability and success of any research project. According to Oppenheim (1992), all instruments and all stages of the research should be piloted. In the sense that a pilot study is a miniature of the main study (Knapp 1998), there were two main reasons for piloting the instruments used in this study.

First, was to test the instruments, particularly in relation to validity and reliability of questions - the extent to which they were sensitive in evoking and capturing specific information about constructs in the questions. It was also necessary to ascertain if participants experienced difficulty in understanding and responding to questions, and identify if there were any specific problems in collecting the data.

Second, the researcher needed to test the methodology. Since the dominant survey questionnaire was constructed through sequential triangulation, that is, through discrete but linked stages, piloting allowed the researcher to evaluate the questionnaire as it was developed.

For Experience survey with experts – Phase One, two people were selected to pilot the Interview Schedule for the experience survey. The reason for selecting these two people was because they had responsibility for quality in their organizations and came from similar work backgrounds to those from the Task Group on Quality. Two issues arose from piloting the instrument. First was the time allocation for the interviews, as these were planned as in-depth interviews, the time allocated was too short to explore all the questions in depth. Second were the questions, both participants felt the range of issues were appropriate but one felt the time required to do ‘justice’ to the issues was too long.

The two participants drew attention to four particular questions, which they saw as leading questions that in their opinion, needed modification. As a result of the pilot exercise, changes were made to the wording of these questions.

For Focus Group Interviews with nurses – Phase One, the pilot procedure was different. Krueger (1994) says that piloting focus groups cannot be done in the same way as for personal interviews or survey questionnaires. According to Krueger, piloting a focus group involves assessing the characteristics of the participants; the interactions between them, the moderator procedures and the questions used for the group. Thus, the piloting procedure had to be different. The procedure adopted for piloting the focus group interviews was that suggested by Krueger (1994). This proceeded through a number of steps:

Step 1. Involved asking two experts on quality and two professional colleagues, to review the 9 open-ended key questions and the probes that were to be used to elicit the fullest information. While these four people had little experience of focus groups they were familiar with the aims of the research study.

Step 2. Involved a review of the first focus group meeting. The researcher and moderator discussed the room arrangements and seating for participants, the time given to key questions and the questions that generated the most comment and interaction. As a result of this discussion, slight changes were made to the time allocation of questions and to the earlier use of prompts and probes on the Schedule of Questions.

Step 3. Involved the use of a final summary question. This question sought additional comments from participants and asked ‘Have we missed anything?’ Even at the end of a two-hour group interview, this question stimulated valuable discussion. It was also useful

in understanding the summary thinking of individuals about the topic of the meeting and provided insight into the nuances of the group interaction.

For Survey Questionnaire with a random sample of nurses – Phase Two, the pilot procedure for the main Questionnaire involved mailing the anonymous questionnaire with a cover letter to a random sample of 30 nurses working in residential centres for persons with intellectual disabilities in the Republic of Ireland (please see appendix 9). The pilot study was carried out during November and December 1999 and An Bord Altranais undertook this on behalf of, and in collaboration with the researcher. The random sample for the main survey (N: 460) represented 11% of the total population of registered nurses in mental handicap (N: 4,200). The number selected for the pilot sample (N: 30) constituted 6.5% of the random sample for the main survey.

The response to the mailed questionnaire for the pilot study was initially a return of 17 questionnaires (57%) but after a follow-up letter to the non-respondents this increased to 21 questionnaires (70%). The analysis of these questionnaires involved looking at questionnaire non-response, item non-response, and whether there were any obvious errors in item completion that might indicate respondent difficulty or confusion with items on the questionnaire. The aim was to reduce the amount of bias in the findings by minimizing the degree of non-response error. All of the returned questionnaires were completely filled-in. In speculating on the reasons for the 9 non-returned questionnaires (30%), it is possible that some respondents were employed in day services and chose not to respond, or that some respondents were no longer working. Two non-respondents contacted the researcher at least three months after receiving the questionnaire to explain

that they had been out of the country. The questionnaire contained 56 items divided into 4 sections. Respondents completed all the question items. Summary results were:

Section A (Biographical details) no change was required to this section.

Section B (Organisational details) required a change to question 15 that asked if '*centres had an active parents and friends association*'. This appeared ambiguous as 7 of the 21 respondents were unclear what was meant by the word active. To amend this and avoid confusion, an explicit operational definition was provided for this question.

Section C (Organisational service quality details) required a change to question 25 that asked '*does your centre have a quality system in place.*' This was confusing for a number of respondents. To make clear what was meant by a quality system an operational definition was provided for this question.

Section D (Nursing quality care details) contained the largest number of questions and required no changes to be made.

6.19 Phase 2. Distribution of the Main Survey Questionnaire to Nurses

Following the amendments to the pilot questionnaire for the quantitative survey, the final draft was prepared for distribution to a random sample of nurses working in clinical practice. During the summer of 2000, the final questionnaire was sent to respondents. A sample of 460 nurses (11%) was randomly selected from the Mental Handicap Division of the register' of mental handicap nurses maintained by An Bord Altranais. Each questionnaire was sent with a covering letter and stamped addressed envelope for return.

The cover letter explained the purpose and significance of the study, asked for the respondent's co-operation in completing all questions, and gave assurances of confidentiality of information. Respondents were asked to return their completed questionnaire on or before 31st July 2000. A copy of the covering letter and the main questionnaire can be found in appendix 10 and 11 respectively.

6.19.1 Response Rate for the Questionnaire

The overall response rate was 191 (42%). A total of 185 nurses returned completed questionnaires (40%) and 6 nurses sent letters instead of questionnaires. The initial response to the main survey was a return of 171 questionnaires (37%). A follow-up letter reminding respondents to return the questionnaire was sent to the non-respondents two weeks after the return date. To preserve anonymity, the researcher returned a list of the 171 coded questionnaires to An Bord Altranais and they sent the reminder letter to the non-respondents. Within four weeks of the reminder letter being sent, a further 14 questionnaires were returned which brought the questionnaire response rate to 185 (40%). Of the 6 letter-responses received, 4 were from nurses explaining they were no longer working and 2 were from parents of nurses explaining that their son/daughter was working abroad.

6.19.2 Reason for the Response Rate

Bearing in mind the disadvantages with using questionnaires, particularly the low response rate, the final response rate was (40%). This was considered quite acceptable since Burns & Grove (1997) suggest that returns between 25 – 30 percent can be expected with mailed questionnaires. However, the response has implications for

generalizing the findings and so must be treated with caution. While the sample of nurses was homogenous with respect to education/training, work setting and general duties, the questionnaire was mailed to respondents during the summer time and this may well have had an effect on the response rate although the period for return of questionnaires extended over several weeks.

A number of things were done to improve the response rate. These included the care taken with wording the semi-personal cover letter, the ordering of questions and the careful layout and presentation of the questionnaire (Nachmias & Nachmias 1996).

Also, the address for returning the questionnaire was that of the university. This was done in the belief that respondents might be more likely to complete and return the questionnaire if it had a high status official address.

6.20 Data Analysis

Analysis proceeded continuously and sequentially. The raw data collected from each phase of the study was examined and sorted before analysis.

6.20.1 Experience Survey Analysis

For the experience survey with the seven experts, responses to their questions were checked with respondents before the completion of each interview. When all the interviews were completed the data were analysed but without recourse to descriptive statistics as there were only 7 respondents.

6.20.2 Focus Group Analysis

As the focus groups were used sequentially to help understand and develop the variables for the main survey, their analysis is discussed here. After the completion of each focus group and following checks and crosschecks with the moderator, transcripts from the tape-recorded discussions were prepared, read and analyzed. As the literature on focus group methodology seems to devote little attention to detailed analysis of focus groups, the researcher used a framework advanced by Krueger and Casey (2000). Prior to the conclusion of each of the focus groups, member checks were conducted with the interviewees. This related specifically to confirmability and served as a means of validating the data. Rigor was also achieved by using a form of inter-rater reliability that involved a second reader - the moderator, looking at and commenting on the detailed notes of the researcher. In addition, and bearing in mind the sequential triangulation used, thematic outcomes from the interviews were examined in association with the systematic review of the literature and with expert opinion -the findings from the experience survey of experts.

According to Krueger and Casey (2000) the depth of intensity of analysis of focus groups should be determined by their purpose. As the purpose of these focus groups was to use them to help generate variables for constructing the dominant survey questionnaire (see 6.12.1 above), the analysis process reflected this purpose. Krueger and Casey discuss three approaches to analysis depending on the purpose but emphasise that whichever approach is used it should be systematic, sequential, verifiable and continuous. The approaches they describe are transcript based, tape based and note based analysis. Transcript based analysis uses unabridged transcripts with the addition of field notes

taken by the researcher. Tape based uses an abridged transcript of relevant portions of discussion. Note based analysis relies chiefly on field notes with audio notes used as back up for clarification. This approach according to Krueger and Casey is only possible where the researcher has a thorough understanding of the purpose of the study and where the focus group is being used sequentially and in addition to other research methods.

The approach used was note-based analysis supplemented with the audio tape recording. The method involved researcher and moderator jointly reading and listening to the audio playback for each participant's views and opinions on each of the focus questions in turn. Listening to the audio playback section in association with the detailed notes, enabled the researcher and moderator in understanding and clarifying the frequency of issues raised, the extensiveness of how many people in the group said the same thing and the intensity or emotion with which each person felt about the issues they raised. Audio playback was listened to by the researcher and moderator together and immediately after the conclusion of each focus group. As the purpose of the focus groups was experiential to gain insight into the sameness as against differences in the views of participants (Fern 2001), responses from each person for each of the questions on the interview schedule were placed on a matrix. The researcher and moderator used this matrix to understand and record the views of all participants. A copy of the matrix can be seen in appendix 7.

6.20.3 Dominant Survey Analysis

Analysis for the dominant survey questionnaire involved using both univariate descriptive statistics and inferential statistics. Descriptive statistics are a group of statistics that are used to organise and summarise numerical data from a population or

sample. Univariate descriptive statistics are statistical procedures for analyzing single variables for the purpose of description (Polit & Hungler 1995) and are used in this study for describing frequencies, percentages and measures of central tendency where appropriate. Inferential statistics are parametric and non-parametric. These statistics permit inferences about whether relationships in a sample are likely to occur in a larger population of concern. Parametric statistics are the more powerful of the two types but require that four conditions must be met: 1) data must be of an interval/ratio level, b) data should be approximately normally distributed, c) subjects should be randomly selected and d) the range of data corresponding to each group of subjects should be fairly similar (Clifford & Harkin 1997).

As the level of statistical measurement was nominal and ordinal with some Likert scales, non-parametric statistics were used. These statistics, which do not rely on a set of parameters, are less sensitive than parametric statistics and are most often used for nominal/ordinal level measurement (Clifford & Harkin 1997). The Wilcoxon signed ranks test and the Chi – square test are the two non-parametric tests used in this study for analyzing ordinal and nominal data respectively. The Wilcoxon test is a test of statistical significance used for comparing two paired groups based on the relative ranking or ordering of values between the pairs (Polit & Hungler 1995). It shows if there is a difference between ordinal level variables and is expressed as $Z =$.

The Chi-square test can be used when comparing proportions to assess if there is a relationship between two nominal-level variables and is expressed as $\chi^2 =$. It is a test used to compare two independent proportions where the data are placed on a 2 X 2

contingency table. These are tables of frequencies that are used to illustrate data that are presented in frequencies where the observed and expected frequencies in each cell of the table are compared (Nieswiadomy 1998). The test is based on probability distribution that approaches the normal distribution for large degrees of freedom. Degrees of freedom (df) refer to the number of sample values that are free to vary.

While the Both statistical tests report the P value, which refers to the probability (p) that an observed difference occurred by chance. In terms of significance level, the convention is to accept an observed difference as real if the likelihood that it is due to chance is less than 1 in 20, that is, a P value less than 0.05. P values of less than 0.05 are considered to be statistically significant (Polit & Hungler 1995). The alpha level (the probability of making a type 1 error) for a statistical test is usually selected before analyzing data and reflects how careful the researcher wishes to be. The alpha level for this study is 0.05.

Finally, the researcher is aware of the difference between statistical significance and substantive meaningfulness. As Knapp (1998) warns, with a sufficiently large sample (≥ 100), even the tiniest relationship can be statistically significant and according to Munro (2001), statistically significant results say little about clinical or practical importance or meaningful significance of results. Bearing this in mind, findings from the survey of nurses were cross-referenced with findings from the experience survey of experts so as to assist the researcher in interpreting the results for each of the research questions in terms of their importance and meaningfulness.

6.21 Conclusion

This chapter discussed the background, rationale and methodology for the study. The theoretical issues to emerge from the literature about service quality and quality care were outlined. The purpose of the study and the research questions were stated. The rationale and justification for using a two-phase dominant-less-dominant design was discussed. An explanation was provided for using sequential triangulation as a methodology for developing the constructs and variables for the dominant survey. Finally, the construction of the dominant survey questionnaire was discussed using the process of sequential triangulation. The less-dominant small-scale experience survey of experts together with the two focus group interviews with nurses constituted the less-dominant phase 1 of the study. The main survey of nurses constituted the dominant phase 2 of the study and the relationship between these two phases was discussed. Sample selection was discussed with an explanation for how samples were selected. Ethical issues were reviewed and the limitations and delimitations of the study were explained.

The rationale for using a survey for the dominant component of the study together with the processes used to construct, test and pilot the questionnaire instrument were all explained. Issues of reliability and validity were discussed and an explanation was provided for how the dominant survey questionnaire was distributed to the random sample of nurses. The response rate for the main dominant (phase two) survey was discussed and a tentative explanation was suggested for this. Finally, the process for analyzing the data from the three empirical phases was outlined and a brief explanation was provided about the statistical tests used in the study. Chapter seven presents the findings from the dominant phase two: the survey of nurses in clinical practice.

CHAPTER SEVEN

RESEARCH FINDINGS AND ANALYSIS

7.1 Introduction

This chapter is divided into two sections. Section A discusses the findings from the survey of nurses. Section B presents the analysis and interpretation of the survey findings pertinent to answering each of the five research questions. As part of the analysis, findings from the survey of nurses are cross-referenced with the findings obtained from the experience survey of experts in quality. Although the experience survey was used sequentially to develop the main survey questionnaire, the rationale for cross-referencing is because it was used with non-nurse experts whose experiences and perspectives will add to the understanding of findings.

SECTION A

FINDINGS FROM THE SURVEY OF NURSES

7.2 Biographical Details

Section A consisted of 7 questions to collect biographical details about respondents. Frequency findings for responses are summarised in tables' 7.2.1 to 7.2.5 and are discussed following the summary tables.

	Professional work					
	Staff		Charge		Othe	
	Gender		Gender		Gender	
	Count	%	Count	%	Count	%
Male	35	26.1%	6	33.3%	11	40.7%
Female	99	73.9%	12	66.7%	16	59.3%
Total	134	100.0%	18	100.0%	27	100.0%

Table 7.2.1. Summary of findings for question 1: gender, and question 2: professional work title

Gender by Number of Years Working in Current Employment						
Gender	1-5 Years	6-10 years	11-15 years	16-20 years	21-25 years	26-36 years
Female (n: 133)	42 (31.57%)	33 (24.8%)	18 (13.53%)	18 (13.53%)	20 (15%)	3 (2.25%)
Male (n: 52)	22 (42.30%)	8 (15.38%)	6 (11.53%)	5 (9.6%)	8 (15.38%)	2 (3.84%)
Total (n : 185)	64 (34.59%)	41 (22.16%)	24 (12.97%)	23 (12.43%)	28 (15.13%)	5 (2.70%)

Table 7.2.2 Summary findings for question 4: Gender by years in current employment.

Do you have a dual Registration Qualification?					
Registration Qualification	Male (n: 51)	Percent	Female (n: 133)	Percent	Total
RPN	16	31.37%	6	4.51%	22 (11.95%)
RGN	5	9.80%	14	10.52%	19 (10.32%)
RSCN	1	1.96%	3	2.25%	4 (2.17%)
Total	22	43.13%	23	17.29%	45 (24.45%)

Table 7.2.3. Summary responses for question 5: Do you have a dual Registration qualification?

If you have other qualifications please specify					
Other Qualification	Male (n: 52)	Percent	Female (n: 133)	Percent	Total (n:185)
Certificate	19	36.53%	44	33%	63 (34%)
Diploma	12	23%	37	27.81%	49 (26.48%)
Primary Degree	7	13.46%	5	3.75%	12 (6.48%)
Master's Degree	3	5.76%	2	1.50%	5 (2.70%)
Total	41	78.84%	88	66.16%	129 (69.72%)

Table 7.2.4. A summary of Question 6: Other qualifications by gender of respondents

If you have further training needs, please list them in order of priority to you.						
Gender (N: 119)	Title	(1) Management training	(2) Behaviour Modification	(3) Information Technology	(4) Managing Challenging Behaviour	(5) First Aid
Male	Staff Nurse	11 (9.24%)	6 (5.04%)	5 (4.24%)	3 (2.52%)	4 (3.36%)
	Charge Nurse	1 (0.84%)	1 (0.84%)	2 (1.68%)	2 (1.68%)	1 (0.84%)
	Other	4 (3.36%)	3 (2.52%)	2 (1.68%)	1 (0.84%)	
Female	Staff Nurse	13 (10.92 %)	14 (11.76)	6 (5.04%)	12 (10.08%)	11 (9.24%)
	Charge Nurse	3 (2.52%)	2 (1.68%)	4 (3.36%)	4 (3.36%)	1 (0.84%)
	Other	4 (3.36%)		5 (4.20%)	1 (0.84%)	
Total		36 (30.25%)	26 (21.84%)	24 (20%)	23 (19.32%)	17 (14.28%)

Table 7.2.5. Summary of responses for question 7: training needs by gender and work title.

For gender and work title (table 7.2.1) six did not reply to this question. Over two thirds were female and the majority were staff nurses. It is interesting to note that while females' outnumbered males more than two to one, proportionally more males were charge nurses (17%) compared to females (12%).

Years qualified and working in current employment (table 7.2.2) ranged from 42.7% qualified less than 10 years (mean 4.78 years) to 42% qualified from 20 – 36 years (mean 24.26 years). Just over half of all respondents were in their current employment less than 10 years and 17.29% of females and 19.23% of males were in their current employment for more than 20 years. Overall, a higher proportion of females were in the same post for a longer number of years. A possible explanation for this might be a greater mobility of males changing employment and seeking promotions.

For qualifications (tables 7.2.3), a significantly higher proportion of males had dual registration qualification (43.13%) compared to females (17.29%). It is interesting to note that in the majority of cases, psychiatric nursing was the second qualification of males whereas for females it was general nursing.

On additional qualifications (table 7.2.4), proportionately more males had other qualifications in particular at primary and master degree level. This situation may now be different, as more nurses have been pursuing degrees since this data was collected.

On further training needs (table 7.2.5), of the five most frequently identified areas, the commonest was management. Given the relative autonomy of nurses running a home/unit, the budgetary requirements involved and the need for staff nurses to acquire management experience in order to get promotion, it is not difficult to understand this.

7.3. Organizational Details

Section B consisted of 9 questions to collect demographic details about organizations.

7.3.1 Size and Type of Administration of Centres (Questions 8 and 14)

How many residential places does your entire centre provide for?

5 of the 185 respondents did not answer this question. Of the 180 who did, 18 (10%) worked in the smallest category with 50 or less places, 26 (14%) worked in centres with 50-99 places, 61 (33.8%) worked in centres with 100-199 places, and 75 (41.6%) worked in the largest category with 200 or more places.

Residential service providers include health boards and voluntary agencies. In consideration of the possibility that the type of provider administration could differ in ways such as size of centre, funding, staffing and management practices, it was considered useful to ask about the type of centre administration.

How is your centre administered?

17 of the 185 (9.00%) respondents did not answer the question. Of the 168 (90.00%) who did, 96 worked in voluntary centres and 72 worked in health board centres. Table 7.3.1 summarizes the responses for size of centres by type of centre administration.

How many residential places does your entire centre provide for? (n: 180)	How is your centre administered? (n: 168)	
	Voluntary	Health Board
50 or Less	6 (3.57%)	8 (4.76%)
50 - 99	15 (9%)	7 (4.16%)
100 – 199	26 (15.47%)	31 (18.45%)
200 or More	49 (29.16%)	26 (15.47%)
Total	96 (57%)	72 (43%)

Table 7.3.1. Summary of findings for Type of Centre Administration by size of Centres

7.3.2 Mixed Sexed Homes and Adaptive Functioning of Residents (Q 12 and 13)

Are there mixed sexes living in the home you work in?

14 respondents (7.5%) did not answer this question. Of the 171 who did, responses were nearly equal with 90 (52.63%) reporting they had mixed sexes in the home and 81 (47.36%) reporting they did not.

What is the level of adaptive functioning of the residents in the home you work in?

181 (98.00%) of the respondents answered the question and 4 did not. Table 7.3.2 presents a summary of the finding for questions 13.

What is the level of adaptive functioning of the residents in the home/unit you work in? (n: 181)		
Level of adaptive functioning	Numbers	Percent
Profound disabilities	79	43.6%
Severe disabilities	147	81.2%
Moderate disabilities	97	53.6%
Mild disabilities	40	22.1%

Table 7.3. 2. Summary of responses for Question 13; Level of Adaptive Functioning

From table 7.3.2 it can be seen that the majority of respondents work in homes/units where clients have profound and severe levels of adaptive functioning. It can also be seen that over a fifth of respondents (22.1%) work in homes/units where there are clients with only a mild level of adaptive functioning. While it is hardly surprising that the majority of respondents care for clients with severe or profound disabilities, this has implications for the dimensions of care they may concentrate on and thus the type of quality care they provide. In contrast, respondents caring for clients with moderate or mild disabilities may concentrate on other types of care dimensions.

7.3.3 Stakeholder Involvement in Service Quality (Q 15 and 16)

Stakeholders who are organized for the specific purpose of influencing quality care can contribute to service developments and to quality-related innovations for care (National Association for the Mentally Handicapped of Ireland 1999, National Disability Authority 2003). Two such groups are parents and friends associations and nurse training schools. Reasons for asking questions about these stakeholders is the expectation that such groups will be proactive and deliberately seek to promote the quality of care provided to clients.

Does your centre have an active Parents and Friends Association?

Of the 185 respondents, 143 (77.30%) said their centre had an active parents and friends association and 42 (29.70%) said their centre did not. Of the 143 respondents whose centres had an active parents and friends association, 75 worked in voluntary centres and 54 worked in health board centres. Table 7.3.3 presents a summary of findings for centres with active parents and friends associations compared with type of centre administration.

Does your centre have an active parents and friends association?	How is your centre administered? (n: 168)		
	Voluntary	Health Board	Total
Yes	75 (44.6%) ⁴	54 (32.00%)	129
No	21 (12.5%)	18 (10.70%)	39
Total	96 (57.03%)	72 (42.7%)	168 (100.00%)

Table 7.3.3. A summary of responses for question 15: does your centre have an active parents association and question14: how is your centre administered

Does your centre have a nurse training school?

Respondents were equally divided between centres with and without nurse training schools. Of the 185 respondents, 92 (49.72%) worked in centres with a nurse training school and 93 (50.28%) worked in centres without a nurse training school.

Seven of the eight nurse training schools are located in the voluntary centres. When compared to the distribution of respondents from voluntary and health board centres (N: 168), 57 respondents came from voluntary centres with nurse training schools compared to 28 from health board centres with training schools. Table 7.3.4 presents a summary for centres with nurse training schools by type of centre administration.

How is your centre administered? (n: 168)	Does your centre have a nurse training school on campus? (n: 185)		
	Yes	No	Total
Voluntary	57	39	96
Health Board	28	44	72
Total	85	83	168

Table 7.3.4. Summary of findings for question 16: does your centre have a nurse training school, and question 14: how is your centre administered

7.4 Organizational Service Quality Details

This section collected information on broad quality- related issues that the literature identifies as important for service quality. It consisted of 10 fixed-response questions.

7.4.1 Mission Statement and Service Philosophy (Q 17 and 18)

Has your centre a written mission statement for the service?

149 (80.54%) said their centres had, 13 (7.03%) said they had not, and 23 (12.43%) said they did not know.

Has your centre a written philosophy outlining its beliefs and values?

146 (78.9%) said their centres had, 18 (9.7%) said they had not, and 21 (11.4%) said they did not know. Table 7.4.1 presents a summary of the findings for questions 17 and 18.

As can be seen from the findings, approximately eighty percent of respondents said their centres had mission and philosophy statements. Since mission and philosophy statements should be in writing, it is of note that some twelve percent don't know if their centres have a mission or value statement.

