EMPLOYING STANDARDISED LANGUAGE TO DEFINE THE UNIQUE INTERVENTIONS OF INTELLECTUAL DISABILITY NURSING

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Summary

Communication is central to group activities, both within the human and animal worlds, incorporating systems of signs, symbols, actions or sounds (Oxford University Press 2002) in order to transmit meaning, through the interpretation of shared concepts (Ogden and Richards 1972). In the professional nursing arena, the medium for such communication is language, whether written or spoken. The need to be able to communicate the essence of nursing – its foci, interventions, outcomes, decisions and rationales – was instrumental in the evolution of the nursing diagnosis movement. The development of taxonomies of standardised nursing terminology furthered this process, providing terms which could be used to facilitate description of those components of nursing practice, and permitting explication of the unique contribution of nursing to care.

This thesis aims to describe the unique interventions of intellectual disability nursing in Irish residential services, through the employment of standardised nursing language. A group of 614 respondents, comprising nurses, non-nurse care staff, multidisciplinary team members and service managers provided the main body of information for the research.

The study was set against a background of changing service provision, with increasing development of community-based residential services and redesignation of direct-care roles as generic positions. Thus, whereas such direct-care positions had previously been nursing discipline specific, the new roles were open to persons with a range of qualifications (including nursing). In view of a similar development that had occurred in the United Kingdom, and the restructuring and refocusing of *learning disability* nursing there and in the absence of any detailed study into the contribution of intellectual disability nursing in the Republic of Ireland, this study aimed to identify both the issues upon which such nursing was focused, and the interventions that Registered Intellectual Disability Nurses (RNID) employ to address them.

The study specifically sought to answer the following questions:

- What are the interventional foci of nursing in residential intellectual disability services?
- What is the current contribution of nursing in residential intellectual disability services?
- Is the nursing terminological approach useful for describing the unique contribution of nursing?

A two-stage methodological design was employed, with the first stage incorporating a qualitative approach – Delphi study, focus groups and key informant interviews – which was investigatory in nature, and provided a grounding for the second, quantitative stage. This pan-organisational survey explored the frequency of employment of specific interventions as well as investigating various staff groupings' perceptions of who was responsible for their performance.

The central finding of this study suggests that interventional caring in intellectual disability services is a generic entity which transcends professional boundaries and overlaps greatly with the tasks undertaken by non-nurse care staff, and posits that specialised nursing has, with very few exceptions, no unique interventional complement to add to such caring in residential settings for this population. It is acknowledged, however, that this study expressly set out to address the empirical component of such nursing and that there may be a unique qualitative aspect which will require further investigation.

The findings of this study pose a significant challenge for specialist intellectual disability nursing, which has not demonstrated any concerted attempt to address the issues that the changing service context has posed. It is recommended that further research be carried out to examine the qualitative aspect of the intellectual disability nurse’s role and to explore the viability, or perhaps, the restructuring and refocusing, of such nursing.

Abbreviations

ERHA	Eastern Regional Health Authority
FVB	Federation of Voluntary Bodies
HSEA	Health Service Employers Agency
NAMHI	National Association for People with an Intellectual Disability
NCRS	Nurses working in community residential services.
NCNM	National Council for the Professional Development of Nursing and Midwifery
NIRS	Nurses working in institutional residential services.
NNCRS	Non-nurses working in community residential services.
RGN	Registered General Nurse
RMHN/RNID	Registered Mental Handicap Nurse/Registered Nurse Intellectual Disability
RPN	Registered Psychiatric Nurse
RSCN	Registered Sick Children’s Nurse

Glossary

An Bord Altranais: the Irish Nursing Board

Classification Scheme: descriptive information for an arrangement or division of objects into groups based on characteristics, which the objects have in common (ISO/IEC 11179-1:2004E)

Community Group Home: a residential setting, modelled on a standalone bungalow/house, providing accommodation for up to six persons with intellectual disability, located outside of a residential centre, in close proximity to mainstream community housing, and with 24 hour staffing.