Does your centre have a mission statement for the service?			Does your centre have a written philosophy outlining its beliefs and values?		
Yes	149	80.54%	Yes	146	78.9%
No	13	7.03%	No	18	9.7%
Don't know	23	12.43%	Don't know	21	11.4%
Total	185	100.0%	Total	185	100.0%

Table 7.4.1 Summary of findings for question 17: Has your centre a written mission statement? and, question 18: Has your centre a written philosophy outlining its beliefs and values for the service?

7.4.2 Multidisciplinary Teamwork (Q 19 and 20)

Multidisciplinary or interprofessional approaches to caring for persons with mental handicap is repeatedly emphasized in the literature (Fraser 1995, Department of Health 2001, McCray 2003) and is further evidenced in the large number of multidisciplinary conferences that take place in this area of human services.

Is service provision to residents based on multidisciplinary teamwork?

Four of the respondents did not answer the question. Of the 181(97.8%) that did, 162 (89.50%) said service provision in their centres was based on a multidisciplinary approach to care. 19 (10.50%) respondents said it was not.

Are nurses' members of the multidisciplinary team in your centre?

Ten of the respondents did not answer the question. Of the 175 that did, 148 said they were members of the multidisciplinary team and 27 said they were not members. Table 7.4.2 presents the summary findings for questions 19 and 20.

Is service provision to residents based on a multidisciplinary approach to care? (n:181)			Are nurses' members of the multidisciplinary team in your centre? (n: 175)		
Yes	162	89.50%	Yes	148	84.6%
No	19	10.50%	No	27	15.4%
Total	181	100.0%	Total	175	100.0%
Missing	4	2.2%	Missing	10	5.4%

Table 7.4.2. Summary of findings for questions 19 and 20

7.4.3 Consultation with Nurses and Families on Service Quality (Q 21and 22)

Consultation and involvement of nurses in their organisation has been identified as necessary for service quality (Rose 1998, Irish Health System Accreditation Authority 2002, National Disability Authority 2003).

Are nurses consulted on matters of service provision to residents?

Six respondents did not answer the question. Of the 179 (96.75%) who did, 45 (25.01%) said they were always consulted, 117 (65.4%) said they were consulted sometimes, and 17 (9.5%) said they were rarely consulted. Nurses are at the frontline of caring, they are accountable and responsible for the care they provide to residents round-the-clock.

Bearing this in mind, it is a matter of concern that 10% of respondents said they were rarely consulted and nearly two-thirds (65.4%) said they were only consulted some of the time. Table 7.4.3 presents a summary of the findings for question 21.

Are nurses consulted on matters of service provision to residents? (n: 179)			Does your centre consult with the families of residents on matters of service provision? (n: 182)	
Always	45	25.1%	54	29.7%
Sometimes	117	65.4%	101	55.5%
Rarely	17	9.5%	27	14.8%
Total	179	100.0%	182	100.0%
Missing	6		3	

Table 7.4.3. Summary findings for questions 21 and 22

Organisational consultation with families is seen as central to the quality of the services provided to clients (Grant et al 1994, NAMHI 1999, Irish Health System Accreditation Authority 2002, National Disability Authority).

Does your centre consult with the families of residents on matters of service provision?

3 respondents did not answer the question. Of the 182 (98.37%) that did, 54 (29.7%) said they were always consulted, 101 (55.5%) said they were consulted sometimes, and 27 (14.8%) said they were rarely consulted. Table 7.4.3 above presents a summary for findings for question 22. The current service rhetoric and practice concerns itself with holistic care, espoused values relating to quality of life, and the now established practice of relocating residents into homes in the community (Felce & Perry 1997). It is reasonable therefore, to suggest that families as important stakeholders should always be consulted about the services their son or daughter receives. Bearing this in mind, it is of concern that 27 (14.8%) of the respondents said families were rarely consulted and 101 (55.5%) said families were only consulted sometimes.

7.4.4 Quality Accreditation for Centres (Q 23 and 24)

Questions 23 and 24 were asked to find out if centres had any form of accreditation in the center where they worked.

Does your centre have any type of service quality accreditation?

10 respondents did not answer the question. Of the 175 (94.6%) who did, 34 (19.4%) said their centre had some form of accreditation, 81 (46.3%) said their centres had no accreditation, and 60 (34.3%) respondents said they did not know. Table 7.4.4 summarises the findings for question 23.

Does your centre have any type of service quality accreditation? (n: 175)		
Response	Frequency	Percent
Yes	34	19.4%
No	81	46.3%
Don't Know	60	34.3%
Total	175	100%
Missing	10	
Total	185	

Table 7.4.4. Summary responses for question 23:

If your centre has a service accreditation please specify type of accreditation

Of the 185 respondents, only 17 (9.18%) reported having a specific type of quality accreditation for their service. A total of 8 different approaches were reported for accreditation but only 5 of these were accredited for standards or quality service by an accreditation body. The other 3 included staff assessments, an association with a university school of nursing and, organizational policies and procedures for the centre. Table 7.4.5 and figure 7.4.1 presents the summary findings for question 24.

If your center has a service quality accreditation, please specify the type of accreditation (N: 17).		
Accreditation Type	Frequency	Percent
Q Mark *	5	29.4
Yearly Staff Assessment	1	5.9
ISO 9000 *	5	29.4
DCU School of Nursing	1	5.9
Excellence Ireland *	2	11.8
National Rehabilitation Board *	1	5.9
Policies and Procedures	1	5.9
Quality Council System *	1	5.9
Total	17	100.0
Missing	168	
Total	185	

Table 7.4.5. Summary findings for question 24: * Indicates quality accreditation system.

To remind the reader, accreditation initiatives such as those of the Irish Health System

Accreditation Authority (2001) or the National Disability Authority's National Standards

(2003) had not been introduced to disability services at the time of this research study.

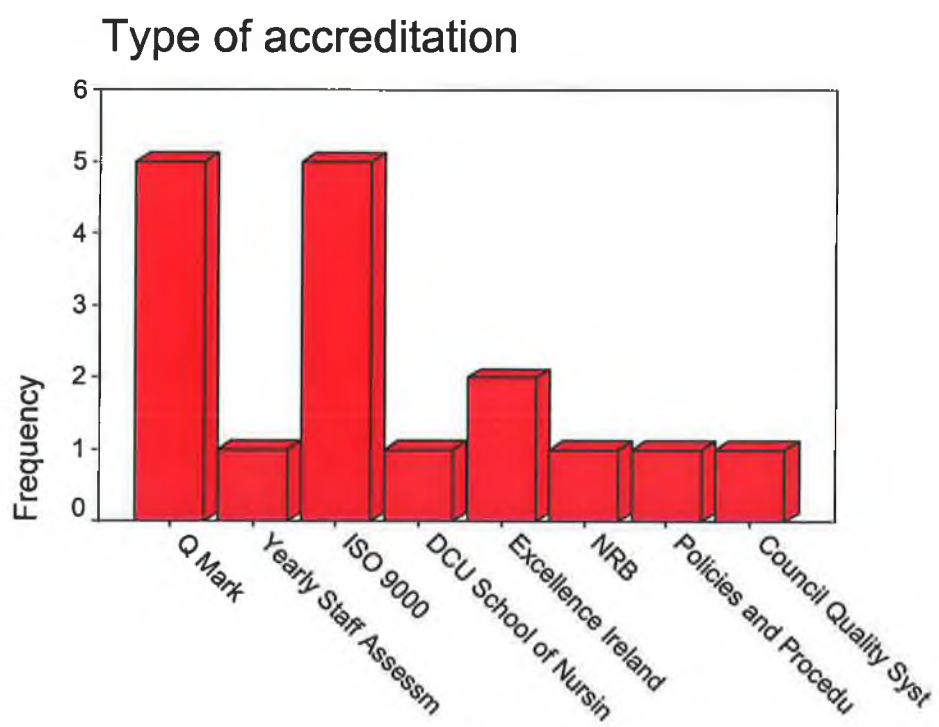


Figure 7.4.1: Type of accreditation in place

7.4.5 Quality Systems in Centres (Q26)

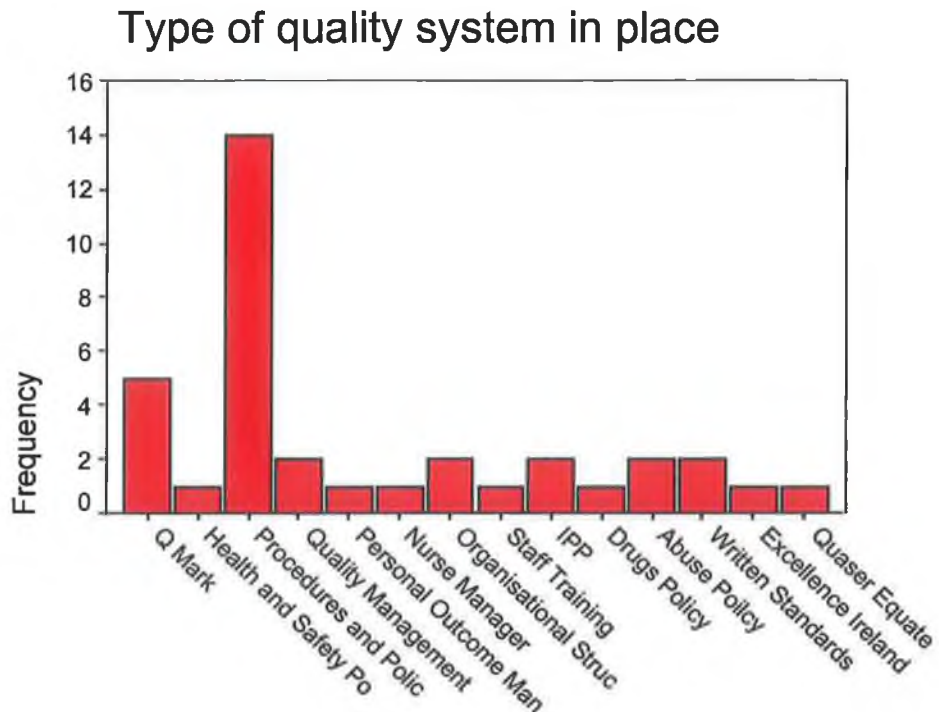
Question 26, the last question in this section asked respondents about quality systems in their centers. An operational definition was provided for a quality system.

If your center has one or more quality systems in place please specify?

This question was asked in the expectation that centers might have more than one type of quality system given the number of systems available, the different sizes and administrations of centers and their geographic dispersal throughout the country.

Of the 185 respondents, 36 (19.45%) said their centers had more than one quality system in place. A total of 14 different center initiatives were listed but while all of them could reasonably be described as quality-related pursuits or activities, only the five systems listed in table 7.4.5 above (marked with asterisks), incorporate the full requirements of a quality system.

Figure 7.4.2 below, presents a summary of responses for quality systems



Type of Quality System

Figure 7.4.2. Summary responses for type of quality system in place in centres

7.5. Nursing Quality Care Details

This last section of the questionnaire collected information on specific issues to do with quality of nursing care. Of the 30 questions in the section, 5 were rating questions using a Likert- type scale, 10 were rank-ordered questions and 15 were fixed-response questions.

7.5.1 Instruction, Rating and Facilities Available for Quality (Q 27,28 and 29)

How much instruction was provided on quality care during your nurse-training ?

37 (21.1%) respondents said they received a very large amount, 52 (28.3%) said they received a large amount and 51 (27.7%) said they received an adequate amount. 34

18.5%) said they received an inadequate amount of instruction and 10 (5.4%) said they received no instruction. Table 7.5.1 presents the summary responses for question 27.

In your opinion, how much instruction was provided on quality care during your nurse-training course? (n : 185)		
Response	Frequency	Percent
Very large amount	37	20.1
Large amount	52	28.3
Adequate amount	51	27.7
Inadequate amount	34	18.5
None	10	5.4
Total	184	100.0
Missing	1	
Total	185	

Table 7.5.1. Summary of findings for question 27

As can be seen from the table, whereas over three quarters (76.1%) of respondents rated the amount of instruction they received on quality care as ranging from adequate to very large, nearly one quarter of respondents (23.9%) rated the amount of instruction they received as ranging from inadequate to none.

In your opinion, is quality care very high, high, adequate, low or very low?

4 respondents did not answer this question. Of the 181 (97.8%) that did, 39 (21.1%) rated quality care as very high in their centers, 74 (40.9%) rated it as high and 50 (27.6%) rated it as adequate. 16 (8.8%) respondents rated quality care low in their centers and 2 (1.1%) rated it as very low. Table 7.5.2 presents summary responses for respondents rating of quality care in their centres. As can be seen from the table, when combined, 163 of the respondents (90%) rated quality care in their centers as ranging from very high to adequate. 18 respondents (9.9%) rated quality care as low to very low.

How would you rate quality care in your centre? (n : 181)			How would you rate facilities available to residents in your centre? (n: 181)		
Rating	Frequency	Percent	Rating	Frequency	Percent
Very high	39	21.1	Very High	28	15.5
High	74	40.9	High	59	32.6
Adequate	50	27.6	Adequate	68	37.6
Low	16	8.8	Low	22	12.2
Very low	2	1.1	Very low	4	2.2
Total	181	100.0	Total	181	100.0
Missing	4		Missing	4	

Table 7.5.2. Summary of findings for questions 28: and 29

In your opinion, how do you rate facilities available to residents in your center?

Four respondents did not answer this question. Of the 181 (97.8%) that did, 28 (15.5%) rated facilities as very high, 59 (32.6%) rated facilities as high and 68 (37.6%) rated facilities as adequate. 22 (12.2%) of respondents rated facilities as low and 4 (2.2%) rated facilities as very low. Summary findings for question 29 are presented in Table 7.5.2 above. When added together, a total of 155 respondents (85.7%) rated facilities as ranging from adequate to very high. 26 respondents (14. 3%) rated facilities as ranging from low to very low.

7.5.2 Dimensions of Care and Client Behaviours (Q 30, 31 and 32)

Questions 30 and 31 required respondents to rank dimensions of care seen in the literature as important for client care. Question 30 asked respondents to rank dimensions they saw as important for clients and question 31 asked them to rank dimensions they saw as receiving most attention by nurses.

Please number from 1 to 10, the following dimensions of care you see as important for clients (1 for most important to 10 for least important).

The five dimensions of care ranked highest for clients were: physical/ health care, emotional care, safety/security care, engagement, and, relationships. Ranked as least important were: spiritual care, sexuality and occupational/work-related skill development. Table 7.5.3 summarises the rank ordering of responses for each dimension. In interpreting tables 7.5.3 to 7.5.5, dimensions of client care are in descending order of importance. A rank of 1 indicates the dimension respondents considered the most important. 1–5 refers to the combined number of respondents that ranked the same dimension within the first five in importance and 9-10 was ranked as the least important.

Please number from 1 to 10 the dimensions of care you see as important for clients (1 for most important to 10 for the least important)						
Descending Order of Importance (n: 182)						
Dimension	1 Most important		1 to 5 Important		9 to 10 Least important	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Physical/ Health Care	75	41.2	155	85	6	3.3
Emotional Care	36	19.8	150	82.41	12	6.5
Safety/ Security Care	38	20.9	130	71.4	15	8
Engagement of clients	13	7.1	112	61.53	12	6.59
Relationships/ friendships	9	4.9	100	54	16	8.61
Training for self- help skills	5	2.7	95	52.2	17	9.3
Social Care	8	4.4	89	49	13	7
Spiritual Care	/	/	20	9.72	113	62
Sexuality	/	/	22	12	98	54
Occupational/ work skills	/	/	51	28	52	28

Table 7.5.3. Summary of findings for question 30: dimensions of care respondents see as important for clients.

The table shows physical care, as the most important dimension respondents consider important for clients followed by emotional care and safety/security care. It is important

to note that the three least important dimensions identified were considered important with between 10% and 12% of respondents identifying spiritual care and sexuality important and 28 % identified occupational skills as important.

Please number from 1-10 the following dimensions of client care that receive most attention by nurses (1 for most to 10 for least important).

In descending order, the five dimensions identified as receiving most attention by nurses were: physical/health care, safety and security care, emotional care, social care, and training for self-help skill development. Eight respondents did not answer the question. Table 7.5.4 presents a summary of findings for question 31.

Please number from 1 to 10 the dimensions of client care that receive most attention from nurses (1 for most important to 10 for least important)						
Descending Order of Importance (n: 177)						
Dimension	1 Most important		1 to 5 Important		9 to 10 Least important	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Physical/ Health Care	104	58.8	168	95	3	1.69
Safety/ Security	36	20.3	149	84.18	9	5
Emotional Care	12	6.8	124	70	9	5
Social Care	11	6.2	108	61	5	2.82
Training for Self-Help Skills	6	3.4	97	54.80	15	8.47
Engagement	3	1.7	73	41.24	20	11.29
Occupational/ Work Skills	4	2.3	72	40.67	30	17
Sexuality	/	/	9	5	129	72.88
Spiritual care	/	/	40	22.59	79	44.63
Relationships/ Friendships	/	/	47	26.55	37	20.90

Table 7.5.4. Summary of findings for question 31: dimensions of client care that receive most attention from nurses.

Respondents identified the same dimensions that receive most attention by nurses as the most important dimensions for clients. However, occupational skills, was identified as receiving more attention compared to relationships/friendships which, although considered important for clients, was not seen as important for receiving attention by respondents. It can also be observed that the rank order of the five most important dimensions is not the same. It is interesting to observe that the three dimensions identified by respondents as most important for clients (Q30) and the dimensions receiving most attention from respondents (Q31), coincide with the biological, safety/security, and love and belonging needs as advanced by Maslow (1970) in his hierarchy of human needs.

Please number from 1 to 10 the client behaviours that would indicate that a client was receiving good quality care.

The purpose in asking this question was to find out which client behaviours respondents considered best were those that indicated clients were receiving good care. All of the items in the question have been identified as important in the literature (Felce & Perry 1995, Gates 1997, Maes et al 2000, Alaszewski et al 2001). The last item (other) permitted respondents' an opportunity to choose an additional response. The five client behaviours respondents identified as the most important indicators of client quality are listed in descending order in table 7.5.5 below. In commenting on these findings it is interesting to note that in response to questions 30: dimensions important for clients, and question 31: dimensions receiving most attention by nurses, physical/health care was identified as the most important dimension.

Please number from 1 to 10 the client behaviours that would indicate that a client was receiving good quality care in your centre (1 for most important to 10 for least important).						
Descending order of importance (n: 185)						
Client Behaviours	1 Most important		1 to 5 Important		9 to 10 Least important	
	Frequency	Percent	Frequency	Percent	Frequency	Percent
Expressing satisfaction with lifestyle	51	27.56	134	72.4	7	3.78
Expressing personal preferences	37	20	149	80.54	3	1.62
Making choices	36	19.45	133	71.89	16	8.64
Engaging in meaningful activities	11	6	121	65.40	17	9.18
Having regular family contact	14	7.56	84	45.40	18	9.72
Setting own personal goals	8	4.32	81	43.78	33	17.83
Having friends	3	1.62	88	47.56	24	13
Recognizing own health care needs	11	6.0	52	28	30	16.21
Taking risks	2	1.08	33	17.83	75	40.54
Other	No Rank					

Table 7.5.5. Summary findings for question 32: client behaviours nurses see as indicating good quality care

In contrast here, as a client behaviour indicating quality care, the item ‘recognition of health care needs’ was seen as most important by only 11 (6%) respondents and as important by only 52 (28%) respondents. A possible explanation here might be that for clients with severe/profound disabilities and thus with particular needs for physical/health care, nurses operate within a medical model. In this situation, nurses are likely to see themselves as wholly responsible for recognizing and meeting the health needs of clients since clients will be unable to recognize their own health care needs.

7.5.3 Standards, Nursing Models and Nursing Care Plans (Q 33,34, 35 and 36)

Two questions were asked about standards for service provision since these are seen as central to quality initiatives in nursing generally (Sale 2000), and in particular, in residential services for people with disabilities (National Disability Authority 2003).

Is nursing care in your centre based on written standards?

Four respondents did not answer the question. Of the 181 (97.8%) that did, 102 (56.35%) said nursing care was based on written standards and 79 (43.65%) said it was not. Table 7.5.6 presents a summary of findings for centres with nursing care based on written standards.

Is nursing care in your centre based on written standards? (n: 181)		
Response	Frequency	Percent
Yes	102	56.35
No	79	43.65
Total	181	100.0
Missing	4	
Total	185	

Table 7.5.6. Summary of responses for question 33

If written standards are in place, are they based on (a)Structure, (b) Process, (c) Service outcomes. (d) Personal outcomes for clients.

102 respondents (56.35%) who said written standards were in place, 93 (91%) said they were based on structures, 70 (68.62%) said they were based on processes, 79 (77.45%) said they were based on outcomes, and 76 (74.50%) said they were based on personal outcomes for clients. Table 7.5.7 below, presents a summary of findings for standards based on structure, process, nursing outcome and personal (client) outcomes.

If written standards are in place are they based on: (a) Structure, (b) Process, (c) Outcomes, (d) Client Outcomes? (n: 102)					
Type of Standard	Yes	Percent	No	Percent	Total
Structure	93	91.18	9	8.82	102
Process	70	68.62	32	31.38	102
Nursing Outcomes	79	77.45	23	22.55	102
Personal Outcomes	76	74.50	26	25.50	102
Missing					83

Table 7.5.7. Summary of responses for question 34

Two related questions were asked about models of care and nursing care plans. These questions were asked to find out if respondents used a model to underpin their philosophy and approaches to care and if they used a care plan to document and evaluate their care.

Do you use a specific model of care for nursing?

Eight respondents did not answer the question. Of the 177 (95.6%) that did, 119 (67.2%) said they used a model of care and 58 (32.8%) said they did not. Only 32 of the 119 respondents specified models. These were the Activities of Living Model (Roper et al 1990), which 22 respondents said they used and Individual Programme Planning (IPP), which all 32 said they used. Respondents did not describe either of the models.

In commenting here, whereas 32 reported using Individual Programme Planning, this is not a model in the sense of being grounded in concepts or philosophical assumptions about the nature of people or care. Rather, it is a framework that is identified in the literature as a powerful tool for planning and evaluating client care (Cummins et al 1996).

Do you use nursing care plans for client?

Eight respondents did not answer the question. Of the 177 that did answer the question 119 said they used nursing care plans for clients and 58 said they did not. Table 7.5.8 presents summary findings for respondents' use of nursing models and care plans

Question 35: Do you use a specific model of care for nursing? (n: 177)	Yes	Percent	No	Percent	Total
	119	67.2	58	32.8	177
Missing					8
Total					185
<i>Activities of Living (N: 119)</i>	22	18.48	97	81.52	119
<i>Individual Programme Planning (N: 119)</i>	32	27.0	87	73.0	119
Question 36: Do you use nursing care plans for clients? (n: 177)	119	67.2	58	32.8	177
Missing					8
Total					185

Table 7.5.8. Summary findings for use of specific model of care and use of care plans.

7.5.4 Individual Programme Planning (Q 38, 39, 40 and 41)

Four questions were devoted to eliciting information about individual programme planning for clients. Literature on quality care for persons with mental handicap views individual programme planning (IPPs) as an important process for identifying and planning care (Jenkins et al 1988, Cummins 1997) and as important for evaluating both service-led and client-centered outcomes (Kaplan & Kauffman 1992, Wright & Moffatt 1992, NAMHI 1999, NDA 2003). In Irish residential centers little is known about the extent to which IPPs are used, the frequency with which they are held, the number of people who attend meetings or the number and type of outcome objectives set for clients.

Is client care based on individual programme plans?

Four respondents did not answer the question. Of the 181 (97.8%) that did, 64 (35.4%), just over a third, said care was always based on IPPs. 95 (52.5%), just over half, said care was sometimes based on IPPs. 22 (12.2%) of respondents, said care was rarely based on IPPs. Table 7.5.9 presents a summary of the findings for question 38.

Is client care based on individual programme plans (IPPs)? (n: 181)		
Response	Frequency	Percent
Always	64	35.4
Sometimes	95	52.5
Rarely	22	12.2
Total	181	100.0
Missing	4	
Total	185	

Table 7.5.9. Summary of findings for question 38: Is client care based on IPP?

In commenting here, little more than a third of respondents said IPPs were always used for clients and the majority report they are only used sometimes or rarely. It would seem that contrary to the views in the literature about the importance of IPPs, they are neither implemented fully nor used consistently by almost two thirds of this sample in Irish residential centers.

If IPPs are held for clients, how often are they conducted?

13 respondents did not answer the question. Of the 172 (93.0%) that did, 51 (29.7%) said IPPs were conducted every 6 months, 65 (37.8%) said they were conducted every 12 months and 56 (32.6%) said they were conducted less often than every 12 months. While the literature suggests that IPPs should be held as often as is necessary for clients, it is argued that they should take place at least every 6 months (Jenkins et al 1988, Cummins et al 1996). As can be seen here, only 51 (less than a third) report IPPs at frequencies of 6 months and 121 respondents (70.34%) more than two-thirds, report the frequency as 12 months or less often. A question was asked to find out the number and type of objectives used in IPP meetings. This was asked because the literature suggests that where IPPs are critically reviewed, little mention is made of either the type or number of objectives involved. It is argued by Dagnan & Sturney (1994), Cummins (1996) and

Stancliffe et al (1999) that if IPPs are to be used for quality care, there should be a balance between skill-building and social-activity objectives with between 1 and 3 of each type. Skill building refers to practical self-help skills like personal hygiene. Social activities refer to skills like communication. While both types of skills are important for personal development it is necessary to have a balance between them when planning education and training programmes.