Institutional Residential Unit: a residential setting, modelled on a hospital ward environment, or on a standalone bungalow/house, providing accommodation for more than six persons with intellectual disability, located within the confines of a residential centre, in close proximity to other such units, and with 24 hour staffing.

Intellectual Disability: a significant impairment of intelligence combined with impairments in social functioning (Slevin and Sines 2005). Synonymous terms: developmental disability; mental retardation; mental handicap; learning disability.

Mild Intellectual Disability: Approximate IQ range of 50-69 (in adults, mental age from 9 to under 12 years). Likely to result in some learning difficulties in school. Many adults will be able to work, and maintain good social relationships and contribute to society (WHO 2005a).

Moderate Intellectual Disability: Approximate IQ range of 35-49 (in adults, mental age from 6 to under 9 years). Likely to result in marked developmental delays in childhood but most can learn to develop some degree of independence in self-care and acquire adequate communication and academic skills. Adults will need varying degrees of support to live and work in the community (WHO 2005a).

Profound Intellectual Disability: IQ under 20 (in adults, mental age below 3 years). Results in severe limitation in self-care, continence, communication and mobility (WHO 2005a).

Severe Intellectual Disability: Approximate IQ range of 20-34 (in adults, mental age from 3 to under 6 years). Likely to result in continuous need of support (WHO 2005a).

Taxonomy: Classification according to presumed natural relationships among types and their subtypes (ISO/IEC 11179-1).

Terminological System: A concept system with designations for each concept (ISO/IEC 11179-1).

Terminology: A set of terms representing the system of concepts of a particular subject field (ISO 1087).

CHAPTER 1

Overview

1.0. Introduction

Ever since the professionalisation and regularisation of nursing in the 18th century, there have been attempts to describe what exactly nursing is. Thus, Florence Nightingale, commencing with the premise that “the very elements of nursing are all but unknown” (Nightingale 1860 p.8), proposed that nursing is that which contributes to “the success of Nature’s reparative processes” (p.9). She expanded on this to separate out the activity of nursing (handicraft) and foci of such nursing handicraft (environmental management) and to propose that a key component of nursing is “prevention” (p.127). What evolved from this was a rule-based approach to the preparation and practice of nursing which was centred on the curative context of medical intervention (Dolan et al 1983). It should be considered, though, that Nightingale’s attempt to describe nursing may be seen to have achieved the end of confirming the social *status quo* of the Victorian era, and, so, by defining the regularised nursing within the context of the prior regularisation of the medical profession, she was also defining the role and relationship of man to woman.

Thus, the new nursing was defined within the context of the male-run and more powerful medical profession, for, although nursing and medicine had been inextricably linked throughout their histories, and, many current aspects of the medical role *originally* had fallen within the realm of nursing, medicine became professionalised and regularised at the expense of nursing (Ehrenreich and English 1973; Webster 1993).

It was within this context that nursing developed, particularly within the United Kingdom, of which Ireland was a part, and, to a lesser degree, within the United States of America (Fealy 2005).

1.1 Attempts to Define Nursing in the 20th Century

1.1.1 Concept and Theory Development in Nursing

In the mid-twentieth century new attempts were made to define nursing. Alligood (2002) has characterised these periods as the curriculum, research, graduate education and theory eras. During the initial era, it is suggested that the focus was on identifying what constituted the fundamentals of nursing practice and on standardising curricula (Alligood 2002). Whereas this related to developments, during the 1930-50s, in the United States of America, it is clear that a similar era occurred a couple of decades later in the Republic of Ireland (Chavasse 2000). The research era is argued to have occurred during the 1940s and 1950s in the USA (Alligood 2002) with the focus being on exploring the essence of nursing through research methods (Nordmark and Rohweder 1959, Simmons and Henderson 1964). Wald and Leonard (1964), though, criticised what they saw as a propensity to address this through descriptive, empiric methodologies, suggesting that practice approaches would answer the questions that were key to nursing. Nightingale had, however, previously attempted to answer key nursing questions using research methodologies and statistical analyses and with some effect (Small 1999).

This period, which Alligood (2002) suggests to be closely related to the graduate education era is being mirrored within the Irish context at this time, with the widespread development of post-graduate and doctoral degree courses in nursing. Donaldson and Crowley (1978) posited this relationship as being of prime importance in coming to understand and describe the discipline of nursing, and suggested that “appropriately prepared nurse researchers must generate and test descriptive theories”(p.114). They further suggested that three central themes were consistently present in nursing: 1) concern with principles and laws that govern the life processes; 2) well-being, and optimum functioning of human beings – sick or well; 3) concern with the patterning of human behaviour in interaction with the environment in critical life situations; and concern with the processes by which positive changes in health status are affected (Donaldson and Crowley 1978). These, they considered amounted to a boundary for nursing from other disciplines.

The emergence of the theory era in the 1980s in the USA led to further attempts to describe nursing with this boundary of nursing being explored conceptually. Hence, Fawcett’s (1995) ‘metaparadigm’ and Meleis’ (1997) ‘domain’ of nursing; terms which defined the realm of nursing within which the key concepts of interest were to be found. Whilst general agreement developed around four key concepts which were seen to be central to nursing, the practice of nursing, and the concepts of health, the person and environment (Fawcett 1994), there were some dissenters, notably Stevens (1979) who excluded *environment*, and Leininger (1984) (cited in Morgan 2002) who considered *caring* to be the essence and central concept of nursing. Whilst the early part of this era focused on theory development, the latter part centred on theory utilisation by nurses.

1.1.2 Clinical Decision-Making

At the same time as these attempts to identify the key conceptual foci of nursing were taking place, Benner (1984) was publishing her ideas on expertise and on the role of intuition in the expert practice of nursing, a role hotly contested by English (1993) who denounced “the ‘hunches’ of Benner’s experts” (p.393). Inherent in Benner’s work was the suggestion that, at the root of expert practice was expert decision-making. This challenged the idea that the nurse unquestioningly carried out activities that were prescribed by others (Chinn and Kramer 1991), for now the reality of autonomous practice was being recognised, thus prompting Carnevali and Thomas (1993) to state that "recognized or not, these clinical judgements and decisions are a part of professional nursing practice" (p.2). This gave rise to – amongst others - two specific considerations: what do nurses make decisions about and how do they make these decisions? The first of these questions has been addressed by the North American Nursing Diagnosis Association (NANDA) who suggested that nurses make decisions about "individual, family, or community responses to actual or potential health problems/life processes" (NANDA International 2003 p.263). This has been further expanded to include nursing problems that "form part of the domain of the nurse" and about which there is agreement as to "nomenclature (standardization of names and terms), definitions (the conceptual content of a name or term), supporting data or defining characteristics (empirical phenonema upon the basis of which a diagnosis can be determined)" (Leih and Salentijn 1994, p.314). The latter aspect of this explanation addresses some of the issues inherent in the second question: how do nurses make decisions? Early theorists had quickly identified that the process that was employed by nurses was diagnostic in character (Gordon 1994). Although some considered that diagnosis [Greek – diagignoskein – discernment] was a cognitive process uniquely employed by the medical profession, this was dispelled by King (1967), for, as Gordon (1994) notes "a cognitive, or intellectual process does not belong to any one group" (p.3). The initial attempts to understand how nurses make decisions or diagnose, were strongly aligned to the psychological conceptualisation of memory and its role in the hypothetico-deductive diagnostic reasoning process (Carnevali and Thomas 1993). Within the context of this, the suggestion arose that integral to this process were activities involving collection, interpretation and clustering of information, as well as naming of the clusters. This constituted the initial stages in the development of a standardised nursing language.