If IPPs are held for clients, what is the average number of skill-building and social activity objectives planned for clients?

For Skill-Building Objectives – Of the 149 (80.5%) respondents who answered this question, 102 (68.5%), over two thirds, said IPPs in their centers had between 1 to 3 objectives. 35 (23.5%), nearly a quarter, said IPPs had between 4 to 6 objectives and 12 (8.1%) said IPPs had between 7 to 12 objectives.

For Social Activity Objectives – Of the 153 (82.7%) of respondents that answered this, 92 (60.1%), less than two thirds, said IPPs in their centers had between 1 to 3 objectives. 47 (30.7%) said IPPs had between 4 to 6 objectives and 14 (9.2%) said IPPs had between 7 to 12 objectives. Table 7.5.10 presents a summary of findings for question 40.

If IPPs are held for clients, what is the average number of:				
(a) Skill-building objectives (n: 149)				
(b) Social activity objectives (n: 153)				
Number of Objectives	Skill-Building Objectives		Social Activity Objectives	
	Frequency	Percent	Frequency	Percent
1 - 3	102	68.5	92	60.1
4 - 6	35	23.5	47	30.7
7 - 12	12	8.1	14	9.2
Total	149	100.0	153	100.0
Missing	36		32	
Total	185		185	

Table 7.5.10. Summary of findings for question 40

The literature on IPPs provides no absolute directions for the number or the types of stakeholder that should attend meetings. Depending on the particular client and his or her needs, a number of different people might attend or be invited to attend an IPP meeting (Stancliffe et al 1999). Based on the notion of interprofessional or multidisciplinary teamwork, the last question was asked to find out which stakeholders attended meetings and how often they were invited to attend.

If IPPs are in place, please indicate the people who attend the meetings and those who are invited

Of the 166 (89.7%) respondents who answered this question, only 20 (12.%) said clients always attended and 79 (47.6%) said they rarely attended meetings. 40 (24.1%) of the respondents, less than a quarter, said a family member always attended and 79 (47.6%) said they rarely attended meetings. For members of the professional team, 154 respondents (92.8%) said nurses always attended meetings. For attendance by other team members, just over half the respondents said the psychologist always attended meetings, 63 (38.0%) said the social worker always attended meetings and 54 (32.5%) said the psychiatrist always attended meetings. 26 respondents (15.6%) said the physiotherapist always attended meetings. Table 7.5.11 presents a summary of findings for question 41.

In interpreting this table, the second row shows the people that attend or are invited to attend meetings. The first column shows the frequency with which people attend or are invited to attend. Although the various members of the multidisciplinary team can all make valuable contributions to clients IPP meetings, there are too few of these professional team members to attend all meetings.

As a consequence of this, many of these professional are likely to be invited more often than they are able to attend meetings.

In commenting on these findings it is interesting to note that professional attendance as reported here is quite good given how few psychologists, physiotherapists and social workers there are likely to be in any center compared with the number of clients and the frequency with which they have IPP meetings. However, bearing in mind that IPPs are about addressing and discussing any or all the needs and requirements of clients, it is noteworthy that only 20 respondents, (12%) said family members always attend meetings.

If IPPs are in place, please indicate the people who attend the meetings and those who are invited (n: 166)								
Response	Client	Family member	Advocate or friend	Care staff	Nurse	Psychologist	Social worker	Physio-therapist
Always	20 (12%)	40 (24.1%)	13 (7.8%)	71 (42.8%)	154 (92.8%)	91 (54.8%)	63 (38.0%)	26 (15.6%)
Sometimes	46 (27.7%)	49 (29.5%)	24 (14.5%)	57 (34.3%)	9 (5.4%)	50 (30.1%)	54 (32.5%)	66 (39.8%)
Rarely	79 (47.6%)	57 (34.3%)	85 (51.2%)	27 (16.3%)	2 (1.2%)	15 (9.0%)	25 (15.1%)	40 (24.1%)
Never but invited	4 (2.4%)	10 (6.0%)	5 (3.0%)	2 (1.2%)	1 (.6%)	5 (3.0%)	8 (4.8%)	6 (3.6%)
Never but not invited	17 (10.2%)	10 (6.0%)	39 (23.5%)	9 (5.4%)	/	5 (3.0%)	16 (9.6%)	28 (16.9%)
Total	166 (100.0%)	166 (100.0%)	166 (100.0%)	166 (100.0%)	166 (100.0%)	166 (100.0%)	166 (100.0%)	166 (100.0%)
Missing	19	19	19	19	19	19	19	19
Total	185	185	185	185	185	185	185	185

Table 7.5.11. Summary of responses for question 41

7.5.5 Consultation with Families of Clients (Q 42 and 43)

The literature has identified discussion and consultation with families of clients as necessary for service quality (Grant et al 1994) and for quality care responsive to the needs of clients and their families (Ming Ho Lau & Mackenzie 1996). Two related questions were asked about discussion/consultation with clients' families and the person who initiates contact for discussion.

On average, how often do you consult with family members of clients?

Five respondents did not answer the question. Of the 180 (97.2%) that did, 69 (38.3%) said they always contacted the family. 96 (53.3%) said they contacted the family sometimes, and 15 (8.3%) said they rarely contacted clients family members.

In discussions between client, their family and the nurse, who initiates the discussion?

Eighty-one respondents, just under half, did not answer this question. Of the 104 (56.2%) that did, 79 (76.0%) said the nurse most often initiated discussions, 14 (13.4%) said it was the social worker, 7 (6.7%) said it was the family and only 2 (2.0%) said it was the client. While it should not be surprising that in the majority of instances it was the nurse who initiated contact with the family, one can only speculate on why so many respondents did not answer this question. A possible reason could be that since many clients in centres are maturing adults, they may have no family members alive

7.5.6 Nurses Involvement and Participation in the Service (Q 44, 45 and 46)

Employee commitment to service quality is dependent on the level of participation they perceive themselves to have in the service and the extent to which they feel involved in making decisions (Gardner & Carlopio 1996, Guimaraes 1997, Evans & Lindsay 2002). Based on this, three questions were asked about participation, decision-making and making suggestions to management.

To what extent are you involved in decision-making practices for clients in your centre?

Of the 181 (97.8%) respondents that answered this question, 80, (44.2%) said they were always involved. 90, (49.7%) said they were sometimes involved, and 11 (6.1%) said they were rarely involved. Table 7.5.12 presents a summary of findings for question 44.

To what extent were you involved in decision making practices about care for clients in your centre? (n: 181)		
Response	Frequency	Percent
Always	80	44.2
Sometimes	90	49.7
Rarely	11	6.1
Total	181	100.0
Missing	4	
Total	185	

Table 7.5.12. Summary of findings for question 44

How would you rate your participation in the overall service in your centre?

Of the 181 (97.8%) respondents that answered this question, 60 (33.1%) said they participated on all matters and 102 (56.4%) said they participated on nursing matters only. 16 (8.8%) said they participated only during a crisis and 3 (1.7%) said that they rarely participated. Table 7.5.13 presents a summary of the findings for responses to question 45.

How would you rate your participation in the overall service in your centre? (n: 181)		
Response	Frequency	Percent
Participate on all matters	60	33.1
Participate on nursing matters only	102	56.4
Participate only during a crisis	16	8.8
Rarely participate in any matters	3	1.7
Total	181	100.0
Missing	4	
Total	185	

Table 7.5.13. Summary responses for question 45

Are you encouraged to make suggestions to management on matters of care for clients?

Of the 183 (98.9%) respondents that answered this question, 74 (40.4%) said they were always encouraged to make suggestions to management. 84 (45.9%) said they were only encouraged to make suggestions sometimes, and 25 (13.7%) said they were rarely encouraged to make suggestions. Table 7.5.14 presents a summary of the findings for question 46.

Are nurses encouraged to make suggestions to management on matters of care for clients? (n: 183)		
Response	Frequency	Percent
Always encouraged	74	40.4
Sometimes encouraged	84	45.9
Rarely encouraged	25	13.7
Total	183	100.0
Missing	2	
Total	185	

Table 7.5.14. Summary of findings for responses to question 46

7.5.7 Management Practices Impacting on Quality Care (Q 49 and 50)

While the literature puts forward the view that quality is everyone's responsibility it emphasizes that the management of service quality is a function of top management (Kehoe 1996, Evans & Lindsay 2002). Two related questions were asked about

management practices in centres concerning the extent to which they assisted or hindered nurses in the provision of quality care to clients. Respondents were asked to rank-order 7 management practices seen as important in both the general management literature (McGregor 1960, Blake & Mouton 1978, Daft 1995, Wheeler & Grice 2000) and the quality management literature (Deming 1986, Smith 1995, Oakland 2000, Evans & Lindsay 2002).

Please number from 1 to 7 the management practices that in your opinion best facilitate you providing quality care to clients

In descending order, the three management practices respondents said best facilitated provision of quality care were: good communication with staff, involving staff in decision making, and providing adequate staff and equipment.

Please number from 1 to 7 the management practices that in your opinion are barriers to you providing quality care to clients

In descending order, the three management practices respondents saw as the biggest barriers to quality care were: poor communication with staff, not involving staff in decision making, and having a bureaucratic style of management.

Tables 7.5.15 and 7.5.16 presents summary responses for quality facilitating and quality barrier practices respectively. In interpreting these tables, 1 indicates the number of respondents that ranked a management practice as best facilitated or formed the biggest barrier and 1-3 indicates the combined number of respondents that ranked the same management practice as best facilitating or biggest barrier to quality care overall.

Please number from 1 to 7 the management practices that in your opinion, <u>best facilitate</u> nurses providing quality care (n: 181)				
Descending Order of Facilitation.				
Management Practice	1 Best Facilitate		1 to 3 Overall Best Facilitate	
	Frequency	Percent	Frequency	Percent
Good communication with staff	85	47	153	84.53
Involving staff in decision making	24	13.2	126	69.61
Providing adequate staff and equipment	27	14.91	77	42.54
Democratic style of leadership	20	11	73	40.33
Participative style of management	17	9.39	61	33.70
Delegating responsibility to staff	5	2.76	45	24.66
Other	Did not Specify			

Table 7.5.15. Summary of responses for Question 49

Please number from 1 to 7 the management practices that in your opinion, are <u>barriers</u> to nurses providing quality care (1 for biggest barrier to 7 for least barrier). (n:179)				
Barriers in Descending Order of Importance.				
Management Practice	1 Biggest Barrier		1 to 3 Overall Biggest Barriers	
	Frequency	Percent	Frequency	Percent
Poor communication with staff	80	44.69	147	82.0
Not involving staff in decision making	21	11.7	113	63.12
Bureaucratic style of management	30	16.75	96	53.63
Not providing adequate staff and equipment	22	12.29	85	47.48
Autocratic style of leadership	28	15.64	77	43.0
Not delegating responsibility to staff	3	1.67	28	15.64
Other	Did not specify			

Table 7.5.16. Summary of responses for Question 50

7.5.8 Monitoring and Evaluating Care (Q 51, 52, 53, 54 and 55)

In this last section, findings for evaluation are presented together and are followed by the summary tables. In the context of residential care and depending on the functional ability

and needs of clients, the function of nursing is chiefly concerned with holistic care across the lifespan of individuals (Roth & Morse 1994, An Bord Altranais 2000, Gates et al 2003). In view of this, a question was asked to find out the methods respondents used to measure (monitor) the quality of nursing care to clients. It is important to point out here that whereas monitoring and measuring are not the same, some methods nurses might employ would be observational (auditing standards of care) while others would lend themselves to precise measurement (bio-physical measurement).

Please number from 1 to 8, the methods you use to measure (monitor) quality of care

In descending order, the three most common methods reported for measuring (monitoring) quality of care were: behavioral observations, talking and listening to clients and, reviews of nursing care plans. The two least common methods reported were auditing of standards and biophysical measurement. Table 7.5.17 below, presents a summary of the findings for both the most and least common methods reported by respondents for question 51.

Please number from 1 to 8, the methods you use to measure (monitor) quality of nursing care to clients in the home/unit you work in (1for most common method to 8 for least common method) (n:179)				
Descending Order of Commonly Used Methods				
Method	1 Most Common		1 – 3 Overall Most Common	
	Frequency	Percent	Frequency	Percent
Behavioral Observations	87	48.6	149	83.24
Talking and Listening to Clients	39	21.78	106	59.21
Reviewing Nursing Care Plans	30	16.75	93	51.95
Auditing of Standards of Care	7	3.91	66	36.87
Bio-Physical Measurement	3	1.67	35	19.55
Other	Did not Specify			

Table 7.5.17. Summary of findings for question 51

In commenting on these findings it is interesting to note that whereas physical/health care was reported as the most important dimension of care for clients (Q: 30 & 31), and standards were reported as being in place in most centers (Q: 33) both bio-physical measurement and monitoring of standards were reported as being the two least commonly used methods for monitor nursing care.

Evaluation of service delivery is a necessary component of quality management (Evans & Lindsay 2002). It is central to quality care for people with intellectual disabilities (Gardner 1997, Maes et al 2000) and to the quality of nursing care (Marquis & Huston 2000, Kozier et al 2000). Because of this, the last five questions on the questionnaire were asked to find out the methods, approaches and extent to which nurses evaluated the structures, processes and outcomes of care they provided to clients. Most of these are rank-order questions and only the highest or significant frequency responses are reported.

Please number from 1 to 10, the resources (structures) you use to evaluate care

In descending order, the resources used were number of staff on duty in the home/unit; skill-mix of staff on duty, access to specialists services for clients and, equipment for providing care for clients. Table 7.5.18 presents a summary of findings for question 52.

Please number from 1 to 10, the resources (structures) you use to evaluate provision of care for your clients . (1 for most important to 10 for least important) (n: 181)				
Descending order of importance				
Resources	1 Most important		1 – 3 Overall Most Important	
	Frequency	Percent	Frequency	Percent
Number of staff on duty	114	63.0	154	85.0
Skill-mix of staff	28	15.46	99	54.70
Access to specialist services	13	7.18	84	46.40
Equipment for providing care	7	3.86	77	42.54

Table 7.5.18. Summary of findings for question 52

Please number from 1 to 10; the methods you use to evaluate efficiency of nursing care

In descending order, the methods used to evaluate *efficiency* of nursing care were: staff meetings about client care; responsiveness to client needs, review of assessments and, collaboration with other professionals. Table 7.5.19 presents a summary of findings for question 53.

Please number from 1 to 10, the <u>methods</u> you use to evaluate the <u>efficiency</u> of nursing care for clients (1 for most important to 10 for least important). (n: 176)				
Descending Order of Importance of Methods				
Methods	1 Most Important		1 – 3 Overall Most Important	
	Frequency	Percent	Frequency	Percent
Staff meetings on client care	66	37.5	130	73.86
Responsiveness to client needs	56	31.81	112	63.63
Review of assessment documentation	22	12.5	72	41.0
Collaboration with other professionals	6	3.40	56	31.81

Table 7.5.19. Summary of findings for question 53

Please number from 1 to 10, the client outcomes you use to evaluate effectiveness of care

In descending order, the overall client outcomes ranked as most common were: being able to make choices in their lives, having good health, expressing satisfaction with the care they receive and, being involved in decisions about their care. Table 7.5.20 below presents a summary of the findings for question 54.

The last two questions on the Questionnaire were asked to find out if nurses evaluated their nursing care of clients and if so, which areas of care did they evaluate most often.

Please number from 1 to 10, the Client Personal Outcomes you use to evaluate the effectiveness of care (1 for most common to 10 for least common) (n:172)				
Descending Order of Use				
Client Personal Outcome	1 Most Common		1 - 3 Overall Most Common	
	Frequency	Percent	Frequency	Percent
Being able to make choices	29	16.86	87	50.58
Having good health	40	23.25	73	42.44
Expressing satisfaction with care they receive	42	24.41	70	40.69
Being involved in decisions about care	18	10.46	64	37.20

Table 7.5.20. Summary of findings for question 54

(A) Do you evaluate the outcomes of nursing care? (B), if yes, please describe how?

For part (a) of question 55, nearly two thirds of respondents said they evaluated the outcomes of their nursing care and one third said they did not. There were no responses (description of evaluation) for part (b) on how nursing care outcomes were evaluated.

If you evaluate your care, please number from 1 to 8, the areas you evaluate most often.

Just over three quarters of respondents answered this last question. The areas of care ranked from 1 to 3 as being evaluated most often were: physical well being, personal well being , emotional well being and, social well being. The areas of care least often evaluated were: material well being, sexual well being and, spiritual well being. Table 7.5.21 presents a summary of findings for question 56.

If you evaluate your nursing care, please number from 1 to 8 the areas of care you evaluate most often (1 for most often to 8 for least often). (n: 141)				
Descending Order of Areas Evaluated				
Nursing Areas Evaluated	1 Most Often		1 – 3 Overall Most Often	
	Frequency	Percent	Frequency	Percent
Physical Well Being	74	52.48	123	87.23
Personal Well Being	37	26.24	115	81.56
Emotional Well Being	27	19.14	85	60.28
Social Well Being	6	4.25	70	49.64

Table 7.5.21. Summary of findings for question 56

7.6. Conclusion to Section A

This section described the findings from the survey of a random sample of nurses working in residential centers for persons with intellectual disabilities. The survey formed the dominant component of the empirical research and findings were described for each of the four sections of the questionnaire. Major findings relevant to answering the research questions are analyzed and discussed in the next section.

SECTION B

ANALYSIS OF FINDINGS FROM SURVEY OF NURSES

Analyses and interpretation follows a thematic approach using two broad themes and concentrates on the main findings specific to answering each of the research questions. *Theme one* is dimensions and processes of care. Research questions 1 – 3 are used to present this theme and include dimensions of care, evaluation of care and organisational processes for care.

Theme two is organisational management practices. Research questions 4 – 5 are used to present this theme and include participation, decision-making and management practices.

Theme One: Dimensions and Processes of Care

7.7. What if any, are the differences between dimensions of care that nurses see as important for nursing and dimensions nurses see as important for client care?

A dimension of care refers to an aspect or component of care for an individual. It is defined here as meaning a distinct subset of the total or holistic needs and requirements which are recognised as important for any person (e.g. physical needs), and which to varying extents can be observed, recorded, measured and evaluated.

7.7.1 Dimensions of Care

While the median ranking for the *physical health care* dimension for nurses was 2 with 104 (58.8%) nurses deeming this to be the most important, the median ranking nurses gave for clients was 3 with only 75 (41.2%) of nurses seeing this as most important for clients. The application of the Wilcoxon test for two related samples confirms a statistically significant difference between the importance of physical health care for nurses and its importance for clients ($Z = 5.773$, $p < 0.001$). While overall results confirm physical health care is the most important dimension of care for nurses and clients, the significance of this result indicates that nurses perceive physical health care to be a more important dimension to them as nurses than it is to clients.

The *safety/security dimension* for nurses was given a median ranking of 2 and 36 (20.3%) of the respondents saw this as being the second most important dimension receiving nursing attention. For the importance of safety/security to clients, slightly more

respondents gave this dimension a median ranking of 3 with 38 respondents (20.9%) seeing it as being important to clients. The Wilcoxon test confirms a statistically significant difference between how nurses see the dimension of safety/security for nursing care compared to how they see its importance to clients ($Z = -3.690$, $p < 0.001$).

The *emotional care dimension* for nurses was given a median ranking of 5 with only 12 (6.8%) of respondents seeing this as the third most important dimension receiving nursing attention. In contrast to this, respondents saw emotional care as being much more important to clients than to nurses with 36 (19.8%) of respondents giving the dimension a median ranking of 3 for its importance to clients. The application of the Wilcoxon test confirms that there is a statistically significant difference between how nurses see the importance of emotional care for nurses and how they see the importance of emotional care to clients ($Z = -6.216$, $p < 0.001$). A conclusion from these results is that while nurses may be too busy, especially with the more demanding clients, or be unable to make emotional contact with clients with complex disabilities, they are nonetheless likely to recognize that emotional needs are important to clients.

7.7.2 Dimensions Considered Least Important

The dimensions of care considered least important were sexuality and spiritual. Only just over half (54%) ranked relationships within their first five dimensions of importance. For nurses the *sexuality dimension of care* was seen as least important with 129 (72.88%) of the respondents giving sexuality a median ranking of between 9 and 10 (see table 7.5.4). However, for clients, 98 (54%) of respondents gave this dimension a median ranking of

between 9 and 10. While close to three quarters of respondents considered sexuality least important for nurses, just over half considered it least important to clients. The application of the Wilcoxon test confirms a statistically significant difference between how nurses see the importance of sexuality for nursing care and how they see its importance to clients ($Z = -4.577$, $p = < 0.001$).

Spiritual care was given a median ranking of between 9 and 10 and was seen as least important for receiving attention from nurses by 79 (44.63%) of respondents. For clients, spiritual care also received a median ranking of between 9 and 10 and was seen as being least important for clients by 113 (62%) of respondents. Application of the Wilcoxon test confirms a statistically significant difference between spiritual care receiving attention by nurses and how they view its importance to clients ($Z = -5.243$, $p = < 0.001$). Table 7.7.1 below presents a summary of the median ranking of the most and least important dimensions that respondents identified for nurses and clients together with levels of statistical difference.

Results and Cross Tabulations for Dimensions of Care for Nurses and for Clients (1 for most important to 10 for least importance)			
	Most Important Dimensions	Median Ranking of Dimension	Wilcoxon Level of Significance: 0.05
Nurse	Physical health care	2	Z = -5.773, p < 0.001
Client		3	
Nurse	Safety/Security care	2	Z = -3.690, p < 0.001
Client		3	
Nurse	Emotional care	5	Z = -6.216, p < 0.001
Client		3	
	Least important Dimensions		
Nurse	Sexuality care	9 – 10	Z = -4.577, p < 0.001
Client		9 – 10	
Nurse	Spiritual care	9 – 10	Z = -5.243, p < 0.001
Client		9 – 10	

Table 7.7.1. Summary of analysis for Questions 30 & 31 on the differences between the dimensions of care respondents saw as important to nurses and to clients.

7.7.3 Cross-reference of Findings with Findings from Experience Survey

Findings from the experience survey interviews with the experts emphasized the importance of nurses providing holistic care to clients. Participants were asked three broad questions about nurses' activities with clients (Q6), client behaviours indicating quality care (Q7) and nurses recognition of indicators of quality care (Q8).

- *On physical and health related interventions*, All 7 experts recognized these as necessary for persons with profound and multiple disabilities but felt that nurses

focused and concentrated on physical and hygiene dimensions of care to the detriment of other dimensions.

- *On safety/security of clients*, all experts felt that in general, nurses working in residential settings were expected to concentrate on safety and security dimensions of care and to avoid activities or elements of care that involved risks.
- *On emotional care*, all saw this as being important and part of holistic care. They felt this could only be provided within as normative a home situation as possible.
- *On sexuality and spiritual care*, the experts did not explicitly refer to either of these dimensions. However, implicit in the high value they placed on the provision of holistic care for clients is the recognition that caring for the whole person must include their sexual and spiritual dimensions.

7.8. How do the dimensions of care that are the focus of nursing interventions for clients compare with the dimensions of care that nurses evaluate most often?

To find out if there was any relationship between the three most common dimensions of nursing care and the outcomes of care nurses evaluate most often, responses for the two variables were compared. This was important because since nurses see physical and emotional health care as the most important dimensions of care for clients, it is reasonable to expect they should evaluate physical and emotional well being (Q56) as the outcomes of meeting these dimensions of their nursing care.

For the physical care dimension, this was seen as the most important care dimension by 104 of the respondents (58.8%) and as important by 168 (95%). For physical well being as an outcome evaluated, this was seen as most important by 74 (52.48%) respondents

and as important by the 123 (87.23%). The application of the Chi-square test to compare the frequencies for these two nominal variables reveals this finding to be statistically significant ($\chi^2 = 191.841$, $df = 40$, $p = < 0.001$). What this means is that physical care for clients has a strong positive relationship to physical well being as the outcome of nursing care respondents evaluate most often.

For the emotional care dimension, only 12 of the respondents (6.8%) saw this as the most important care dimension for clients but 124 (70%) saw it as important. For the evaluation of emotional well being of clients, just 27 (19.14%) of respondents said they evaluated this the most often but 85 (60.28%) said it was an outcome they evaluated. The application of the Chi-square test to compare the frequencies for these two nominal variables reveals there was no a statistically significant result. The dimension of *safety/security care* had no equivalent or matching item in the evaluation question (Q56) for comparison.

7.8.1 Cross-reference of Findings with Experience Survey Findings

Participants in the exploratory personal interviews were not asked a specific question about evaluation. Nonetheless, they felt that many nurses rarely see evaluation as meaning anything beyond the personal level of care that they and other frontline staff provide to individual clients. Participants saw nurses as being generally unaware of the larger picture of service quality or of management's specific accountability for service quality.

7.9. In what ways are nurses involved in organisational care processes used for planning and delivering care to clients in residential centers?

Organisational care processes refer to the procedures and activities associated with the assessment, planning, implementation and evaluation of care. The processes reported here are the multi-disciplinary teams, standards of care, and programme planning.

7.9.1 Multi-Disciplinary Team Approach.

Findings for multi-disciplinary teams were reported in section A (see table 7.4.2). Based on the necessity of a multi-disciplinary team approach to care, it was considered important to find out if there was any statistical relationship between the use of teams in centres and the extent of nurses' membership of these teams. The use of the Chi Square test was used to compare the frequencies for these two nominal variables and revealed a statistically significant relationship ($\chi^2 = 31.837$, $df = 1$, $p = <0.001$). While this shows a positive relationship between the presence of multi-disciplinary teams in centres and respondents membership of these teams, not all respondents are members of teams. Table 7.9.1 presents a summary of results for multi-disciplinary team approaches and respondents' membership of teams.

As can be seen, while the majority of centres based service provision on a multi-disciplinary approach, not all respondents were members of the team in their centre. This result indicates that in some centres, nurses are either denied membership of teams or are not fully participating in teams. Given that a multi-disciplinary approach has long been seen as necessary for quality care (Russell 1986, Needs and Abilities Report 1990,

NAMHI 1999, NDA 2003) if nurses are denied opportunity for sharing and collaborating with other professionals through teamwork, they will not have access to information and decision-making about care for their clients. As a consequence of this, nurses will be unable to contribute to responsive holistic care.

Summary Results for Multi-disciplinary Team Approach to Service Provision compared with Nurses Membership of Multi-disciplinary Teams in their Centres. Level of Significance: 0.05			
Is service provision based on a multi-disciplinary approach to care (n: 181)		Are nurses members of the multi-disciplinary team (n: 175)	
Yes	Percent	Yes	Percent
162	89.5%	148	84.6%
No	Percent	Level of Statistical Significance (Chi Square)	
19	10.5%	Chi = 31.837, df = 1, p = <0.001).	

Table 7.9.1. Summary of analysis for multi-disciplinary care provision in centres and nurses membership of multi-disciplinary teams in their centres

7.9.2 Standards of Care.

Findings for standards of care and types of standards were reported in section A. Over half the respondents reported they had written standards in their centres and the researcher considered it important to find out if there was any statistical relationship between standards and organisational processes. The reason for this is that if standards are to be responsive to clients needs and attentive to holistic care, there must be organisational processes in place to achieve their outcomes. Standards were compared

with individual programme planning; parents and friends association and quality system. The application of the Chi Square statistic revealed there was a significant statistical relationship between all these nominal variables (processes). Interestingly enough, when standards were compared with nurse training schools no significant statistical relationship was found. Table 7.9.2 shows results for the three variables for which there was a significant statistical relationship with written standards.

For individual programme planning, when combined with standards, fifty six percent had both standards and individual programme planning in centres. Application of the Chi square test for these two nominal variables showed a significant statistical relationship (Chi = 12.827, df = 2, p = .002). What this indicates is that despite the rhetoric on the importance of standards and the need for individual programme planning for holistic care, little more than half the respondents report having both these processes in centres.

Results for Written Standards when compared with Individual Programme Planning, Parents & Friends Associations, Quality System and Nurse Training Schools. Level of Statistical Significance: 0.05			
Written Standards compared with:	Yes	Percent	Level of Significance
Individual Programme Planning (n: 178)	Yes	Percent	Chi = 12.827, df = 2, p = .002
Always	47	26.40%	
Sometimes	45	25.28%	
Rarely	8	4.49%	
Quality System in Place (n: 167)	76	45.50%	Chi = 27.423, df = 1, p = <0.001
Parents & Friends Association (n: 181)	86	47.51%	Chi = 7.413, df = 1, p = .006
Nurse Training School (n: 181)	57	31.49%	

Table 7.9.2. Summary of written standards of care compared with type of individual programme planning, quality system, parents and friends associations, and nurse training schools.

For quality system, whereas over sixty percent said they had a quality system in their centres, less than fifty percent had a quality system with written standards. It is difficult to see how a quality system can be in place without the inclusion or reliance on standards. Use of the Chi-square test reveals this finding to be statistically significant ($\chi^2 = 27.423$, $df = 1$, $p = 0.001$). A possible explanation for this finding is that in answering the question on quality systems, many respondents identified quality-related endeavors in their centre as quality systems despite being provided with an operational definition for a quality system.

For parents and friends associations, nearly forty eight percent of respondents said their centre had a parents and friends association and written standards. However, the use of the Chi-square test revealed only a mild statistical relationship between the two variables ($\chi^2 = 7.413$, $df = 1$, $p = .006$). In commenting on this, it is not unreasonable that a centre with an active parents and friends association would also have standards in place. This could possibly come from pressure from parents and friends or the parents and friends association could be in place because of a proactive centre with standards service standards.

Finally here, it is worth noting that while standards were not widespread in centres, this is set to change when the National Standards for Disability Services (NDA 2003) become mandatory for residential centres in the latter part of 2004.

7.9.3 Individual Programme Planning (IPP).

IPPs provide a framework for nurses to collaborate with other members of the multi-disciplinary team and with families of individual clients (Jenkins et al 1986). However, to be an effective process for quality care, IPPs must take place regularly and should involve the attendance of the client, a member of the client's family and the professional carers responsible for the client. Cummins et al (1996) and Stancliffe et al (1999) view non-attendance of these stakeholders as a major weakness of IPP meetings.

The Chi-Square test was used to compare the frequency of IPP meetings with client, family member and nurse attendance at meetings. For client attendance at meetings, the test revealed a statistically significant relationship ($\chi^2 = 39.183$, $df = 8$, $p = < 0.001$). This result shows a negative relationship between IPP meetings and client attendance at these meetings where even in cases when IPPs were always used, clients were statistically unlikely to be in attendance at meetings. There was no significant statistical relationship found between frequency of IPPs and family or nurse attendance at meetings. However, considering the importance of stakeholder contributions to planning, where IPPs were always used, only 20 respondents (12%) said a family member always attended and where IPPs were sometimes used, only 19 (11.5%) said a family member always attended. Table 7.9.3 below presents a summary of results for the frequency of use of IPPs in centres compared with the attendance of clients, family member and nurses. As can be seen from this table, where IPP was reported as always used, only 11 respondents said clients always attended and 19 said clients sometimes attended.

Results of comparison of frequency of IPP meetings in centres with Clients, Family members and Nurses attending and invited to attend IPP meetings					
Level of Significance: 0.05					
Please indicate the people that attend IPP meetings		Is Client Care Based on IPP?			
		Always	Sometimes	Rarely	Total
Client (n: 165)	Always	11	9		20
	% of Total	6.7%	5.5%		12.1%
	Sometimes	19	26		45
	% of Total	11.5%	15.8%		27.3%
	Rarely	25	48	6	79
	% of Total	15.2%	29.1%	3.6%	47.9%
	Never but Invited	1		3	4
	% of Total	.6%		1.8%	2.4%
	Never & not Invited	7	8	2	17
	% of Total	4.2%	4.8%	1.2%	10.3%
Total		63	91	11	165
% of Total		38.2%	55.2%	6.7%	100.0%
Level of statistical significance: Chi = 39.183, df = 8, p = < 0.001					
Family member (n: 165)	Always	20	19	1	40
	% of Total	12.1%	11.5%	.6%	24.2%
	Sometimes	19	28	1	48
	% of Total	11.5%	17.0%	.6%	29.1%
	Rarely	17	35	5	57
	% of Total	10.3%	21.2%	3.0%	34.5%
	Never but Invited	3	5	2	10
	% of Total	1.8%	3.0%	1.2%	6.1%
	Never & not Invited	4	4	2	10
	% of Total	2.4%	2.4%	1.2%	6.1%
Total		63	91	11	165
% of Total		38.2%	55.2%	6.7%	100.0%
Nurse (n: 165)	Always	61	82	10	153
	% of Total	37.0%	49.7%	6.1%	92.7%
	Sometimes	1	8		9
	% of Total	.6%	4.8%		5.5%
	Rarely	1		1	2
	% of Total	.6%		.6%	1.2%
	Never but Invited				
	% of Total				
	Never & not Invited		1		1
	% of Total		.6%		.6%
Total		63	91	11	165
% of Total		38.2%	55.2%	6.7%	100.0%

Table 7.9.3. Summary of analysis and statistical significance for client care based on IPP and the people attending and invited to attend IPP meetings.

Nurses attend IPP meetings the most frequently. However, only 61 (37%) of respondents said where IPPs are always used, nurses always attend. These findings are significant. Bearing in mind the majority of respondents said their centres used IPP always or sometimes, the poor results for attendance at meetings is disappointing and alarming. Given that the purpose of IPPs is to plan for the individual needs and wants of clients (Stancliffe et al 1999), it is difficult to imagine how this can occur without the attendance and participation of major stakeholders and in particular, nurses. IPPs are not an option for care planning but an entitlement of service users and their families (NAMHI 1999 NDA 2003).

In residential centres, responsibility for organizing IPP meetings usually falls to the nurse because he/she is the frontline professional at the hub of care and around whom other professionals make contact with clients. That said it is particularly disappointing that in most cases meetings are infrequent and clients and family members do not attend. This writer believes that if meetings were to be conducted frequently and regularly and clients or their advocates and family members attend, they will have a platform for verbalizing their perceptions about service delivery and can be assisted if necessary to explain their expectations for future service provision based on their needs and wants.

7.9.4 Cross-reference of Findings with Experience Survey Findings.

The experts in the experience survey were asked four questions about care processes. Two questions related to the multidisciplinary team (MDT) and the nurses involvement in the team (Q 4 & 5), one question concerned standards of care (Q 14) and one broad

question asked them about organisational activities that in their experience worked best for planning and delivering care to clients (Q16).

For Question 4: *From your experience, do you think nurses can provide quality care on their own?*

- All 7 said quality depended on the full participation of all professionals working together as a team so as to provide holistic care responsive to the needs of clients.

For Question 5: *From your experience, are nurses sufficiently involved in the MDT?*

- All 7 said nurses were members of the MDT but it depended on a particular centre if they were sufficiently involved. 4 of the 7 experts believed nurses were not equal participants of the MDT and 3 of the 7 said that nurses were only involved on issues of physical care and management of challenging behaviors.

For Question 14: *From your experience, do you consider written standards of care to be important for providing quality care to clients?*

- All 7 said standards were important and 6 of the 7 emphasized that standards must apply to all aspects of care and not just physical (nursing) care. All said that centres using standards had to audit and respond to standards if they were to have any practical benefit.

For Question 16: *From your experience, what organisational activities work best for planning and delivering good care to clients in residential centres?* In summary, the organisational activities were:

- MDT – all 7 stressed the importance of the team and teamwork for good care.
- IPP – all 7 saw individual programme planning as a central activity for providing individualized care to clients.

Theme Two: Organisational Management Practices

7.10. What organisational management practices do nurses identify as facilitating and inhibiting their ability to provide quality care to clients?

As discussed in the literature, everyone should be involved in quality. However, it is ultimately the responsibility of management to ensure the leadership and resources for service quality and that support structures and management style enable employees to commit to quality and to want to provide the best service they can (Deming 1986, Gardner & Carlopio 1996, Kondo 1997, Evans & Lindsay 2002).

7.10.1 Management-Facilitating and Management-Barrier Practices for Quality

Because good organisational management practices are important for a quality service, the survey asked respondents to number from 1 to 7, the management practices they perceived facilitated quality care and were barriers to quality care. Table 7.10.1 below, presents a summary of the median ranking for the four management barriers and facilitators and the number and percentage of respondents who ranked them important.

Overall, the four management practices seen as best facilitating quality and biggest barriers to quality were the obverse of each other.

Median Ranking of the Four Management-Facilitators and Management -Barriers to Nurses Providing Quality Care to Clients			
Management Facilitators of quality care	Response	Percent	Median Ranking
Good communication	153	84.53	2
Involving staff in decision making	126	69.61	3
Providing adequate staff and equipment	77	42.54	3
Democratic style of leadership	73	40.33	4
Management Barriers to quality care			
Poor communication	147	82.0	2
Not involving staff in decision making	113	63.12	3
Bureaucratic style of management	96	53.63	3
Not providing adequate staff and equipment	85	47.48	4

Table 7.10.1. Summary of analysis of Questions 49 & 50 on management practices that facilitate and are barriers to nurses providing quality care to clients

Communication and involvement in decision-making were identified as the two-facilitator/barrier practices seen as most important and received a similar median ranking score. While the third and fourth facilitators and barriers received different median values and were thus ranked differently, they were nonetheless the opposites of each other.

7.10.2. Cross reference of Findings with Experience Survey Findings

The experts in the experience survey were asked a similar question on the affects of management practices on nurses' care for clients (Q10).

Positive (facilitating) affects were:

- Valuing staff - all 7 considered it was important to value and recognize the contribution of staff in providing good service to clients and the organization.
- Democratic style of management – all 7 considered this to be important if staff were to feel empowered and to feel they have a say in the organization.
- Telling staff what they are expected to do- 5 of the 7 said staff needed to be told what was expected of them and needed direction.
- Resources and sufficient staff - all 7 stressed the importance of management providing adequate staff and equipment for staff to provide good quality of care.

Negative (barrier) affects were:

- Bureaucratic style of management – all 7 said quality care was inconsistent with a bureaucratic management system.
- Staff shortages – all 7 said safe care (and thus quality care) could not be given to clients if there were chronic staff shortages in the home or unit.
- Not telling staff what was expected from them - all 7 felt that if staff were to feel involved and valued, managers need to tell them what is expected from them rather than to be left to carry out their duties without direction.

Interviewees did not explicitly mention communication as an affect although telling staff what is expected from them, having participative management and encouraging staff, would all suggest that communication is important. Effects that concur with barriers identified in the survey are bureaucratic style of management and staff shortages. Poor communication was not mentioned as an affect. Since bureaucratic management is a

negative effect and since this management style is least likely to foster good communication, it is not unreasonable to suggest that good communication is seen as important because democratic style of management is seen as a positive effect.

7.11. How does participation and involvement in organisational decision-making relate to nurses provision of quality care for clients?

Employee participation and involvement in decision-making are both seen as necessary conditions for service quality (Kondo 1997, Evans & Lindsay 2002), and for human services (Edvardsson et al 1997, National Disability Authority 2003). Participation here refers to respondents perceived level of engagement in general organisational activities. Decision-making refers to respondents perceived involvement in making specific decisions. Given their importance, the researcher decided to find out if there was any statistical relationship between respondents level of participation and involvement in decision-making.

7.11.1 Participation and Decision-Making

A higher percentage of respondents (44.2%) said they were always involved in decision-making compared to the percentage of respondents (31%) who said they participated on all matters in their centres. Use of the Chi-square test to compare the frequency of responses for these two nominal variables revealed a significant statistical relationship with more respondents saying they were involved in decision making than were participating in all matters in their centres ($\chi^2 = 33.809$, $df = 6$, $p = <0.001$).

Interpreting this result is not straightforward since participation and decision-making are closely related. A speculative interpretation is that a higher percentage of respondents perceive themselves as being more involved in decisions about client care and the running of the home/unit than the percentage of respondents who perceive themselves as participating on all matters, including non-client matters in their centres.

7.11.2 Consultation and Suggestions to Management

Less than a fifth of respondents (19%) were always consulted and encouraged to make suggestions to management. Over a third (36%) were sometimes consulted and encouraged to make suggestions. The researcher considered it useful to see if there was a statistical relationship between the frequencies of responses for consultation and involvement in decision-making. The reason for this was to find out if respondents who were consulted by management perceived that they were involved in decision-making.

The application of the Chi-square test confirmed a statistically significant relationship between the two nominal variables ($\chi^2 = 36.889$, $df = 4$, $p = <0.001$). This result indicates that those respondents who reported being consulted were more likely to be involved in decision-making. Because employee participation is seen as so important for quality, the level of participation was compared with encouragement to make suggestions to management. Table 7.11.1 below presents a summary of analysis results for responses for participation and decision-making in centres

Results for Participation and Involvement in Decision-Making Level of Significance: 0.05			
	Are nurses consulted on matters of service provision to residents? (Q21)	To what extent are you involved in decision-making practices? (Q44)	Are nurses encouraged to make suggestions to management? (Q46)
Are nurses consulted on matters of service provision to residents? (Q21)		Always 33 (18.64%) Sometimes 67 (37.85%) Rarely 7 (3.95%) Chi =28.851, Df=4, P= <0.001	Always 34 (19%) Sometimes 65 (36.31%) Rarely 6 (3.35%) Chi =36.889, df=4, P=<0.001
To what extent are you involved in decision-making? (Q44)			Always 47 (26%) Sometimes 25 (13.81%) Rarely 5 (2.76%) Chi =28.628, df=4, p=< 0.001
How would you rate your participation in the overall service? (Q45)	<u>On All Matters</u> Always 22 (12.5%) Sometimes 35 (20%) <u>Nursing Matters</u> Always 23 (13%) Sometimes 65 (37%) Chi =17.585, Df=6, p = 0.007	<u>On All Matters</u> Always 42 (23.46%) Sometimes 17 (9.49%) <u>Nursing Matters</u> Always 34 (19%) Sometimes 60 (33.51%) Chi =33.809, df=6, p= <0.001	All Matters Always 38 (21%) Sometimes 53 (29.44%) During Crisis 8 (4.44%) Chi =39.136, Df=6, P= <0.001

Table 7.11.1. Summary of analysis for nurses' level of participation and Involvement in decision making in centres.

As can be seen from table 7.11.1 one fifth said they participated on all matters and were always encouraged to make suggestions to management. Less than a fifth (18%) participated on nursing matters only and were always encouraged to make suggestions to management. Ten percent said they sometimes participated on nursing matters only and were sometimes encouraged to make suggestions to management. Application of the Chi-square test revealed a statistically significant relationship between level of participation and encouragement to make suggestions to management ($\chi^2 = 39.136$, $df = 6$, $p < 0.001$). Table 7.11.1 below presents a summary of analysis results for responses for participation and decision-making in centres.

7.11.3. Forum for Discussion

Nearly sixty percent of respondents said they had no forum for discussion in their centers. Having a forum for discussing client care might reasonably facilitate collective suggestions on matters of care and service quality, and would likely provide staff the opportunity to increase their involvement in decision making and participation in the overall service. Based on this consideration, the frequency of responses for forum for discussion were compared with three other frequency results considered important for quality: involvement in decision making (Q44), encouragement to make suggestions to management (Q46), and respondents consultation on matters of service provision to clients (Q21).

For decision-making, only a quarter of the respondents that were always involved in decision-making in their centres had a forum for discussion. Use of the Chi-square test

revealed a statistically significant relationship between both these variables ($\chi^2 = 14.910$, $df = 2$, $p = .001$) In interpreting this result and as few respondents said they had a forum for staff discussion, it is difficult to see how staff will have a sense of maximizing their involvement in decision-making in centres.

For encouragement to make suggestions to management, only a quarter of respondents that were always encouraged to make suggestions to management had a forum for discussion. Use of the Chi-square test showed a statistically significant relationship between both these variables ($\chi^2 = 24.414$, $df = 2$, $p = .000$). In interpreting this and as for decision-making, without a forum for staff it is difficult to see how staff can make suggestions to management and especially where collective suggestions are involved.

For consultations on matters of service provision to clients, only fourteen percent of respondents who were always consulted on service provision for clients also had a forum for discussion. When the frequencies for these two variables were compared, there was no significant statistical relationship found. Table 7.11.2 presents a summary of results and level of statistical significance for forums for discussion in centres.

Analysis of Results for Forum for Discussing client Care (n: 180) Level of Significance: 0.05				
Is there a forum for nurses to meet to discuss client care? Yes	To what extent are you involved in decision-making practices for clients in your centre?			
	Always	Sometimes	Rarely	Chi = 14.910, df = 2, P = .001
	45 (25%)	25 (13.8%)	4 (2%)	
Yes	Are nurses encouraged to make suggestions to management on matters of care for clients?			
	Always	Sometimes	Rarely	Chi = 24.414, df = 2, P = 0.001
	46 (25.27%)	26 (14.28%)	4 (2%)	
Yes	Are nurses consulted on matters of service provision for clients?			
	Always	Sometimes	Rarely	
	25 (14%)	43 (24%)	5 (2.8%)	

Table 7.11.2. Summary of analysis results for forum for discussion compared with decision making, making suggestions to management, and consultation on matters of service provision.

7.11.4 Cross - reference of Findings with Experience Survey Findings

The experts were not asked a specific question about nurses' decision-making or participation in their centres. However, they felt the only effective way for nurses to provide quality care was through collaboration and teamwork and they stressed the importance of planning for individuals through a teamwork approach. It is suggested here, that implicit in a collaborative and teamwork approach, is the acknowledgement of participation and of being involved in decision making. It is also worth noting that participants considered a democratic style of management to be a facilitating influence on quality care, thus indicating the importance of nurses having some level of participation in their centres.

7.12. Conclusion

Section A of this chapter presented the main findings from the survey of nurses in clinical practice. Section B analysed the findings necessary for answering the research questions. Findings were divided between nursing-related processes, and management practices and these were used as the themes for the analysis. The themes were not used to answer the research questions but were a logical and convenient way of discussing them.

Theme one: dimensions and processes of care were based on research questions 1 to 3. Theme two: organisational management practices based on research questions 4 to 5. Findings from the experience survey of the experts on quality were cross-referenced with those from the survey of nurses and each of the research questions were answered in turn.

Finally here, all major findings relevant to answering the research questions were cross-referenced with findings for similar question items from the experience survey of experts. This process has led to a richness of data that has contributed to the reliability and validity of the findings. The next chapter presents a detailed discussion of the findings from the research study and discusses the confirmation of the conceptual model of needs-based care and two typologies derived from the findings.

CHAPTER EIGHT

DISCUSSION OF FINDINGS

8.1 Introduction

Presented here is a discussion of the results from the analysis of findings from chapter seven. These are discussed in light of the literature in the area and current practice issues. Following discussion of findings, two typologies of needs-led quality care are discussed. First is a typology developed in chapter five from the literature and second, is a typology for managing quality care developed from the findings. The final part of the chapter confirms the model developed from the synthesis of the literature and which was presented in section B of chapter five. Based on this confirmation from the findings, a more integrated conceptual model of needs based quality care is presented and discussed. The last part of the chapter discusses a number of specific conclusions as they relate to both nurses and managers within residential centres generally.

Theme One: Dimensions and Processes of Care

8.2. Discussion on Dimensions of Care

Findings show clients receive most attention from nurses on physical care, safety, and emotional care and these findings are in broad agreement with findings from the literature (Nurse Teachers Group 1995, Felce & Perry 1995, Gardner & Chapman 1997, Alaszewski et al 2001). Overall results indicate that client safety/security is important but nurses perceive this dimension to be more important to them as nurses than it is to clients.

A possible explanation for this is that in residential centres, nurses care for clients with complex disabilities. They feel the need to protect clients from harm while at the same time they may feel that for the development of clients they should allow clients to engage in normal activities that might involve some element of risk.

A likely reason for the sexuality and spirituality dimensions receiving the least attention from nurses can be attributed to the severe disabilities of clients and the concern nurses have within residential centres for safety and security. Nurses are more likely to respond to assisting clients with needs of a practical nature like physical care and self-help skills training. While nurses are likely to see sexuality and spirituality as part of the holistic needs of clients, for clients with severe disabilities these will be subservient to more practical and demanding needs.

Little difference exists between dimensions respondents see as important for nursing and dimensions they see as important for clients. It is reasonable to expect that community, day care, and other changes initiated by the paradigm shift to social development and inclusion for people with intellectual disability would facilitate frontline staff concentrating on more holistic care and thus on all dimensions of care. However, there are a number of points to be made about this.

First, most residential centres accommodate people in groups of eight to ten. These group homes or units provide domestic-like home environments that have the potential to support growth and development of individuals. However, clients in these groups live

within the constraints of residential life where, as with most institutions, people congregate in groups and where the concentration is frequently on safety and protection (Jahoda & Markova 1990, Chapman 1997).