1.1.3 Nursing Diagnoses

McGuire (1991) identified three factors that were important in the development of the nursing diagnosis movement: "a 1947 legal opinion that nurses diagnose; the inclusion of nursing diagnosis as a responsibility of the nurse in the 1973 ANA *(American Nurses Association)* Standards of Practice; and the perceived need to classify nursing practice descriptors" (p.10). In its embryonic form, nursing diagnosis was represented in practice by the assessment, planning, intervention and evaluation (APIE) approach of the nursing process. This continued to be the case for nearly 20 years, until the American Nurses Association published its 'Standards of Nursing Practice' in 1973 (ANA 1973). From 1973 until the mid-1980s, the United States was to be the main focus for developments in the field of nursing diagnoses. The intervention of the ANA into the nursing diagnosis debate expanded the four-stage – Assessment, Planning, Implementation and Evaluation - decision-making process into a five-step process that included the stage of diagnosis, following on from assessment. It may be suggested that this was obvious and that diagnosis was implicit in the first stage when problems were identified. However, the dictionary definition of 'diagnosis' suggests that it involves more than the mere identification of problems – it also includes an understanding of the nature of that problem and implicitly, the naming of it (Oxford University Press 2002). This was particularly significant, for as Pesut and Herman (1998) note, the period in question was marked by the quest for understanding the process of diagnostic reasoning and data processing in nursing.

Following on from the work of NANDA and other groups active in nursing classification systems, an unsuccessful submission was made in 1986 for such systems to be included in the 10th revision of the World Health Organisation's *International Classification on Diseases* (ICD-10). A subsequent proposal was made to the *International Classification of Nurses* (ICN) in Seoul, in 1989, that the "ICN encourage member nurses' associations to become involved in developing classification systems for nursing care, nursing information management systems, and nursing data sets to provide tools that nurses in all countries could use to describe nursing and its contributions to health" (Clark and Lang 1992, p. 110). The aim was that, with a number of classification systems being developed independently of each other, the ICN would work to bring them together under one classification system, namely the *International Classification for Nursing Practice* (ICNP).

The rationale underpinning the ICNP arose out of the realisation that if nursing cannot name the patient problem with which it is concerned then "we cannot control it, finance it, research it, teach it, or put it into public policy" (Clark and Lang 1992, p.109). Thus, the development of nursing classification systems was seen to be synonymous with the on-going development of nursing as a profession, and with the pursuance of autonomous practice. Essentially though, it centred on the failure of nursing to identify what it was they contributed distinctively to health care. As has been noted above, this 'failure' may be attributed to factors *both* within and outside of nursing. In remedying this, the ICNP provides "a terminology for nursing practice that serves as a unifying framework into which existing nursing vocabularies and classifications can be cross-mapped to enable comparison of nursing data" (ICN 2001, p. i), thereby enabling the development of a common international language for nursing. Having passed through a lengthy developmental process, with Alpha and Beta versions, the ICN, in 2005, revealed ICNP Version 1 (ICN 2005). This testing and developmental work has taken place in many parts of the world under local direction. In the European Union, ICNP has been promoted through the TELENURSE project (Mortensen 1999). Across the wider European region, however, projects carried out on national bases have been expanding the body of knowledge in this field, and are linking in to the ICN's initiative.

In an attempt to develop some unity amongst those groups that were working in the European region, and provide a focus for developments within the field of nursing diagnosis, interventions and outcomes, an umbrella group entitled the Association for Common European Nursing Diagnoses, Interventions and Outcomes (ACENDIO) was established in 1995. Although it does not involve itself directly in the development of classification systems, it has rapidly become an important body within the field. As such, it has, through its conferences and publications, provided the opportunity for nurses from diverse backgrounds to share information about their differences and similarities.

1.2 Differentiation within Nursing

This treatise on the evolution of nursing has heretofore considered nursing in generic terms, without taking account of the specialist strands that exist within the profession. These divisions of nursing vary between jurisdictions. The structure of the Register of Nurses in the Republic of Ireland is presented here as an exemplar.