Against this background, service provision is often provided in a controlling, hierarchical and conformist way with little concern for choice, preferences and meaningful engagements or dimensions supportive of personal growth (Raynes 1979, Bradley & Ouvry 1999). Despite the rhetoric for progressive care, these findings indicate that management in most residential centres appears to value dimensions like physical, safety, and emotional care more highly than less visible dimensions or potentially risk-related dimensions like relationships and this may well not be the case for nurses working in day care services.

Second is the findings that in residential group homes located in the community, the lifestyle and quality of life for many clients, especially those with severe and multiple disabilities, is similar to that for clients living in residential centres where in a number of cases, homes were observed to be run like mini-institutions (Rapley & Hopgood 1997).

Third, and despite the observations noted above, all dimensions of care including relationships, sexuality and spirituality are valued as legitimate nursing interventions since nurses subscribe to the ethos of holistic care (An Bord Altranais 2000, Alaszewski et al 2001, Northway & Jenkins 2003). This said, the findings from this study provide little evidence of nurses applying a humanistic or social model in residential centres.

Whether residential managers expect nurses to concentrate on basic needs as part of an ethos of protectionism and thus curtail the range of activities nurses engage in, can only be speculated on here.

Finally, almost all the contemporary literature in the area is directed towards community care. Most is written by non-nurses or at least nurses outside of residential services and is more likely concerned with theoretical issues than with applied research. In addition, most of the literature dealing with people with intellectual disability refers to clients with higher levels of cognitive and social skills. As a consequence of having higher functioning skills these clients are less dependent on continuous care and, according to Gates et al (2003), dimensions like occupation, relationships and sexuality assume greater importance.

In summary, while there are statistical differences between dimensions important for nurses and clients, interpreting findings in light of their practical significance indicates very little differences. While some dimensions received different median values, the same dimensions were ranked as most important for nurses and clients. Thus the first research question has been answered. It is suggested that dimensions other than the three discussed above, are not so much seen as unimportant as less urgent. Physical care, safety/security, and emotional support are likely to be seen as the more visibly practical and recurring needs of clients in residential centres.

8.3. Discussion on Dimensions of Care Evaluated

Literature on intellectual disability (Cass & Kugler 1998, Maes et al 2000) and in nursing care quality (Kemp & Richardson 1995, Slevin et al 1995, Sale 2000) draws attention to the importance of evaluation. Cass & Kugler (1998) for example, argue the necessity for a multi-user approach to evaluation and this view is endorsed by Maes et al (2000) who point out that from an organisational standpoint, evaluation can only be effective if it is done as a dialogue between all stakeholders involved in the service. However, in this study, the aim was to find out if and how, nurses as frontline professionals evaluate their care of clients. Findings from this research indicate most of the respondents do evaluate aspects of their care and employ various methods as part of the process. The majority of respondents said they *monitored their care*.

It is suggested here that behavioural observations - the most common method used to monitor care – is likely to be a reflection of the frequency of challenging or dysfunctional behaviour of clients in residential care as well as a concern for their safety (protection). It is also reasonable to speculate that policies and procedures dealing with care management exist, particularly safety issues, and nurses are the likely professionals to be involved in monitoring these. A noteworthy observation is that whereas physical care was seen as the most important dimension of care for clients and the majority of respondents reported they had written standards in place, the least common methods used to monitor care were auditing of standards and biophysical measurements.

The most important *resource reported for evaluating care* was the number of staff on duty in the home. Adequate and appropriately trained staff as well as what staff do, have been identified in the literature as important considerations for quality of care (Rose 1998). It is suggested here, that in the current climate with staff shortages in hospitals and residential centres generally, this is hardly surprising and is understandable.

Having access to specialist services for clients and having equipment for providing care are important resources if nurses are to meet the needs and requirements of their clients. Given the importance that respondents attached to physical care in particular, could explain why nurses would value access to specialist services and why they would need equipment for doing the job (e.g. technical, educational and play equipment).

The most important *client personal outcomes used to evaluate effectiveness of care* were making choices and having good health. Mention has already been made of the importance of good health for clients, which would indicate good physical care. Expressing choices and personal preferences are identified as important and highly valued outcomes from service provision (O'Brien 1987, Wolfensberger 2001) and as necessary personal outcomes in quality care (Gardner 1997).

Other client outcomes that respondents evaluated were expressions of satisfaction with care, and being involved in decisions about their care. Both of these are seen as important quality-related outcomes for clients (Gardner 1997, Wolfensberger 2001). Evaluation of client personal outcomes is very positive and in keeping with the rhetoric for good

practice. However, it must be acknowledged that the most common client personal outcome (choices) was evaluated by less than sixty percent of respondents with just forty percent reporting they evaluated the other personal outcomes.

Finally here, while two thirds of the respondents said they evaluated the *outcomes* of their *nursing care*, none of them provided a description of their evaluation method/s. Areas of care respondents evaluated most often were physical well being followed by personal well being, emotional well being and social well being. Physical well being was the most frequently evaluated nursing outcome. As physical care is the most important and constant type of care required, it is not surprising that physical well being is evaluated most often. The second research question has been answered and shows respondents evaluate the same dimensions they see as the most important focus of their interventions.

8.4. Discussion on Organisational Care Processes

Teamwork is a central tenant of Deming's philosophy for quality and the literature sees the multidisciplinary team (MDT) as being the fundamental approach to holistic care provision (Gates 1997, White Paper on Learning Disability 2001, National Disability Authority 2003) as well as to service quality initiatives (NAMHI 1999, Evans & Lindsay 2002). Findings indicate that MDTs are present in the majority of centres and that nurses are members. However, a number of the experts in the Experience Survey suggest nurses may not be equal members of the MDT and may only be involved on matters relating to physical/health and behavioural issues as distinct from being full participants at a more general level.

Just over half the respondents said nursing care was based on written standards and the most common standards reported were for structures. However, given the value placed on personal outcomes in the literature (Gardner 1997, NDA 2003) it is interesting and very positive that a similar number of respondents that reported standards for nursing outcomes also reported standards for personal outcomes. These findings are all the more interesting given the fact that draft national standards have only just been developed for disability services (National Disability Authority 2003). These standards take on board the views of people with disabilities, their families, carers and service providers and will be piloted from June this year in 20 centres for a period of 6 to 8 months (National Association of the Mentally Handicapped of Ireland 2003).

Individual programme planning (IPP) is about personal plans for clients but despite their importance (Cummins et al 1997, Stancliffe 1999, NDA 2003) and the significance attached to them from the findings of the experts in the Experience Survey, only just over a third of the respondents said care was always based on IPP. Less than thirty percent of respondents said IPP were conducted six monthly. Speculating on the poor attendance at IPP meetings, many clients in residential centres have severe and multiple disabilities and thus poor cognitive and communication skills and these may account for them not being invited or attending their IPP if they have one. Many clients are also adults who may not have close family relatives still living or with whom contact has been lost and thus have no one to come to their IPP meeting.

Finally and whereas the organisational processes discussed above are not exhaustive, they are common approaches to care and provide a sound bases for conducting service evaluation. Analysis of results shows the extent to which nurses are involved in organisational processes in centres and answers the third research question in this study.

Theme Two: Organisational Management Practices

8.5. Discussion on Management Facilitating and Barrier Practices for Quality

In commenting on the findings, it is interesting to note that the obverse of the four most important facilitating practices for quality were identified as the four most important barrier practices. The most important facilitator was good communication and poor communication was the most important barrier. Communication has been identified repeatedly in the literature as a necessary component of quality management (Oakland 1993, Kemp & Richardson 1995, Beckford 1998, Evans & Lindsay 2002).

It is suggested here, that because they work in specific homes/units with the same group of clients, nurses may feel segregated from other staff in the service and as members of the MDT nurses are likely to feel the need to have close liaison with other members. These considerations then, would mean a high value is attached to communication. In addition, another finding from this research (see below) is that respondents consider it important that management tell them what is expected of them in their work, thus emphasizing the importance of communication.

Involving staff in decision-making was another finding seen as important by respondents. The importance of being involved in decision-making and of participation in the service is seen as crucial for quality management by a number of writers (Crosby 1979, Edvardsson et al 1997, Department of Health Valuing People 2001, Evans & Lindsay 2002, National Disability Authority 2003). These are discussed below.

Providing adequate staff and equipment were identified as management facilitating practices or factors. Respondents also saw having adequate staff on duty and appropriate equipment in the home/unit important for evaluating resources for care. The last management- facilitating practice respondents identified, was the presence of a democratic style of leadership. Marquis & Jorgensen Huston (2000) sees this style of leadership as exhibiting upward and downward communication, involving others in decision-making, and exerting less control. They see this style of leadership as most suitable for small groups and for promoting autonomy and growth in individuals.

In contrast, respondents saw the existence of an organisational structure that was bureaucratic as being a management barrier to their ability to provide quality care. Marquis & Jorgensen (2000) see the type of organisational structure as affecting communication patterns, relationships and autonomy. They see this structure as authoritarian and not consistent with empowerment. Some centres known to the researcher have a more flat-type organisational management structure in place similar to shared-governance. According to Hess (1995), shared governance is an organisational structure that fosters empowerment of professional staff in decision-making. It facilitates

a more egalitarian communication structure between professionals and invests more authority, accountability and control over nursing care with nurses. Recognizing that the experts in the experience survey generally concur with the management practices identified by respondents as facilitating and barrier practices to quality, it can be concluded that the fourth research question has been answered.

8.6. Discussion on Involvement in Participation and Decision Making

The issues discussed in this question are all factors specific to the management of centres. Each factor is seen as important in the literature and the experts in the experience survey and the nurses in the focus groups identified all as important for quality care. While the theoretical literature usually presents these factors separately, and this was the way they were discussed here, in reality, they are all closely interwoven with each other. For example, in the context of management-worker relationships, decision-making, participation, consultation and making suggestions are not dichotomous concepts but a framework for employees taking ownership and responsibility for their work. Collectively, they provide the means whereby employees feel empowered in their work (Beckford 1998, Evans & Lindsay 2002). While the intention behind each may be different, they are similar in as much as they require effective communication, a measure of authority and respect for the involvement of people and a level of agreement and mutual understanding.

Many theorists see employee participation and involvement in decision-making as necessary. In the theoretical work of Maslow (1970) and Herzberg (1977) for example,

they consider involvement in participation and decision-making as necessary for motivating employees. In the realm of quality management, theorists like Crosby (1979), Deming (1986) and Oakland (1993), as well as more contemporary writers like Pietsenpol and Gitlow (1996), Øvretveit (1999), Kondo (1997), and Evans and Lindsay (2002), all consider these factors crucial if workers are to feel empowered and able to commit to service quality.

Few studies were found dealing specifically with residential intellectual disabilities nursing, a reflection perhaps of this discipline of nursing existing only in Ireland and Great Britain. In an empirical study looking at job satisfaction and burnout among direct care staff of a community learning disability service, Dyer and Quine (1998) found that while most of their participants felt supported, this support came mainly from colleagues. Many of the participants felt seriously constrained in their job because of a lack of management support and because of not having involvement in decision-making.

Marquis and Huston (2000) suggest that if nurses are constrained or unable to participate or take decisions on nursing care and nursing issues within the organization, they will become dissatisfied, suffer burnout and may leave the service. Of importance is the forthcoming introduction of the national standards for disability services in the Republic of Ireland (National Disability Authority 2003). While not addressing nurses specifically, the standards draw attention to many of the general issues surrounding participation and decision-making of staff and to good management practices supportive of service quality.

In a study of empowerment and commitment in long term care, Beaulieu et al (1997) found higher levels of responsibility brought with it higher levels of perceived empowerment. Staff nurses had lower empowerment and job excitement than did first line managers who had less than middle managers and this was because of level of participation and decision-making. These researchers found the more frontline staff perceived themselves to have job-related empowerment through participation and taking part in decisions, the greater was their commitment to the organization.

In summary, results for this final research question show only a third of respondents perceive they participate on all matters and just over half participate on nursing matters. Only forty percent were always involved in decision-making and just under half were sometimes involved.

The implications of these results are that nurses may feel less empowered and less involved in their work. If nurses feel undervalued through being denied involvement in decisions about client care, they will be unlikely to interest themselves to commit to service quality. If nursing staff feel uninvolved and lack ownership of the work they do, this will lead to poor job satisfaction and in the extreme, to staff leaving the service altogether.

8.7. Discussion of Two Typologies for Quality Care

This section discusses two typologies for quality in light of the findings from this study.

First, the typology of needs-led care developed from the synthesis of literature reviewed.

This is about clients' needs and outcomes and addresses the first three research questions dealing with the theme of dimensions and processes of care. Second is a typology that is partly developed from the literature and partly developed from the findings. This is about management factors for quality and addresses the last two research questions dealing with the theme of organisational management practices.

8.7.1 Typology for Needs-led Care

The matrix typology in 8.1 below was developed from the literature in chapter five. This is completed here in light of the findings from the present study. As is obvious from the typology, there is limited information included due to the limitations of the survey question items and the focus on nurses' perception of service quality.

HUMAN NEEDS DIMENSIONS (Maslow 1954, 1970)	QUALITY OF LIFE DIMENSIONS (Felce & Perry 1995)				
	PHYSICAL WELL BEING	MATERIAL WELL BEING	EMOTIONAL WELL BEING	SOCIAL WELL BEING	DEVELOPMENT & ACTIVITY
PHYSIOLOGICAL NEEDS	Dimension receiving most attention by nurses (95%) and as most important needs of clients as perceived by nurses (85%) Most common dimension evaluated by nurses	Findings provide no information on how physical needs impact on this dimension	Findings provide no direct information. Nurses have close contact with clients as they provide personal care but may or may not provide affection	Functional ability and residential care will impact on clients opportunity for many social activities	Most (81.2%) had clients with severe/profound disabilities in the home. Because of this, training in self-help and living skills are likely to be very important
SAFETY & SECURITY NEEDS	Seen as second most important dimension receiving attention by nurses (84.18%)	Clothes, food & protection provided. Little independence for choice or personal preferences	Concentration on safety suggesting little opportunity for mixing or close friendships	Limited opportunity for engaging in social activities	Findings indicate concern with risk and harm with only 18% considering taking risks as important
LOVE & BELONGING NEEDS	Seen as the third most important dimension receiving attention by nurses (70%)	32.6% of nurses rated facilities as high/very,	No nurse sees Sexual needs as most important and only 5% see sexuality as important for clients	Just over one quarter (26.55%) see friends as important	Just over half had mixed sexes in the home. Sexuality, spirituality & relationships seen as least important dimensions
SELF ESTEEM NEEDS	Just 81% saw expressing personal preferences as important	Less than two thirds saw activities as important	Less than half saw client contact with family as important	Less than half saw having friends as important	Less than three quarters saw satisfaction with lifestyle as important
SELF ACTUALISATION NEEDS	Recognition of own health needs seen as unimportant	Only 41% saw occupational skills as important	Friendships/relationships and family contact seen as important by less than 50%	Activities, friendships and family contact seen as important by less than 50%	Overall, only 44% saw clients setting own goals as important

Matrix 8.1. A typology for needs-led quality showing the relationship between the five broad needs as dimensions of care exemplified through Maslow's (1954) needs theory and the five broad dimensions of quality of life exemplified thorough Felce & Perry's (1995) dimensions of quality of life. Source: Redmond (2004)

In practice settings, this typology is likely to have a number of uses in residential centres. By presenting the typology in the form of an A4 or A3 sheet to allow completion, the care team can use it in a number of ways:

1. It is a useful aid to thinking about needs and outcomes, as each individual need a client has will be considered across the five dimensions of quality of life as outcomes of care.
2. It will sensitize the care team in their thinking about the effects of their interventions.
3. It will be useful for life planning and especially in the area of setting goals for clients.
4. It will be useful for seeing gaps in care and recognizing the impact of care provision.
5. It will contribute to any record for each client's unique personal development plan.
6. It will assist in evaluating client care at their individual programme planning meetings.

Finally here, while the theoretical positions used in the typology are what the researcher sees as important, practical and relevant for intellectual disability services, these may be modified. For example, the needs and quality of life dimensions can be extended to include others. Alternatively, other needs theories or quality of life dimensions can be substituted for the ones used here.

8.7.2 Typology for Managing Quality in the Home/Unit

This typology is based on the framework developed by Donabedian (1969) and the management-related issues seen in this study as affecting nurses' quality care for clients. Matrix 8.2 shows the typology with the Donabedian framework placed on the horizontal axis and the management factors seen as important in this study placed on the vertical axis. The typology is filled-in light of the findings from research questions 4 and 5.

CRITICAL FACTORS FOR MANAGING QUALITY IN THE HOME/UNIT	STRUCTURE	PROCESS	OUTCOME
FACILITATING FACTORS	Providing adequate staff and equipment (42.54%)	Good communication (84.53%) Involvement in decisions (69.61%) Democratic management (40.33%)	Commitment to quality; better quality care; more job satisfaction from participation
BARRIER FACTORS	Not providing adequate staff and equipment (47.48%)	Poor communication (82%) No involvement in decision-Making (63.12%) Bureaucratic management (53.63%)	Non-commitment to quality Poor quality care Possible poor job satisfaction Staff leaving service
CHANGE FACTORS	Need to provide more staff or review staff cover and deployment	Management should: Consult with staff; tell staff what it expects them to do for clients	Management should meet with staff; Recruit extra staff

Matrix 8.2 Typology of factors for discussing, planning and evaluating factors for managing quality care in the home/unit of residential centres. Source: Redmond 2004.

Like the needs-led typology, this service-led typology can also be modified and extended to include other management factors that might be seen as critical in residential homes or units. It provides a framework for the care team to think and discuss service issues specific to the home/unit circumstances. A particular usefulness is that it can form a basis for negotiating management support requirements for providing quality care.

8.8. Confirmation of the Integrated Model of Needs Based Quality

This discussion section has a threefold purpose:

- 1 To discuss how the findings confirm the model developed in chapter five from the synthesis of the literature on service quality and intellectual disability.
- 2 Develop this model as an integrated conceptual model of needs based quality care.
- 3 Discuss the applications of the conceptual model of needs based quality care.

Figure 8.3 below show the dimensions of care respondents said receive most attention from nurses. What can be interpreted from this is that nurses predominantly concentrate on the deficit or basic needs of clients. As nurses in residential centres seem to attach little importance to other more social dimensions e.g. friendships or work-related activities necessary for esteem and development, this would indicate they are not providing care or support for higher order growth needs.

MASLOW'S HIERARCHY OF NEEDS



Figure 8.3. Schema showing the areas of needs-led care nurses provide to clients in residential centres as exemplified through Maslow's hierarchy of needs theory.

Figure 8.4 below schematically shows the level of needs support provided by nurses as depicted by supporting arrows. As can be seen, support is mostly provided in the areas of physiological, safety and belonging needs. Findings from the study show little support for higher needs like esteem and self-actualization.

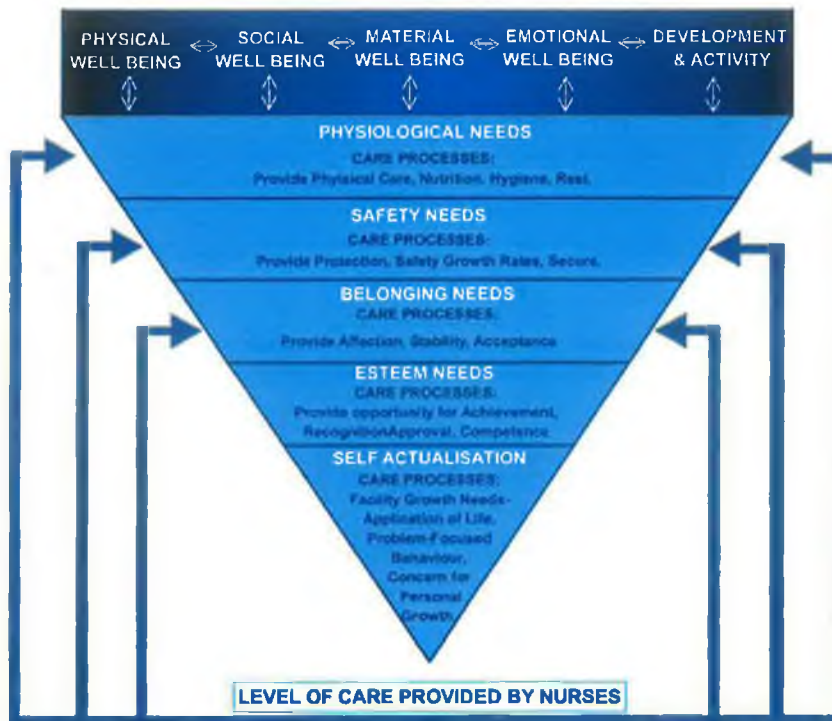


Figure 8.4. Schema showing relationship between dimensions of care and level of care provided by nurses as depicted by supporting arrows. Source: Redmond 2004 (Adapted from Maslow 1954 and Felce and Perry 1995).

From the foregoing discussion it is now possible to advance an integrated conceptual model of needs based quality care. Figure 8.5 is the model and illustrates the relationships and inter-connections of each of the sub-stages as:

- Needs of clients as they relate to specific outcome dimensions of quality of life.
- Needs of clients with examples of processes necessary to achieve specific needs.
- Needs of clients incorporating examples of structures required to meet needs.

Two-way and directional arrows showing the areas of influence and feedback.

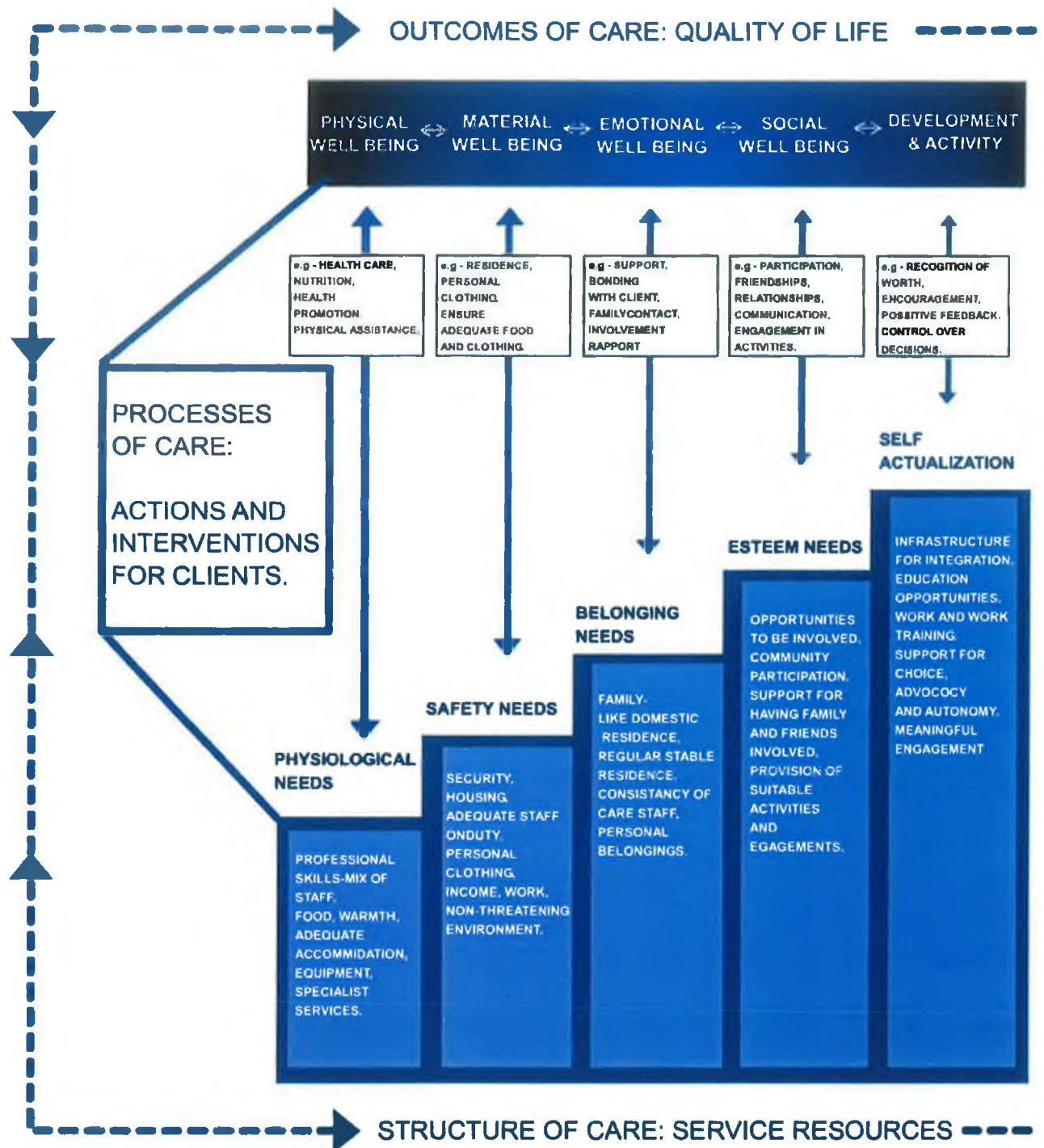


Figure 8.5. The Conceptual Model of Needs Based Quality (Redmond 2004). The model shows the relationships between dimensions of quality of life as outcomes of care and service provision and the process and structures dimensions of service provision to clients. The use of two-way arrows indicates how each dimension of quality of life (outcome) is influenced by processes (care interventions) and structures (services resources).

8.8.1 Discussion on Development and Confirmation of the Needs Based Model

While the model shows a hierarchical order to the needs of clients, this is not meant to suggest that peoples needs occur in this manner. However, findings from this study clearly show that in residential centres, nurses identify and provide care in a hierarchical order with a concentration on the lower (essential) needs of clients. The model is descriptive and provides a framework for describing the relationships between the many complex dimensions involved and that have to be considered for a needs-based quality in intellectual disability. It shows relationships between needs of clients, quality of life of clients and, the connections between them as the process, outcomes and structures elements of service quality for people with intellectual disability living in residential centres.

Needs and their satisfaction are of fundamental importance to all humans, disabled or non-disabled (see chapter three, section 3.4.3). However, as Chapman (1985) says, the nature of a patient/client's disease/disability may well modify the importance of particular needs. While theorists and writers on the subject may differ on their explanation of needs, they generally agree that humans have a range and complexity of needs that operate at different levels. Being able to understand, identify and intervene to meet patient/client needs is seen as a necessary function of nursing care (Holtkamp et al 2001) and as a means of ensuring a needs-led approach to quality care (Mattiasson & Anderson 1997, NDA 2003).

Quality of life is now recognized as the legitimate aim of service provision for persons with intellectual disability (Landesman 1986, Gates 2002, Department of Health &

Children 2003) and the enhancement of quality of life is seen as an indication of a quality service to individuals (Department of Health & Children 2003). As was discussed in chapter three, the construct and its various dimensions are seen as appropriate outcomes of care. In constructing this model, an attempt has been made to link processes of care to meet the needs of clients with dimensions of quality of life as outcomes of care. Specifically, the aim was to illustrate schematically, how particular needs of clients might be conceptually and practically linked to particular dimensions of quality of life as outcomes for clients.

In attempting this, it is stressed that connections and associations between dimensions of needs and dimensions of quality of life must not be taken as over-simplifications of relationships where satisfying one set of needs leads to or causes a specific quality of life outcome. On the contrary, as was mentioned when discussing connections, relationships are not linear but are complex and multi-faceted. Satisfaction of some needs for example, may influence or bring about the emergence of other needs that may affect whether a particular quality of life outcome is achieved. In fact according to Seed and Lloyd (1997) and Schalock (1997), it is more likely that several needs will have to be met before an individual considers an outcome of quality of life is met.

Maslow's contribution to our understanding of human needs may appear less popular and have less scientific credibility today. Despite this, one can hardly find a text in nursing, management, quality or education that does not in some way draw on his work. While Maslow's theory was developed from his reflections and discussions with selective

people, it was not developed empirically. Another criticism of his theory concerns its hierarchical order of needs where higher needs could only be important and met by the person when lower needs were fulfilled. However, before his death, Maslow (1970) recanted on some of his original writing and reformulated his theory to acknowledge that lower order (deficit) needs should be at least partially met before the individual would strive to meet higher order (meta) needs.

In the context in which Maslow's theory of needs are used in this model, needs are conceptualised as being applied in an hierarchical order. Keeping in mind that needs reside within the individual, an important observation from the research findings concerns the way nurses and other carers identify and single out for attention, basic needs in clients in residential centres.

In the context of holistic care in residential centres, it seems that only after basic needs of clients have been addressed do carers progress to identifying and meeting higher order needs thus addressing client needs hierarchically. A likely reason why care is provided in this 'hierarchical' manner can be linked to the use of the medical model to underpin nursing care in centres (see chapter 5). The majority of clients in residential centres have profound or multiple disabilities and many have medical conditions requiring ongoing treatment. As a consequence, findings from this study indicate that identified needs are physical/health care; hygiene and safety with care interventions being focused on addressing these needs.

The fact that care is concentrated on these types of needs is not to be seen as negative or as a criticism of nurses' care. Rather, it is a reflection of the needs of clients who have multiple and complex disabilities for as Chapman (1985) said, a client's disability may well alter their needs with some becoming more important than others. It is also a clear demonstration of the operationalisation of the medical model underpinning care and is supportive of Mercer's (1994) assertion of the re-emergence of the medical model as the predominant model for service provision to people with severe and multiple disabilities. Structures for service provision are physical and human resources and infrastructures.

The last element of the conceptual model incorporates the structural dimensions of service quality in the form of essential resources, physical, human and management. Kitson (1990) identifies these as important for service quality and quality care. According to Donabedian (1998) good structures are important for protecting and promoting quality care though he sees them as relatively unimportant in its assessment. That said, structures in intellectual disability services include adequate trained staff, skill-mix, specialist services and equipment without which it would be difficult if not impossible to provide a responsive quality service to clients.

This last element added to the conceptual model relates structures with processes of care for meeting the needs of clients and with specific quality of life dimensions as outcomes of care for clients. The conceptual model illustrates the relationships between all the concepts involved and examples are provided of specific structure elements (resources) and process elements (needs interventions) for achieving specific outcome elements of quality of life for clients.

8.8.2 Applications of the Conceptual Model of Needs Based Quality

The multilevel conceptualisation of the model is unique in that it permits analysis at several levels of abstraction. While the model is descriptive, it provides an important developmental contribution to service quality in the area of intellectual disabilities on two fronts:

One, it provides conceptual clarity about the complex dimensions of service quality and their relationships to each other. In this sense it adds value to our understanding and perceptions for operationalising quality initiatives in residential services.

Two, it has a fivefold application that encompasses all of the main areas of services:

Policy Making. It signposts and provides insights about care that is useful for policy making. Quality is on the agenda for policy makers (Quality & Fairness 2001, National Disability Authority 2003) and the model will be useful for informing decision-makers at local and national level about issues affecting quality for clients in residential centres. In particular, the model highlights important issues for service provision and can serve as a:

a) Service planning model. The model will be useful for policy makers and senior management when planning new initiatives for their services. It will provide policy makers with a schema for thinking about the complexity of dimensions and their relationships in planning responsive services for clients.

b) Service delivery model. The model will be useful to policy makers and senior management for identifying the multidimensional aspects of their service delivery and where they may need or may wish to concentrate their attention.

c) Service Evaluation model. The model is needs based and highlights processes as they relate to outcomes. It provides a map of the important dimensions of service quality useful for designing a strategy for evaluating service provision.

d) New services model. The model will be useful for policy makers when commissioning new services for people with intellectual disabilities. One utility of the model is its contribution to how a new residential service may be able to recognize issues and influences that affect service quality. Another is its usefulness to any new service organisation preparing its mission, vision and service philosophy in the context of how these relate to service quality.

Care Practices. The model describes the relationships between the various dimensions of care and will be useful for informing care practices. As it highlights the relationships between processes and outcomes it will heighten the awareness of nurses and other professionals about issues and influences affecting the quality of their care.

Education and Training. The model's complexity and the implications of the relationships between all its various dimensions, draws attention to issues for staff education and training, particularly for service quality and quality care. Commitment and preparation for quality requires training as well as awareness. The model describes the intricacies of dimensions of quality care and will signpost areas for training

Management Responsibilities. It provides senior management with a guide for thinking about services that are responsive to needs. Management is responsible for the quality of

the service and this model will help them identify critical factors important for planning and operationalising service quality. It will provide middle managers, especially clinical managers; with a blueprint for planning and implementing care interventions based on holistic clients needs.

Further Research. The model is useful for thinking about and deciding on areas for future research in the area of service quality. At the time of writing this thesis, this is the only research study that has specifically investigated issues and influences affecting nurses' quality of care to clients in residential centres in the Republic of Ireland. This model will provide other researchers with insights, ideas and directions for further research in the area.

8.9. Conclusion

This chapter presented a discussion of the main findings from the research study. The discussion was grounded in the literature and current practice in the discipline. Two typologies were presented and discussed. These were completed in light of the findings and were applied to the practice setting of intellectual disability nursing. In the last part of the chapter the findings were used to confirm and develop the theoretical model developed from a synthesis of the literature in chapter five as a conceptual model of needs based quality care.

It must be said here that drawing conclusions from these findings warrants caution because while the methodology employed for the study was appropriate, it focused on the perceptions nurses have about quality. This may raise some concern for the accuracy,

reliability and validity of findings. However, the purpose of the study was to find out about quality in centres as perceived by nurses. In addition, and as was evident throughout this analysis chapter, all major findings relevant to answering the research questions were cross-referenced with findings for similar question items from the experience survey of experts. The following important conclusions emerged from the analysis and discussion of findings in this study.

Theme One: Dimensions and Processes of Care

Physical/health care is considered by respondents to be the most important of dimensions. Such is the importance of health care for these clients that the literature, in general, would support this finding. However, it is unlikely that all clients will require a sustained concentration on physical/health care and the literature emphasises other dimensions including social, educational, occupational, and relationship/friendships if holistic care and quality of life outcomes are to be achieved. These dimensions have long been recognized within the scope of nursing practice but the findings from the present study show they receive less attention from nurses in residential centres. A conclusion here is that if nurses wish to respond to needs-led holistic care, valuing other dimensions of care in addition to physical/health care would be necessary. A suggested way of doing this is for nurses to utilize a needs-based model related to quality of life outcomes. The model developed from this study would be particularly appropriate.

Organisational care processes are in place in centres but are deficient or incomplete and there are gaps in the literature for their use. Whereas much is known about the theoretical

considerations surrounding organisational processes, no literature was found dealing with the implementation of these in residential care or the extent to which nurses are involved. Standards, individual planning and multi-disciplinary teamwork are three approaches repeatedly singled out for attention in the literature. Despite this, not all nurses are members of multi-disciplinary teams; standards exist but are mostly for structures and are not related to a quality programme. Individual plans are used in only a third of centres and clients or family rarely attend. Based on their code of conduct, scope of practice and professional training, nurses are accountable for the care they provide to clients. This being the case, if nurses are to provide needs-based holistic care, they will have to participate as equal members of the multi-disciplinary team, engage in collaborative care planning with other professionals, and contribute to setting responsive personal outcome standards of care for clients.

Nurses evaluate client care but do so separately from any collaboration with other professionals. They evaluate physical well being more often than other dimensions and based on the fact that they concentrate on the physical/health-related dimension of care, this indicates they operationalise their care predominantly on a medical model. Little evidence exists for the application of the humanistic model through having a more social and holistic approach to care. Evaluation is seen as a critical component of service quality but a gap exists in the literature concerning the processes used in residential care and the extent to which nurses are involved. A conclusion here is that if good quality is to be delivered, nurses must be engaged fully in these organisational processes and be required to participate in a multi-user approach to service evaluation.

Theme Two: Organisational Management Practices

Nurses identified the three most important management-facilitating practices as good communication, participation in the centre and involvement in decision-making. The three barrier practices nurses identified were the obverse of these.. Findings from this study indicate that nurses have a low level of participation and involvement in decision-making in centres.

For nurses to be able to provide responsive care to clients in residential centres requires they have a dialogue with both management and professional colleagues. Despite this, the findings from this study indicate that less than one fifth of nurses were always consulted about client services and only forty percent said they were encouraged to make suggestions to management. Nearly two thirds of nurses said they had no forum to meet each other so as to discuss issues of client care. Based on the foregoing discussion, if management is to take service quality seriously then it should address these issues. Of importance from the literature is that management should not only decrease perceived barriers to quality care but also introduce practices that will deliberately facilitate quality.

Participation and decision-making are important for motivation and staff commitment to quality. Management needs to maximize nurses' level of participation and encourage their involvement in decision-making on matters of client care. If service quality programmes are to achieve their outcomes, nurses need to be consulted by management and to be able to meet colleagues on a regular basis to discuss matters of client care and how it can be improved upon.

The chapter confirmed the model synthesized from the literature and reviewed and developed this as an integrated conceptual model of needs based quality care. The model is composed of four related elements. In summary, dimensions of care are epitomized as the needs of clients and explained using Maslow's human needs theory (1954, 1970). Dimensions of quality of life are explained through the five broad dimensions developed from the literature by Felce and Perry 1995. These integrated through Donabedian's (1986) framework of processes, outcomes and structures. All dimensions and components are linked as "connections" of how they relate and impact on each other (Seed & Lloyd 1997). Several key conclusions can be drawn about this conceptual model and the processes involved in its development:

1. It is a descriptive model grounded in the extant literature in the area and in the findings from the present study.
2. The multidimensional nature of the model serves to signify its complexity and illustrates the interrelatedness of all the dimensions involved in service quality in residential services for people with intellectual disabilities.
3. The model adds value to what is known about service quality in residential services for people with intellectual disabilities in Ireland. In particular, it provides a degree of conceptual clarity not known before. Since it highlights the dimensions of service quality and their connections with each other, it will contribute to peoples understanding of issues and influences affecting provision of quality care.

4. At a practical level, the model provides a descriptive framework or guide for thinking about a methodology and means of operationalising service quality. Most importantly, it has a fivefold application for all of the main areas of services:

1. It signposts and provides insights about care that is useful for policy making.
2. It shows relationships between dimensions useful for informing care practices.
3. It draws attention to important issues for professional education and training.
4. It provides management with a descriptive guide for planning services.
5. It is useful for planning and deciding on areas for investigation and research.

CHAPTER NINE

SUMMARY AND CONCLUSIONS

9.1 Introduction

This chapter presents a summary and conclusion for the main findings of the research study. It will confine itself to a synopsis of findings from the survey of nurses and the experience survey of the non-nurse experts relevant to the research questions. Limitations of the study are summarised and their implications for nursing practice in residential services are discussed. The contribution of the findings to theory in the area is stated and lastly, recommendations are put forward for further research.

9.2 Summary of Main Findings from the Survey of Nurses

This section presents a summary of the main finding under the two broad themes used for the analysis of results in chapter eight. Before doing so, it may be helpful to restate the research questions:

- 1 What if any, are the differences between dimensions of care that nurses see as important for nursing and dimensions that nurses see as important for clients?
- 2 How do the dimensions of care that are the focus of nursing interventions compare with the dimensions of care that nurses evaluate most often?
- 3 In what ways are nurses involved in organisational care processes used for planning and delivering care to clients in residential centres?
- 4 What organisational management practices do nurses identify as facilitating and inhibiting their ability to provide quality care to clients?
- 5 How does participation and involvement in organisational decision-making relate to nurses provision of quality care for clients?

Theme One: Dimensions and Processes of Care

To remind the reader, theme one was based on the first three research questions: dimensions of care, evaluation of care, and organisational processes respectively. Results were cross-referenced with the experience survey of experts.

9.2.1 Dimensions of Care

Dimensions that respondents considered most important for both nursing and clients were: physical/health care, safety/security care, and emotional care. Dimensions considered least important for both nursing and clients were sexuality care and spiritual care. The seven experts considered these three dimensions important but felt nurses concentrate too much on physical/health care and too little on social, occupational and friendships/relationships dimensions.

A conclusion is that since nurses provide care predominantly for the basic needs of clients and in particular, physical/health-related needs, this is a clear indication of the use and influence of the medical model. As other more holistic needs receive little attention by nurses and are seen as less important for clients, there is little evidence that a humanistic or social model predominantly influences nurses' provision of care.

9.2.2 Dimensions of Care Evaluated

Nurses do evaluate their care of clients. Monitoring *care* is based on behavioural observations and physical health. Evaluation of nursing care is mostly based on physical care outcomes. The experts agreed evaluation is very important but felt nurses evaluate only the physical/health care dimension. The focus of evaluation on physical/health needs of clients is again an indication of their importance to nurses

and how they see their importance to clients. A conclusion from this finding is that concentrating predominantly on evaluating physical/ health and behaviour in clients is further evidence for the medical model.

In terms of theory, findings for dimensions of care differ from contemporary theoretical and ideological thinking that emphasises a social or humanistic model. It must be said however, that most of the current literature stems from community integration which generally speaking is for people with less severe disabilities. In contrast, people in residential centres have severe, multiple or complex disabilities likely to require frequent and repeated physical/health care interventions.

9.2.3 Involvement in Organisational Care Processes for Clients

Multidisciplinary teams were present in the majority of centres but nurses were not included as team members in all centres. Standards of care are in place in just over half the centres and the commonest type of standards is for structures. Individual programme planning is in use in the majority of residential centres but meetings are infrequent and irregular. Nurses always attend IPP meetings but clients or family members are rarely invited to attend.

Experts felt nurses were members of the multidisciplinary team but were consulted only on physical/health matters - a reflection of the dimension of care they concentrated on. Standards were important but must apply to all dimensions of care and to outcomes as well as structures and processes. Individual programme planning was important but must involve the client and his/her family or advocate. Contemporary theoretical approaches to organisational care in intellectual disability

services are based on these processes for planning and evaluating care. It is clear that nurses are involved in organisational care processes but the processes themselves are not uniform and how they are managed differs between centres. However, with the introduction of the National Standards for Disability Services in 2005, clear and precise guidelines will be provided for how these processes are to be operationalised and for the involvement of clients, their families and staff.

Theme Two: Organisational Management Practices

Theme two was based on the last two research questions dealing with management practices for quality and nurses participation and decision-making in centres. Results were cross-referenced with findings from the experience survey of experts.

9.2.4 Management Practices Facilitating and Inhibiting Quality of Care

Management-facilitating practices for quality care were: good communication with staff, involving staff in decision-making, providing adequate staff and equipment, and having a democratic style of leadership. *Management-inhibiting practices* for quality care were: poor communication with staff, not involving staff in decision-making, having a bureaucratic style of management, and not providing adequate staff and equipment.

Experts support these findings. All felt a democratic management style, valuing staff, telling them what is expected of them and, providing adequate staff and resources to be most important. All seven felt bureaucratic management, chronic staff shortages and, not telling staff what is expected of them was important barriers to quality care.

9.2.5 Participation, Decision-Making and Quality of Nursing Care

That employees perceive themselves to be participating in the organisation and feel involved in decision-making is repeatedly emphasised as necessary for service quality. Despite this, most of the nurses in this study did not perceive themselves as participating in their organisations and less than half participated on nursing matters. Most were not involved in decision-making about care for clients and were not free to make suggestions to management. In the majority of centres nurses had no forum or formal means of meeting regularly to discuss matters relating to care of their clients.

Experts were not asked anything specific about participation or decision-making. However, implicit in their views about teamwork, management telling staff what is expected of them, and the importance of a democratic management style, is the value they place on nurses participation and involvement in decision-making. All the experts considered staff meetings were necessary for communicating with and allowing staff to discuss care, thus supporting the importance of a forum for staff to discuss issues relating to client care in centres. Service quality theory sees management style as impacting on employees' ability to deliver service quality and considers participation and decision-making as necessary if employees are to commit to quality. However, a conclusion here is that management practices in many centres are not supportive of nurses providing quality care.

9.3 Limitations of the Research

Despite the mixed methods and sequential triangulation approaches for this study, the researcher considers there were a number of inherent limitations with the design. One limitation concerns the use of surveys and the construction of the questionnaire.

Response rates to mailed surveys are considered to be low in general. However, for this study the response rate was forty percent. While such a response rate is likely to be considered average for surveys, caution must be exercised in generalising the findings to the whole population of nurses working in residential centres in the Republic of Ireland.

The questionnaire was constructed by the researcher and while an effort was made to ensure its reliability and validity through testing, the instrument has had limited usage. However, as the survey instrument was developed through sequential triangulation of the literature, the experience survey of experts and the focus groups with nurses, the researcher believes this process contributed significantly to its reliability and validity.

Another limitation with survey research is not being able to collect qualitatively rich data. However, an aim of this study is generalising the findings beyond the sample to all nurses working in residential centres in the Republic of Ireland, and the survey method was the most appropriate method to use.

As the purpose of this study was to collect information on quality as perceived by nurses, information was not collected from clients and no direct observations were made in centres. This said, information was collected from nurses on what they perceived about clients needs. Obtaining a proxy or third party information about clients is a limitation as is self-reports because of their 'halo effect.' Recommendations are made for addressing these limitations in future research and it is the intention of the researcher to pursue further research in these areas.

Finally, this study collected information about quality of nursing care in residential centres and as such, findings cannot be generalised to nurses working in community care or day services in the Republic of Ireland.

9.4 Implications of the Research Findings

Findings have theoretical and practical implications for evidence-based nursing in the three areas of practice, management and education in residential centres.

Practice implications are that these findings support the influence of the medical model. The limited and narrow dimensions of care indicate that nurses are not providing total or holistic care for clients. In addition, and given the rhetoric for the enhancement of quality of life, findings indicate that nursing care falls short of addressing personal outcomes important for the quality of life of clients.

Theoretically, these findings point to a theory/practice gap between contemporary theories supporting holistic, inclusive care using a social or humanistic approach and the less inclusive care nurses actually provide in residential centres using a medical approach. Not unreasonably, nurses concentrate on these dimensions because they are important. It is the researcher's view that while fulfilling the basic needs of clients is necessary, in the context of residential settings these areas of care might often be all that is required from management and thus they might become the most valued by nurses. Implications for nursing practice also mean that nurses in residential centres need to re-evaluate and reflect on their caring roles and in particular, their responsibilities for providing total care as distinct from selective care.

Management Implications are that unless management explicitly values holistic care for clients, it is unlikely that nurses will respond to client needs on all dimensions of care. Implications for management are associated with organisational care processes related to restrictions of use and limited involvement of nurses. While the organisational processes referred to in this study are not the only processes, they are important and common approaches and the extent to which they are used has implications for the quality of care for clients. It is the view of the researcher that in keeping with the research and rhetoric for best practice, these organisational care processes need to be extended to cover all aspects of service provision and involve all the appropriate stakeholders.

Implications also extend to management practices that either facilitate or inhibit nurses providing quality care. Implications are that there is a need for an effective network of communication and for leadership and management styles supportive of participation and involvement as well as making available the resources required for quality nursing care.

Findings from this research show respondents' participation; level of involvement in decision-making, and consultation about service provision, are all very limited and occur in only certain circumstances and in certain areas in centres. In addition, the majority of nurses had no forum for meeting to discuss matters relating to client care in centres. Although not measured in this study, possible implication of these findings compared to the literature in the area is that if nurses are not made to feel involved or are not consulted by management, they may not commit to the service or be willing to accept responsibility for providing quality care.

Finally, implications for management also extend to empowerment and job satisfaction of staff. To a large extent these are dependent on the level of participation and decision-making that employees perceive themselves to have. If nurses perceive they have limited participation and involvement in decision-making, this can cause them to feel undervalued and unrecognised for their contribution. It is the view of the researcher that such feelings can lead to a sense of disempowerment and poor job satisfaction. A further consequence of disempowerment is that it can contribute to professional burnout with staff leaving the service.

Educational implications of these findings point to the need for organisations to reflect upon the function of nurses in the context of its mission and expectations for service quality. This can be achieved through ongoing education and where necessary, initiating changes to maximise the level of participation and involvement in decision-making of nurses and is consistent with the existence of a learning organisation.

Theoretically, implications extend to the role of nurses, the educational preparation they receive in their curriculum and the expectations of the Irish Nursing Board. The prescribed role of the nurse is expected to provide care for all the needs of clients.

Despite this, findings show that in residential centres, nurses predominantly see their caring role relating to the physical/ health care, safety and emotional care of clients.

Whilst recognising these may be the commonly recurring needs of clients, they will have other needs and these can only be identified if nurses use a needs-led approach.

If nurses are not willing or are not supported in providing care across all dimensions, then perhaps there should be different expectations for their role with a resultant change in their curriculum of training.

9.5 Outcomes of the Research Study

Bearing in mind these limitations and implications, this study makes an original contribution to knowledge in the area of service quality in residential centres for the following reasons:

1. It shows dimensions of nursing care to be predominantly for the basic needs of clients in residential centres. Despite differing service ideologies for framing disability practice and the rhetoric on holistic care, the significant service model underpinning nurses' practice in residential care is the medical model.
2. It is the only empirical study undertaken to date in the Republic of Ireland that has looked specifically at issues relating to quality of nursing care for persons with intellectual disability living in residential centres. Study findings provide a useful direction for further studies and for generating hypothesis for research
3. It provides important knowledge and insight into issues and influences affecting the quality of nursing care for persons with intellectual disability in residential centres. This knowledge will be useful for organisations thinking about service quality and for planning change.
4. It advances a conceptual model of needs-based quality that:
 - Signposts and provides insights about care that is useful for policy making.
 - Shows relationships between domains useful for informing care practices.
 - Draws attention to important issues for professional education and training.
 - Provides management with a guide for planning services responsive to needs.
 - Is useful for planning and deciding on areas for investigation and research.
5. It advances a needs led and a service-led typology with particular practical application to needs based quality and service based management respectively.

9.6 Recommendations for Further Research

This research study has identified a number of issues and influences affecting nurses' provision of quality care in residential centres. As the dominant phase of the study consisted of an extensive survey and as a result of its main findings, further research is suggested. While the study looked at a number of aspects relating to service quality and in particular nursing care quality, it is recommended that:

- More in-depth studies are carried out. Valuable studies that could make a significant contribution to what is known would be smaller, more intensive studies of specific or fewer residential centres. Such studies could use a more detailed questionnaire with information collected through personal interviews.
- Studies in the qualitative paradigm would be particularly appropriate and would provide a richness of data not possible with quantitative studies. Use of studies employing ethnographic methods or small-scale observational methods might be especially appropriate.
- As mentioned in chapters one and four, although this study focused on nurses, overall service quality requires involvement of clients, their families and other important stakeholders. Studies involving service users and their families would be useful, as they could indicate expectations and perceptions clients have for the quality of services.
- This study is located in residential services where clients have severe and multiple disabilities. Findings are likely to be different in day or community services where clients are more functionally able. Comparative studies are needed to compare differences and approaches between types of services and these can function to assist with benchmarking processes.

9.7 Conclusion

This final chapter presented a summary of the main findings from the research study. The limitations and implications of the study were discussed and five major outcomes were outlined for their original contribution to knowledge about service quality. Finally and in light of the limitations and implications of the study, recommendations were put forward for further research in the area.

The thesis has described and analysed a number of issues and influences that affect nurses' provision of quality care to clients with intellectual disability in residential centres in the Republic of Ireland. Although much is known about service quality generally and about health care quality in particular, much less is known about quality of care for persons living in residential centres.

The Task Group on Quality set up in 1998/1999 by the Federation for Voluntary Bodies for Persons with Intellectual Disability has drawn attention to the urgency for quality systems. Since 2002 many quality-related developments have been taken place. Among these are ongoing quality initiatives and accreditation activities in health care generally and in the area of intellectual disability many voluntary services are introducing quality programmes based on personal outcome measures.

As if in response to local or ad hoc developments in residential centres, national standards for disability services are now being introduced across all disability services. These standards will be mandatory and are a testament to the importance of service quality. Given that service quality and quality care are only now being introduced into services, they are fertile areas for research and development.

To this end, this research study makes an important knowledge contribution to what is happening in service quality developments in this area. It makes an original contribution to nursing care quality by describing and explaining issues and influences that affect nurses' provision of quality care to clients in residential centres. As a consequence of these specific contributions, the study makes a significant and timely contribution to evidence for nursing practice, management and education. Through the application of the descriptive conceptual model of needs-based quality, clarity and signposts are brought to our thinking and planning for advancing quality services.

APPENDICES

APPENDIX 1

(Letter of confirmation for participation in Experience Survey Interview)

29th October 1998.

Ms..

Dear ...

Further to our recent telephone conversation and my request for an interview on quality-related issues, I wish to confirm our arrangements for the interview as Friday, November 20th at 1.30PM.

I wish to thank you for agreeing to the interview and look forward to our meeting.

Yours sincerely

Richard Redmond

APPENDIX 2

Quality Service and Quality Nursing Care for Persons with Intellectual Disabilities Living in Residential Centres in the Republic of Ireland

An Experience Survey of experts in service quality to assist with the construction of a survey questionnaire for administration to a random sample of nurses working in residential centres for persons with intellectual disabilities.

Introduction

- Welcome
- Outline of the aims & objectives of the study in general.
- Explanation of the aims & objectives of the experience survey.
- Statement of anonymity & confidentiality of information.
- Invitation to ask questions about the interview before commencing.

1. In what capacity or circumstances have you experience of working with nurses in residential centres?

2. What do you think nurses perceive quality care to mean?

3. In your view, are nurses sufficiently informed or educated about quality?

4. From your experience, do you think nurses can provide quality care on their own?

5. From your experience, are nurses sufficiently involved in the multidisciplinary team?

6. In your opinion, what particular activities should nurses focus on in caring for persons with mental handicap? (e.g. leisure, personal care, skill training)

7. In your experience, are there any particular client behaviours that would indicate to you that he/she was receiving quality care?

8. Do you think nurses recognise situations that might indicate quality care for clients? (e.g. expressing satisfaction, making choices).

9. From your experience, to what extent is quality care for clients in residential centres dependent on contact/consultation between clients and their families?

10. From your experience, do you think organisational management practices have any affect on how nurses care for clients?

11. From your experience, is participation and involvement in decision making in centres important for nurses to be able to provide quality care to clients?

12. In your view, what resources are required for nurses to achieve quality of care?

13. From your experience, what resources are important for nurses to provide quality care?

14. From your experience, do you consider written standards of care to be important for providing quality care to clients?

15. From your experience, what aspects of care for clients do you consider nurses should evaluate most often?

16. From your experience, what organisation activities work best for planning and delivering good care to clients in residential centres?

17. From your experience, is there a particular model of care or framework that best covers all the needs of persons living in residential care?

18. Can you see implications for nurses when circumstances outside their control affect the provision of good care for clients? (e.g. inadequate staffing, bad leadership, poor equipment)

19. Finally, can you think of any other considerations or issues that nurses might be asked about providing quality care?

Thank you

Date: _____

APPENDIX 3

Matrix of Findings from the Experience Survey of Members of the Task Group on Quality. November 1998

Q	ID. 01	ID. 02	ID. 03	ID. 04	ID. 05	ID. 06	ID. 07
1	As trainer, not manager	Yes	Yes	Not Employed as nurses but expected to use skills as nurses	Yes, they need more experience for teaching	Yes, had opposition from nurses to the Introduction to quality programme	Consider RMHN as non- nurses
2	Provision of physical care – older nurses see hygiene & younger nurses see activities	As good care and standards - do not refer to quality	Good care, resources, outcomes of service	As good care but as hierarchical and institutional	Activities and types of engagements, pursuit of goals	Personal physical care-ignorant of service quality	Meeting needs of clients- fulfill treatment as directed
3	Yes, from training & professional code of conduct	Yes, from standards for clients-not referred to as quality	Yes, good care, acting as advocate, ignorant of Q systems	Yes, for QOC & good practice, ignorant of Q systems	Yes, see need to develop person not just care	Yes, aware of QOC but not of Q systems	Yes, own interpretation of quality, not aware of organisational initiatives
4	No. a team approach necessary	Teamwork necessary	Might provide physical and hygiene care but needs others	Needs a team to provide all the needs of clients	No- nurses must co-operate and work with others	Multidisciplinary teamwork and everyone working together	Must work as a team member and collaborate with other professionals
5	Depends on centre – but must be involved if quality care is to be provided	Yes-but depends on particular centre. Nurses have a major role and MDT is way of ensuring quality care for clients	Yes are members but not necessarily equal members-don't attend all meetings of MDT	Depends on centre and client group-some nurses more involved if problems with health or behaviour	Not always made to feel involved-nurses need to assert their role and make clear what they do	Nurses are usually involved but only for own clients and mostly for clients with physical or behavioural problems	Usually involved but more likely to be consulted about physical or behavioural problems and not education, work or where they live
6	Depends on needs of clients-good health care but equal emphasis on social needs	Depends on individual clients-nurses concentrate too much on physical needs	Should see to all needs and not just physical or hygiene	Different clients have different needs –some needs more important at certain times	Physical needs for multiply handicapped and social/communication needs for more able clients	Depends on clients but nurses concentrate too much on physical and hygiene care	Some needs more important for particular clients but should not spend all their time on physical/healthcare needs.

Matrix of Findings from the Experience Survey of Members of the Task Group on Quality. November 1998

Q	ID. 01	ID.02	ID.03	ID.04	ID.05	ID.06	ID.07
7	Having contact with their family-useful things to do each day- encouraged to express preferences	Being able to participate in activities they choose –having contact with family and having friends	Being physically well-having a say in what they do-having friends and family contact	Having a say in what they engage in- Encouragement to talk and express themselves-having good health	Family contact-spending time outside of centre-mixing and having friends	Being physically and emotionally well-mixing with others incl non-handicapped people	Expressing preferences communicating their wants and needs-engagement in things they like doing- having contact with family
8	Good physical care safety and security having a nice home for clients	Clients involvement in activities being well expressing needs	Safety and security Being well Being emotionally stable.	Having outside activities Regular family contact Nice home, food and warmth	Having things they like doing Family contact Being well Being well cared for	Doing different things Visits and trips outside of centre Contact with family	Having nice home Being well Not being bored with routine Family contact
9	Very important	Very Important	Important for more able clients	Very important	Important	Very important	Very important
10	Necessary for mgt leadership creating a climate for Q, learning org important	Necessary to have mgt support, climate & culture for quality in org. Consultation with staff	Leadership style, important Support for staff, climate, mission & philosophy Staff participation	Good leadership, resolution of conflict Staff told what is expected of them Involvement in decision making	Good leadership style necessary, resources from mgt to support nurses. Staff consulted and listened to	Necessary to have mgt leadership, openness, beaurocracy inhibits quality Participation of staff	Valuing of staff, climate for quality, openness, utilisation of skills Communicating with staff Opportunities to make suggestions
11	It is important nurses feel they participate and are consulted about clients and service developments.	Involvement and making a contribution is part of good management	Being consulted and involved in decision-making is necessary if quality care is to be provided to clients.	Different levels of involvement in decision making Nurses need to have a say and be consulted.	Participation and involvement in decisions necessary for quality care	Participation and involvement in decision making part of the multidisciplinary process	Yes, nurses, as professionals need to be involved in decisions for practice if quality care is to be provided.

Matrix of Findings from the Experience Survey of Members of the Task Group on Quality. November 1998

Q	ID. 01	ID. 02	ID. 03	ID. 04	ID. 05	ID. 06	ID. 07
12	Optimum staff, equipment, training. Skill mix	Optimum staff, skill mix, equipment, training & retraining	Optimum staff, skill mix, equipment, training.	Optimum staff deployment, feedback to mgt, training	Optimum Staff & deployment, support of mgt, back-up, training.	Collection of data from client & family, optimum staffing	Mgt support optimum staff. Support & counselling for staff
13	No, need resources or quality of care will be compromised	No but nurses will continue to provide care which may be dangerous care	No, nurses can do a lot at personal care level but need organisational resources, mgt support and leadership	Depends on mind set and attitude but mgt support and leadership necessary incl staffing and skill mix	No, resources necessary incl staff numbers, knowledge and skills	No, something can be done but material and skill resources are necessary	Depends on setting Minimum care can be provided in absence of adequate resources But resources necessary for quality care
14	Yes, if they apply to all aspects of care.	Standards necessary as part of a quality system in the organisation	Standards nurses see apply only to physical care and not to whole person	Yes, as part of a quality system and must apply to wide area of care.	Standards always important but not written down	Standards necessary but must be audited and updated	Important if they are used correctly and followed
15	In this centre, evaluation on individual clients done by professionals and at clinic meetings and at IPP meetings.	In here, evaluation is responsibility of the MDT. Nurses, evaluate client care with psychologists and doctors	Evaluation is done through IPP meetings, staff meetings and the MDT at their regular meetings	Evaluation done on plans and programmes and is discussed for individual client's at their IPP meeting	Different professionals s evaluate particular aspect of clients and discuss their evaluation at the MDT meetings	Evaluation done by MDT and at , IPPs meetings and outcomes reported to management	Various approaches nurses and care workers assess clients every day, IPPs, staff meetings in the home. Must involve client in evaluation
16	Teamwork and cooperation is necessary between everybody, IPP meetings, staff meetings, MDT meetings	Involving and delegating responsibility to staff. Regular meetings. IPPs, staff meetings	Staff meetings, Staff management meetings, IPP meetings MDT meetings	Giving staff authority and responsibility for care, using IPP meetings and MDT meetings.	Teamwork and collaboration, regular meetings, IPP meetings and MDT meetings	Keeping staff up to date, having regular IPP and MDT meetings for planning and assessing care.	Involvement of staff and clients in plans and decisions about care, IPP and MDT meetings

Matrix of Findings from the Experience Survey of members of the Task Group on Quality , November 1998							
17	If there is a model it should refer to all the needs of clients and this cannot be as they live in institutions.	No particular model for all needs. Older model was the medical model but a social or integration model is now the most appropriate	Not just one model because clients have different needs A social care model values client living a normal existence	Different models, a medical model for multiply disabled and a social/educational model for the more able	Depends on particular clients a medical model for some and a model of community inclusion for others	Depends on clients abilities medical model for profoundly disabled and a more social model for the less disabled	A social or inclusion model that values a normal existence is the most appropriate. The medical model is only appropriate for profoundly disabled.
18	Low morale, loss of commitment, leave service	Poor morale & job satisfaction but can challenge nurses to consider different ways to do things.	Low morale, leave service, inhibits Service quality initiatives being achieved.	Tension & stress. Low morale, poor job satisfaction & frustration, leave service.	Tension & stress, may leave service, influence others from working in org.	Low morale, professional frustration, non-involvement, poor QOS, leave org.	Demoralized, frustration, but may challenge nurse to work differently.
19	Dimensions of quality care they see as important for clients, how they evaluate quality care	How do they identify components (dimensions) of quality care, how do they evaluate the care they provide	How do they monitor and evaluate the care they provide to clients.	Does their organisation have a quality system? What is the level of their contact with families of clients?	Whether their centres has some sort of quality system and their knowledge about it.	What knowledge and skills they consider they need for providing quality care	How they feel about their management supporting them. How they see the importance of communication for quality



Department of Nursing Studies
Stewart's Hospital Services Ltd;
Palmerstown
Dublin 20
18th March 1999.

APPENDIX 4

(Copy of letter for permission to hold two Focus Group Meetings)

Ms...

Dear ...

As part of my doctoral research, which is on the subject of quality care as provided by registered nurses, I am planning to conduct two focus group meetings during the period of May to June. With this in mind, I am seeking permission to use the venue of Stewart's Hospital Services Ltd. for the meetings that will each last about two hours.

Participants for each group will consist of about eight nurses only one of whom will be from Stewart's and the rest from different centres around the country. This arrangement is necessary so as to have divergent views represented and to provide for richness of data. No clients or family members are to be involved nor will any other staff members be participating.

All participants will be selected on the bases of their ability to contribute to the discussions, that is, on their clinical experience in the area. Following informal consent, each participant will receive a formal invitation to attend the meetings. Confidentiality of information will be assured together with anonymity for centres where the participants are employed.

Finally, I am also seeking permission to use the Department of Nursing Studies notepaper for the formal correspondence with participants which will consist of a letter before and after the focus group meetings.

Yours sincerely,

.....
Richard Redmond



Department of Nursing Studies
Stewart's Hospital Services Ltd;
Palmerstown
Dublin 20

6th April 1999.

APPENDIX 5

(Letter of Invitation to participate in Focus Group Discussions)

Ms...

Dear ...

I wish to thank you for accepting my invitation to attend the focus group meeting on Thursday, 13th of May. The discussion will take place at 3PM and will last about two hours. The venue is the Conference room of the Day Activity Centre in Stewart's Hospital.

The success of our discussion is dependent on the willingness of people to attend and since you have accepted the invitation, your participation in the discussion is anticipated and will aid in making the research project a success.

Essentially the discussion will be a forum of nurses from mental handicap centres who are, or have recently been, engaged in clinical nursing practice. It is part of a research project that will be discussing issues relating to practice in the area of residential care for people with mental handicap. Your views and opinions on the subject will be most welcome.

If for some reason you find you are unable to attend, please let me know as soon as possible. My extension number is 1208.

I look forward to seeing you on May 13th.

Yours sincerely,

.....

Richard Redmond

APPENDIX 6

Facilitators Guide and Schedule of Questions for Focus Groups **Focus Group on Quality Care for People with Mental Handicap** **Living in Residential Centres**

Introduction and welcome

Good afternoon everybody, thank you for participating in this afternoon's meeting. My name is... and I will be facilitating the discussion. Richard Redmond will be listening to what you say and taking notes on your comments which are also being tape-recorded. What you say is confidential and participants or their place of work will not be identified by name.

The rules for the discussion are simple – only one person may talk at a time and address your comments to the group. Please speak up and be honest with your comments and responses.

Purpose

The purpose of the discussion is to explore the perceptions, experiences and perspectives of the group, on care as provided by nurses to their clients in residential services for the mentally handicapped. The information will form part of a research study on the subject.

Opening Question

1. Have you all had recent clinical experience working with clients in residential services?

Introductory Question

2. When you hear the term "good nursing care" what comes to your mind? **(10minutes)**

Key Questions

3. On the card provided, take a few minutes and write down what you think quality care is for people with mental handicap. **(3minutes).**

Can each of you please say what you think quality care means? **(12minutes)**

4. From your experiences, what aspects of care receive most attention by nurses?

Prompts: social care; health care; activities; relationships. **(12minutes)**

5. From your perspective, what aspects of care do you consider important to clients?

(12minutes)

6. What outcomes for a client might indicate that he/she was receiving quality care?

Prompts: satisfaction; preferences; activities; choice; respect **(12minutes)**

7. How would you know if nurses were providing good care to clients?

Prompts: standards; monitoring; evaluating outcomes. **(12minutes)**

8. Are there any special needs or requirements that nurses have for providing quality care in their organisations? **(10minutes).**

Prompts: involvement; training; feedback from management; opportunity to suggest.

9. From your experience, how do you think organisational management can best facilitate nurses providing quality care? **(12minutes).**

10. From your experience, are there organisational management practices that are barriers to nurses providing quality care? **(12minutes).**

11. Just to pretend for a moment, if your CEO were to drop in to this meeting and you had the chance to make one suggestion for improving good care, what would that be? **(5minutes).**

Summary **(5minutes).**

Final Question

12. The purpose of this meeting is to discuss issues in relation to a research study on quality of care for people with mental handicap living in residential centres. From the issues discussed, can you think of anything else of importance or that we have forgotten? **(5minutes).**

Thank you all very much.

APPENDIX 7 SUMMARY OF PARTICIPANT RESPONSES FROM FOCUS GROUP ONE				
	What does QC mean for people with mental handicap?	From your experience, what aspects of care receive most attention by nurses?	From your perspective, what aspects of care do you consider important to clients?	What outcomes of care for client indicate that he/she was receiving QC?
Eileen	Holistic, consistent with Values of org, given by a reflective practitioner	Nurses don't interact with clients, Mgt. accept that routine is most important		
Margaret	Based on Evidence, individual care, advocating for person		Treated in age-related manner, respect, dignity, treated as a person, not patronized, treated as adult	Many outcomes are service outcomes rather than personal outcomes-medical rather than social/educational
Brendan	Individual, client based, holistic, fostering choice & respect & empathy	Nurses not involved in decision making with management	That they be given choice & allowed to express preferences, communication with carers, contact & involvement with family, participation in relationships, planned care.	Satisfaction with how he/she is treated, having a sense of belonging, being valued given choice. Relationship issues not dealt with. Protecting clients from exploitation
Martha	Individual, client based, foster empowerment, valuing client	Care by non-nurses with limited perspective on how care should be provided	They must be involved in decisions about their care and know what is going to happen to them. Nurses see client as a person	Not intruding too much into their lives, privacy. Evaluation by service not by client
Margaret M	Use resources properly, skill mix, person- centred, advocate for client	Hygiene emphasized for high dependency clients, less involvement in social development of client.	Allowed to be themselves, respect their wishes for what they want to do.	Assess clients QoL, to make comparisons between their lives & those of non-handicapped people.
John (psy)	Equality, family contact, supports for client, health care.	Mostly routine ritualistic care, task oriented. N-admin wishes certain activities (hygiene) over others.	Clients feel a sense of security in a family-physical & emotional sense of belonging, normalized living. Should see abilities not disabilities.	Not being put on drugs
Annette	Holistic, measured by audit standards, multidimensional individual	Nurses attend to more vocal clients (c/behaviour) more attention to problem behaviour. Own values dictates care	Say in decision making about their care & what happens to them.	To live in the community
Elizabeth (psy)	Individual, observing client, responding to client's needs, wants & wishes, c/centred	More demanding clients receive most attention from nurses. Nurses don't connect with clients	That they are the central figure	
Laura	Individual c/ centred care, consistency of care, advocating for client	Hygiene most often nurses priority, less emphasis on personal development	That they receive the care they want.	Comparison by client between residential & community living experience. Displaying positive attitudes

Name	How would you know if nurses were providing quality care to clients?	Are there special needs that nurses have for providing QC in their organisations?	From your experience, how do you think organisational Mgt. can best facilitate nurses providing QC?	From your experience, are there organisational mgt. practices that are barriers to nurses providing QC to clients?
Eileen	Planning & evaluation, existence of relationships & family contact & involvement. Level of staff support from mgt.	Mgt. support & acknowledgement of staff needs and requirements to do their jobs well. Mgt. concern for how staff wish to develop themselves. Autonomy for staff with accountability.	Mgt must see nurses (& frontline staff) as most valuable resources in their service.	
Margaret		More education & training for role in quality systems.		Bureaucratic style of mgt., no coherent plan for change that involves staff
Brendan	Level of interaction mixing of staff & clients, the way they talk to each other. Linked to the philosophy of care. Client satisfaction, décor of home	Better treatment and attitude from middle & top mgt. towards frontline staff. Preparation of staff by mgt., anticipating & responding to staff needs	Nurses given control of care including budgetary control, provision of necessary resources to provide QC. Say in service quality Valuing staff.	Too little communication with staff. Need an appraisal system. Feedback needed for staff Few examples of staff told they are doing well but lots of negative comments by mgt. Mgt. need to develop a supportive culture for QC
Martha	Way clients are provided privacy, respect, access to all areas, presence of home-like environment. Mingling. Absence of hierarchical structures.	Development of nurses skills and attitudes for providing quality care. Mgt. should work with staff to reflect on what they are doing. Teamwork is necessary. Public vision & mission for the service.	Why are nurses not in senior mgt. posts?	Mgt. frequently do not treat staff as adults. Presence of fear, Mgt. needs to encourage assertiveness in nurses.
Margaret M	Documentation-for Q accreditation if not written down then clients did not receive good care		Provide ownership of care for nurses	Staffs need appraisal & feedback for their job.
John (psy)	Sense it in atmosphere-contentment or fear, climate. Good client appearance creates impression of good care. Evidence of leadership. Staff attitudes & job satisfaction.	Appreciation of staff by mgt. Giving feedback to staff on how they are doing.	Mgt. Acknowledgement & commitment to nurses as highly skilled resources in their services.	Failing to give staff autonomy
Annette	See IPPs & nursing care plans			Not communicating well with staff or involving them in decision-making. Hierarchical structure works against quality, mistrust of staff. Mgt should welcome staff that will challenge the systems in place- not 'yes people'

Elizabeth (psy)				Moving staff around too often
Laura	Non-threatening atmosphere. Ask client.	Caring for the carers	Mgt need to value what nurses do.	Management of change in the service. Management need education themselves.
ame	If your CEO were to drop in to this meeting what one suggestion for improving QC would you make?	Summary	From the issues discussed on QC, can you think of anything else of importance or forgotten?	Additional Comments
Eileen	Value staff & clients, Mgt. need to look at why staff are living services, valuing & utilizing talents of staff		Responsive service to clients and their families as a right.	
Margaret	Provide an open forum for staff to suggest & discuss important issues for care			
Brendan	Value the contribution of staff, provide resources for staff e.g. training, information. Staff need a forum, a say in how things are done & to be listened to.		Continue to reduce institutional care & size of centres & provide homelike care in community. Provide more respite care.	
Martha	Dismiss senior lay mgt. & promote nurses to mgt. posts, Provide shake-up in ABA.		Need to look at role of RMHN vis a vis care staff & role of nurses in community care.	
Margaret M	Channel resources for clients better		QC very important but nurses need training, involvement & a say in how this is to be achieved for clients	
John (psy)	Release more resources, put MH nurses in Health Board			
Annette	Dismiss all central mgt. & put nurses in charge. Mgt. should not put policies in place without regard to nurses' knowledge & involvement.		Develop role of community nurse.	
Elizabeth (psy)	Take staff opinion on board			
Laura			Find out what family feels	

			what they see as good nursing care.	
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SUMMARY OF PARTICIPANT RESPONSES FROM FOCUS GROUP TWO					
Name	What does QC mean for people with mental handicap?	From your experience, what aspects of care receive most attention by nurses?	From your perspective, what aspects of care do you consider important to clients?	What outcomes of care for clients indicate that he/she was receiving QC?	How would you know if nurses were providing quality care to clients?
Caroline O'Mahoney	Home life, involvement in decision making shared action planning, family contact, and relationships-friendships.	Health issues especially for severe and profound clients and social care for moderate clients	Depends on level of ability of clients, too many clients to respond to, being happy to help them have family contact	Having relationships and friendships with non-disabled people.	Way everybody mixes together, happy atmosphere in home.
Jererny	Home life, involvement in decision making, allows risk taking, personal goals, use of generic services, respect, and self-esteem. Living with others means compromise	Depends on org and nurses expectations- org value nurses addressing health needs of clients, org expects accountability and documentation and conformity of nurses.	Knowing the individual-reaction to particular client at particular times. Adaptability based on knowledge of clients needs; nurses should be encouraged to challenge service systems.	Opportunity and encouragement to self-advocate	Presence of a good atmosphere in home depends on particular area. Intuitive understanding of climate in living area.
Mary	Making choices, setting goals for life, and being empowered. Participation in IPPs, family contact When dealing with a large group individual's miss out	Depends on rhythm of day, role of nurse changes during the day in response to clients needs but based on org values- org-specified activities but not client specified.	Responding to needs of client as they arise which change during the day and over time. Depends on ethos and philosophy of service	Setting and achieving goals for clients, increase in self-confidence and self-esteem of clients, opportunity to express choice and preferences	Level of interaction between staff and clients, meaningful engagement of clients in activities. Evidence of goals set and objectives pursued through IPPs, client activities.
Caroline Lane	Home life, personal possessions, freedom in home, meaningful activities, family contact, meeting Health needs	Older people need special care and windings down of activities e.g. work. Often mgt. role especially if nurse is only nurse on duty	Responding to clients individual and personal needs and wants, nurses need good general nursing experience especially for working with severe and profound clients.	Opportunity and encouragement to assert themselves	Climate and atmosphere in home, interaction of staff with clients.
Fiona	Atmosphere of contentment, respect, empathy, friendships.	Depends on client group-nursing care for severe/	ABA emphasizes physical needs as against	Contentment of client and satisfaction with how they	Happy atmosphere in the home, staff and

	Decision making,	profound and social care for mild and moderate clients.	social/educational needs.	are cared for, good self-esteem. Opportunity to challenge and evaluate the service they receive.	clients mixing, client initiated communication Comfortable home, having personal belongings.
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Name	Are there special needs that nurses have for providing quality care to clients?	From your experience, how do you think organisational Mgt. Can best facilitate nurses providing QC?	From your experience, are there organisational mgt. Practices that are barriers to nurses providing QC to clients?	If your CEO were to drop in to this meeting what one suggestion for improving QC would you make?	From issues discussed on QC, can you think of anything else of importance or forgotten
Caroline O'Mahony	Training for quality and quality systems, further education and re-education for nurses.	Provide a level of autonomy for nurses, trust nurses , support nurses in their care for clients.	Bureaucratic mgt.- paper work, red tape, centralization of mgt. constraints of budgeting requirements that is not based on needs of clients.	Understanding of what is the job of nurse- having empathy with the nurses work.	Relationships –sexual and affectionate for persons with mental handicap.
Jeremy	Nurses need a forum for discussing client care within their organisation.	Forum for staff, opportunity for staff to interact with others and share experiences and discuss good practice	Working system-shift system, lack of contact with colleagues which affects continuity of care and thus quality of care. Employment of untrained staff and conflict between trained and untrained staff.	Open dialogue with staff and nurses in particular about care and care policies affecting clients.	Role and contribution of community nurses.
Mary	Encouragement and opportunity to use all their skills, training in decision-making skills. Nurses need to be a member of the MDT, need to assert themselves.	Control of variability, standards of care based on personal outcomes for clients.	I have control of my budget for community care	Recognise nurses for the skills they have at their disposal.	Need for clients to have relationships if they choose
Caroline	Nurses need constant updates of knowledge and skills. Need for a forum for nurses to communicate about	Allow nurses to take on responsibility for their job	Mgt. do not really understand needs of clients nor needs of nurses for caring for clients		

	client care.				
Fiona	Need patience, perceptiveness of needs of clients, support from mgt. Depends on service-nurses valued in some areas and not in others.	Use of policy and procedures in organisation.	Red tape, requisitions and delays in getting what is ordered for clients. Community care budgeting is different from residential services.	Employ more staff, especially trained staff.	

1st February 2000

APPENDIX 8

Ms. Deirdre Carroll,
Assistant General Secretary,
National Association for the
Mentally Handicapped in Ireland,
5 Fitzwilliam Place,
Dublin 2.

Dear Deirdre,

Further to our telephone conversation this afternoon and your consent to ask some parents to look at my Questionnaire, please find enclosed six copies of the Questionnaire which I hope you can give to parents attending next Saturday's meeting .

As I explained, if parents would look at the questions about quality care and in particular how nurses provide quality care and comment on whether or not there might be other useful or more searching questions to ask nurses.

I am attempting to find out what particular interventions nurses engage in with clients and what interventions nurses consider important to clients in residential centres. I also wish to find out what types of activities take place in centres for providing good care to clients and the extent to which nurses are involved in these activities.

Parents are not to fill-in the Questionnaire, but just comment on the questions. The Questionnaire will only be given to nurses working in residential services for persons with Mental handicap.

Stamped addressed envelopes are provided and I would be grateful if parents could return the Questionnaires as soon as possible.

Your assistance is much appreciated. I will be happy to provide a copy of summary findings of the research in due course.

Yours sincerely,

.....

Richard Redmond

APPENDIX 9
(Cover Letter Accompanying Pilot Survey Questionnaire)

22nd November 1999.

Dear Colleague,

I am conducting a study to look at the perceptions and experiences of Registered Mental Handicap Nurses regarding quality of care for people with intellectual disabilities. The study forms part of a research project to find out what aspects of caring nurses see as important and the value they attach to these for their practice. A major aim of the study is to describe the focus of nurses' interventions for clients and the organisational processes in use for providing quality care to clients and the extent of nurses' involvement in these processes.

To assist in the collection of this valuable information, your name was randomly selected by An Bord Altranais for participation in a pilot study for this research.

I have attached a copy of the questionnaire that will take about 30 minutes to complete. I would much appreciate if you would complete this by answering all questions and return it to me in the stamped addressed envelope provided. Please return completed questionnaire on or before Friday December 3rd.

The success of the project depends on a good response rate so I earnestly request your cooperation. All responses to the questionnaire will be confidential. I will not know your name or the name of the centre where you work, no one apart from me will see your questionnaire and you will not be asked to complete a second questionnaire.

If you would like a copy of the summary of findings of the study please tick the box on the last question.

Yours sincerely,

.....
Richard Redmond RMHN.

APPENDIX 10

(Cover Letter Accompanying Main Survey Questionnaire)

30th June 2000.

Dear Colleague,

I am conducting a study to examine the perceptions and experiences of Registered Mental Handicap Nurses regarding quality of care for people with intellectual disabilities. The study forms part of a research project to find out what aspects of caring nurses see as important and the value they attach to these for their practice. A major aim of the study is to describe the focus of nurses' interventions for clients and the organisational processes in use for providing quality care to clients and the extent of nurses' involvement in these processes.

To assist in the collection of this valuable information, your name was randomly selected by An Bord Altranais for participation in the study.

I have attached a copy of the Questionnaire that will take about 30 minutes to complete. I would much appreciate if you would complete this by answering all questions and return it to me in the stamped addressed envelope provided. Please return completed questionnaire on or before Monday 31st July.

The success of the project depends on a good response rate so I earnestly request your cooperation. All responses to the Questionnaire will be confidential. I will not know your name or the name of the centre where you work, no one apart from me will see your questionnaire and you will not be asked to complete a second Questionnaire.

If you would like a copy of the summary of findings of the study please tick the box on the last question.

Yours sincerely,

.....

Richard Redmond RMHN.

Appendix 11

QUALITY SERVICE AND QUALITY NURSING CARE FOR PERSONS WITH INTELLECTUAL DISABILITIES IN RESIDENTIAL CENTRES IN THE REPUBLIC OF IRELAND.

**A Study of Issues and Influences Affecting the Quality of Nursing Care Provided by
Registered Nurses of the Mentally Handicapped Working in Residential Centres.**

A

SURVEY

QUESTIONNAIRE

July 2000

**POSTAL QUESTIONNAIRE ON QUALITY SERVICE AND QUALITY NURSING
CARE FOR PERSONS WITH INTELLECTUAL DISABILITIES LIVING IN
RESIDENTIAL CENTRES IN THE REPUBLIC OF IRELAND**

Questionnaire No:

General Instructions and Information

1. All responses to this Questionnaire will be strictly confidential.
2. The researcher will not know your name or the name of the centre where you work.
3. No one apart from the researcher will see your Questionnaire.
4. Please complete the Questionnaire by placing a tick (✓) unless instructed otherwise in the box/s provided for each question.
5. Please complete all questions.

Section A. Biographical Details

Q1	What gender are you?	Male <input style="width: 30px; height: 20px;" type="checkbox"/>	Female <input style="width: 30px; height: 20px;" type="checkbox"/>	<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">1</div>
Q2	What is your professional work title?	Staff Nurse <input style="width: 30px; height: 20px;" type="checkbox"/>	Charge Nurse <input style="width: 30px; height: 20px;" type="checkbox"/>	<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">2</div>
	Other please specify <input style="width: 30px; height: 20px;" type="text"/>			
	<hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/>			
	<hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/>			
	<hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/>			
Q3	How many years are you qualified as a RMHN?	<div style="border: 1px solid black; width: 120px; height: 25px; display: flex; align-items: center; justify-content: center;"></div>		<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">3</div>
				<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">4</div>
Q4	Please state the number of years working in your current employment.	<div style="border: 1px solid black; width: 120px; height: 25px; display: flex; align-items: center; justify-content: center;"></div>		<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">5</div>
				<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">6</div>
Q5	If you have a dual Registration qualification, please tick the appropriate box/s.	RPN <input style="width: 30px; height: 20px;" type="checkbox"/>	RGN <input style="width: 30px; height: 20px;" type="checkbox"/>	<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">7</div>
		RSCN <input style="width: 30px; height: 20px;" type="checkbox"/>	Other <input style="width: 30px; height: 20px;" type="checkbox"/>	<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">8</div>
				<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">9</div>
				<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">10</div>
Q6	If you have other qualifications please specify:	Certificate	<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">11</div>	
		<hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/>		
		Diploma	<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">12</div>	
		<hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/>		
		Primary Degree	<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">13</div>	
		<hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/>		
		Master's Degree	<div style="border: 1px solid black; width: 30px; height: 30px; display: flex; align-items: center; justify-content: center;">14</div>	
		<hr style="border: 0; border-top: 1px solid black; margin: 5px 0;"/>		

- Q7** If you have further training needs, please list them in order of priority to you.
1 the most important to 5 the least important.

1		<input type="checkbox"/>
2		<input type="checkbox"/>
3		<input type="checkbox"/>
4		<input type="checkbox"/>
5		<input type="checkbox"/>

<input type="checkbox"/>	15
<input type="checkbox"/>	16
<input type="checkbox"/>	17
<input type="checkbox"/>	18
<input type="checkbox"/>	19

Section B. Organisational Details

- Q8** How many residential places does your entire centre provide for?
- | | |
|-------------|--------------------------|
| 49 or less | <input type="checkbox"/> |
| 50 – 99 | <input type="checkbox"/> |
| 100 – 199 | <input type="checkbox"/> |
| 200 or more | <input type="checkbox"/> |

<input type="checkbox"/>	20
--------------------------	----

- Q9** How many residents live in the home/unit **You** work in?
-

<input type="checkbox"/>	21
--------------------------	----

- Q10** How many nurses work in the home/unit **You** work in?
-

<input type="checkbox"/>	22
--------------------------	----

- Q11** How many carestaff work in the home/unit **You** work in?
-

<input type="checkbox"/>	23
--------------------------	----

- Q12** Are there mixed sexes living in the home **You** work in?
- | | | | | |
|-----|--------------------------|--|----|--------------------------|
| Yes | <input type="checkbox"/> | | No | <input type="checkbox"/> |
|-----|--------------------------|--|----|--------------------------|

<input type="checkbox"/>	24
--------------------------	----

- Q13** What is the level of adaptive functioning of the residents in the home/unit **You** work in? (tick as many as appropriate).
- Profound ☐ 25
- Severe ☐ 26
- Moderate ☐ 27
- Mild ☐ 28
- Q14** How is your centre administered? Voluntary ☐ Health Board ☐ 29
- Q15** Does your centre have an active parents and friends association? (see definition below) Yes ☐ No ☐ 30
- Q16** Does your centre have a nurse training school on campus? Yes ☐ No ☐ 31

Active Parents & Friends Association.

In this instance, an active Parents & Friends Association refers to parents/family and other people being organised for the purpose of participating in the service provision to clients or, being active in contributing in some manner to improving services for clients in the centre. This could take the form of being involved in promoting service quality, arranging or providing leisure facilities for clients, or fund raising for needed equipment.

Section C. Organisational Service Quality Details

- Q17** Has your centre a written mission statement for the service? Yes ☐ No ☐ Don't Know ☐ 32
- Q18** Has your centre a written philosophy outlining its beliefs and values? Yes ☐ No ☐ Don't Know ☐ 33
- Q19** Is service provision to residents based on a multidisciplinary team approach to care? Yes ☐ No ☐ 34

Q20 Are nurses' members of the multidisciplinary team in your centre? Yes ☐ No ☐ ☐ 35

Q21 Are nurses consulted on matters of service provision to residents? Always ☐ Sometimes ☐ Rarely ☐ ☐ 36

Q22 Does your centre consult with the family of residents on matters of service provision? Always ☐ Sometimes ☐ Rarely ☐ ☐ 37

Q23 Does your centre have any type of service quality accreditation? Yes ☐ No ☐ Don't Know ☐ ☐ 38

Q24 If your centre has a service quality accreditation e.g. ISO 9000, please specify type of accreditation: ☐ 39

Q25 Does your centre have a quality system in place? (see definition below) Yes ☐ No ☐ ☐ 40

Q26 If your centre has one or more quality systems in place please specify: ☐ 41

[1]

[2]

[3]

Quality System.

Refers to the organisational structure, responsibilities, policies, procedures and resources for implementing quality management in the centre.

Section D. Nursing Quality Care Details

Q27 In your opinion, how much instruction was provided on quality care during your nurse/ training course?	Very large <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> Large amount <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> Adequate amount <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> Inadequate amount <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> None <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 42			
Q28 In your opinion, is quality care in <u>Your</u> centre:	Very High <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> High <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> Adequate <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> Low <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> Very Low <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 43			
Q29 In your opinion, how do you rate facilities available to residents in your centre?	Very High <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> High <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> Adequate <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> Low <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/> Very Low <input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 44			
Q30 Please number from 1 – 10 the following dimensions you see as important for clients. 1 for most important -to- 10 for least important.					
(a) Social care, e.g. activities, leisure.	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	(b) Engagement e.g. involvement by clients in activities they	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 45	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 46
(c) Emotional care, e.g. sympathy, listening and Supporting clients.	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	(d) Physical/health care, e.g. physical nursing needs.	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 47	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 48
(e) Spiritual care.	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	(f) Safety/security care.	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 49	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 50
(g) Relationships/Friendships	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	(h) Training for self-help skills.	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 51	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 52
(i) Occupational/work-related skill development.	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	(j) Sexuality e.g. recognition of sexual needs of clients	<input style="width: 30px; height: 20px; border: 1px solid black;" type="text"/>	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 53	<div style="border: 1px solid black; width: 30px; height: 30px; margin: 0 auto;"></div> 54

Q31 Please number from 1 – 10 the following dimensions of client care that receive most attention from nurses.

1 for most important -to- 10 for least important.

(a) Social care, e.g. activities, leisure.	<input type="text"/>	(b) Engagement e.g. involvement by clients in activities they	<input type="text"/>	<input type="text"/>	<input type="text"/>
				55	56
(c) Emotional care, e.g. sympathy, listening and Supporting clients.	<input type="text"/>	(d) Physical/health care, e.g. physical nursing needs.	<input type="text"/>	<input type="text"/>	<input type="text"/>
				57	58
(e) Spiritual care.	<input type="text"/>	(f) Safety/security care.	<input type="text"/>	<input type="text"/>	<input type="text"/>
				59	60
(g) Relationships/Friendships	<input type="text"/>	(h) Training for self-help skills.	<input type="text"/>	<input type="text"/>	<input type="text"/>
				61	62
(i) Occupational/work-related skill development.	<input type="text"/>	(j) Sexuality e.g. recognition of sexual needs of clients	<input type="text"/>	<input type="text"/>	<input type="text"/>
				63	64

Q32 Please number from 1 – 10 the client behaviours that would indicate that a client was receiving good quality care.

1 for most important -to- 10 for least important.

(a) Expressing personal preferences	<input type="text"/>	(b) Engaging in meaningful activities	<input type="text"/>	<input type="text"/>	<input type="text"/>
				65	66
(c) Expressing satisfaction with their lifestyle	<input type="text"/>	(d) Taking risks in their life	<input type="text"/>	<input type="text"/>	<input type="text"/>
				67	68
(e) Having friends	<input type="text"/>	(f) Recognising their health care needs	<input type="text"/>	<input type="text"/>	<input type="text"/>
				69	70
(g) Having regular family contact	<input type="text"/>	(h) Setting their own personal goals	<input type="text"/>	<input type="text"/>	<input type="text"/>
				71	72
(i) Making choices in their life	<input type="text"/>	(j) Other (please specify)	<input type="text"/>	<input type="text"/>	<input type="text"/>
				73	74

Q33 Is nursing care in your centre based on written standards?

Yes

No

75

Q34 If written standards are in place, are they based on:

(a) Structure e.g. resources,
staffing, equipment?

Yes ☐

No ☐

☐ 76

(b) Process e.g. staff
performance and what staff
does for clients?

Yes ☐

No ☐

☐ 77

(c) Outcomes e.g. end result of
care interventions?

Yes ☐

No ☐

☐ 78

(d) Personal outcomes, e.g.
needs and wants of clients?

Yes ☐

No ☐

☐ 79

Q35 Do you use a specific model of care for nursing? If yes, please describe.

☐ 80

Q36 Do you use nursing care plans for
clients?

Yes ☐

No ☐

☐ 81

Q37 In caring for clients who are unable
to communicate, from which staff is
information most sought about their
needs and wants?

Unit Manager ☐

Nurse ☐

Key-
workers ☐

☐ 82

Other please specify ☐

Q38 Is client care based on individual
programme plans (IPPs)?

Always ☐

Sometimes ☐

Rarely ☐

☐ 85

Q39 If IPPs. are held for clients, how often are they conducted? Every 6 months ☐ Every 12 months ☐ Less often than 12 months ☐ 85

Q40 If IPPs. are held for clients, what is the average number of:

(a) Skill building objectives. 1 - 3 ☐ 4 - 6 ☐ 7 - 12 ☐ 86

(b) Social activity objectives. 1 - 3 ☐ 4 - 6 ☐ 7 - 12 ☐ 87

Q41 If individual programme plans (IPPs) are in place, please indicate the people who attend the meetings and those who are invited:

	Always	Sometimes	Rarely	Invited	
(a) Client	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	88
(b) Family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	89
(c) Advocate or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	90
(d) Keyworkers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	91
(e) Nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	92
(f) Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	93
(g) Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	94
(h) Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	95
(i) Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	96

Q42 On average, how often do you consult with family members of clients? Always ☐ Sometimes ☐ Rarely ☐ 97

Q43	In discussions between client, their family and the nurse, who most often initiates contact?	Nurse <input type="checkbox"/>	Family <input type="checkbox"/>	Client <input type="checkbox"/>	Social Worker <input type="checkbox"/>	<input type="checkbox"/>	98
	Other please specify <input type="checkbox"/>						
<hr/>							
<hr/>							
Q44	To what extent are you involved in decision making practices about care for clients?	Always involved <input type="checkbox"/>	Sometimes involved <input type="checkbox"/>	Rarely involved <input type="checkbox"/>			100
Q45	How would you rate your level of participation in the overall service?	Participate on all matters <input type="checkbox"/>	Participate on nursing matters only <input type="checkbox"/>	Participate only during a crisis <input type="checkbox"/>	Rarely participate in any matters <input type="checkbox"/>	<input type="checkbox"/>	101
Q46	Are nurses encouraged to make suggestions to management on matters of care for clients?	Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Rarely <input type="checkbox"/>			102
Q47	In your centre, is there a forum for nurses to meet regularly to discuss matters relating to care for clients?	Yes <input type="checkbox"/>	No <input type="checkbox"/>				104
Q48	In your centre, are nurses encouraged to undertake continuing training for their job?	Yes <input type="checkbox"/>	No <input type="checkbox"/>				105

Q49 Please number from 1 – 7 management practices that in your opinion, best facilitate nurses providing quality care.

1 for best facilitate to 7 for least facilitate.

(a) Good communication with staff

☐

106

(b) Participative style of management

☐

107

(c) Involving staff in decision making

☐

108

(d) Providing adequate staff and equipment

☐

109

(e) Democratic style of leadership

☐

110

(f) Delegating responsibility to staff

☐

111

(g) Other (Please specify).

☐

112

Q50 Please number from 1 - 7 management practices that in your opinion, are barriers to nurses providing quality care to clients.

1 for biggest barrier to 7 for least barrier.

(a) Poor communication with staff

☐

113

(b) Not involving staff in decision making

☐

114

(c) Bureaucratic style of management

☐

115

(d) Not providing adequate staff and equipment

☐

116

(e) Not delegating responsibility

☐

117

(f) Autocratic style of leadership

☐

117

(g) Other (Please specify).

☐

118

Q51 Please number from 1 – 8 methods you use to measure (monitor) quality of nursing care to clients in the home/unit.

1 for most common to 8 for least common.

(a) Behavioural observations	<input type="checkbox"/>	(b) Bio-physical measurement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				119	120
(c) Nursing care plan review	<input type="checkbox"/>	(d) Talking/Listening to clients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				121	122
(e) Progress on Training Programmes	<input type="checkbox"/>	(f) Talking to family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				123	124
(g) Auditing of standards of care	<input type="checkbox"/>	(h) Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				125	126

Q52 Please number from 1 – 10 resources (structures) you use to evaluate provision of care for your clients.

1 for most important to 10 for least important.

(a) Number of staff on duty	<input type="checkbox"/>	(b) Skill-Mix of staff on duty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				127	128
(c) Budget for running the home/unit	<input type="checkbox"/>	(d) Funds for clients' clothes and leisure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				129	130
(e) Access to transport for client	<input type="checkbox"/>	(f) Maintenance/Décor of the home/unit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				131	132
(g) Access to specialist services for clients	<input type="checkbox"/>	(h) Access to leisure facilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				133	134
(i) Equipment for providing necessary care	<input type="checkbox"/>	(j) Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				135	136

Q53 Please number from 1 – 10 methods (processes) you use to evaluate the efficiency of nursing care for clients.

1 for the most important to 10 for least important.

(a) Assessment documentation	<input type="checkbox"/>	(b) Planning documentation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				137	138
(c) Programme documentation	<input type="checkbox"/>	(d) Evaluation documentation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				139	140
(e) Staff meetings on client care	<input type="checkbox"/>	(f) Collaboration with professionals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				141	142
(g) Responsiveness to client needs	<input type="checkbox"/>	(h) Sufficient resources/ equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				143	144
(i) Audit of care standards	<input type="checkbox"/>	(j) Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				145	146

Q54 Please number from 1 - 10 Client Personal Outcomes you use to evaluate the effectiveness of care.

1 for the most common to 10 for the least common.

(a) Expressing satisfaction with care	<input type="checkbox"/>	(b) Being able to make choices in their life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				147	148
(c) Expressing personal preferences	<input type="checkbox"/>	(d) Having Relationships/ friendships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				149	150
(e) Having family contact	<input type="checkbox"/>	(f) Having good health care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				151	152
(g) Being involved in decisions about their care	<input type="checkbox"/>	(h) Being engaged in meaningful activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				153	154
(i) Achieving a measure of social competence	<input type="checkbox"/>	(j) Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				155	156

Q55 (a) Do you evaluate the outcomes of nursing care in your clients?

Yes ☐

No ☐

☐ 157

(b) If yes, please describe how you evaluate care.

Q56 If you evaluate your nursing care, please number from 1 – 8 the areas of care you evaluate most often.
1 for most often to 8 for least often.

(a) Personal well being (self-help skills, personal hygiene).

☐

☐ 159

(b) Social well being (interaction, friendship, communicating with others).

☐

☐ 160

(c) Physical well being (health/dental care, nutrition, physical comfort, activity).

☐

☐ 161

(d) Material well being (personal possessions, clothes, money, comfortable home)

☐

☐ 162

(e) Emotional well being (contentment, happiness, self-esteem).

☐

☐ 163

(f) Spiritual well being (attendance/participation at religious services).

☐

☐ 164

(g) Sexual well being (identity, expressing sexuality, mixing with opposite sex).

☐

☐ 165

(h) Other (Please specify).

☐

☐ 166

Thank you for completing this questionnaire. If you would like a copy of the summary findings of the research please tick the box. This will be sent to you by An Bord Altranais.

☐

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