Registration of nurses in Ireland was commenced in 1919, on foot of the Nurses' Registration (Ireland) Act. This act provided for the establishment of the General Nursing Council for Ireland, the responsibility of which was to regulate nurse training and practice, and to maintain a register of general nurses. This register contained supplementary parts for general male nurses, mental nurses and sick children's nurses (Robins 2000a). In 1950, the General Nursing Council was dissolved and the An Bord

Altranais (the Irish Nursing Board) became the regulatory body for nursing and midwifery. During the 1950s the register contained nine divisions: general; general (male); infectious disease; sick children’s; mental; sanatorium; tuberculosis; orthopaedic and midwives. During the following decades the sanatorium and infectious disease divisions were closed, and five new divisions opened: mental handicap; public health; advanced psychiatric; clinical teachers and nurse tutors. The most recent stage in the regulation of the profession in Ireland saw An Bord Altranais reconstituted and the number of divisions of the Register of Nurses reduced to seven: general nursing; psychiatric nursing; intellectual disability nursing; sick children’s nursing; public health nursing; midwifery and nurse tutors.

Many of the developments in nursing theory, decision-making and language had their origins within the broader realm of general nursing. This is understandable when one considers that general nursing is probably the most common manifestation of nursing throughout the world - it certainly accounts for the majority of nurses (An Bord Altranais 2005a) - whereas other divisions may not have such widespread recognition. One division, intellectual disability nursing, has developed over the past 45 years in the United Kingdom and Ireland to become one of the main branches of the profession, but, because of its perceived variance from the norm (general nursing), maintains an uneasy relationship to the main division (Turnbull 2004).

1.3 Intellectual Disability Services in Ireland

1.3.1 Service Provision

The provision of intellectual disability care in Ireland has been hugely inconsistent, with the State absenting itself from such activities until the late 1980s. Prior to this, formalised approaches were provided by religious and voluntary bodies, as well as by parents and friends groups. The general custodial approach to care mirrored that evidenced in other countries, with institutionalisation, sexual segregation and repression (Finnane 1981; Robins 1986, 1992). By the late 1800s, the paradigm of care was medically focused on account of the Lunatics Act of 1845 and the transfer of Poor Law Institutions to medical governance (Finnane 1981; Chung and Nolan 1994). It was, therefore, within the context of the psychiatric medical model (Hall 1996) that Irish ‘mental handicap’ nursing developed. Although specialised nurses were first introduced to Irish services, in the 1960s, general and mental health nurses had been working for many years in the institutions. The introduction of the ‘mental handicap’ nurse, a move sparked off by the advent of ‘mental subnormality’ nursing in the United Kingdom in the late 1950s, and by pressure from parent groups (Robins 1992), was not characterised by revolutionary change in service provision. Conceptually, it served to continue the custodial approach to caring for people with intellectual disability that had its roots in the scientific, positivistic approaches of the 19th century. As the number of ‘mental handicap’ nurses grew, however, a more total person approach became evident, albeit in the context of a hospital nursing environment. *The Commission of Inquiry on Mental Handicap* (Department of Health 1965) took on board the developing understanding of intellectual disability and broadened the scope of ‘mental handicap’ nursing to include 'treatment, care and training'. It also advised that nursing focus more on social and emotional issues of intellectual disability.

In the 1970s, with the onset of normalisation, integration and social role valorisation (Nirje 1969; Wolfensberger 2000), there developed a growing realization that a medical paradigm was not appropriate for guiding service provision for intellectually disabled people. The emphasis moved towards a social model with a focus on education (Department of Health and Social Welfare 1983; Mercer 1992). In many countries there have been concomitant developments in the realm of choice, advocacy and human rights (Nehring 1994).

In terms of living environments, much has changed. In the United Kingdom, North America and Australia there was a movement from long-stay hospitals to 'community care'. It became clear, however, that care in the community was quite different from care by the community (Bayley 1973), with the latter being most desired. With the consequent redirection of economic resources, intellectual disability nursing in the UK, responded by developing a strong community care focus with the employment of nurses as members of community teams. Unfortunately the model of community care that developed in the UK and Northern Ireland (Parahoo and Barr 1994) did not come into being in the Irish setting, with services largely opting for a care in the community approach (Department of Health 1990; Department of Health and Children 1997). Thus, whilst institutions are being scaled down with clients being relocated in the community, it is principally group-homes that they are moving to with varying degrees of integration and inclusiveness (Barron and Mulvaney 2004; McConkey et al 2005).

This has meant that intellectual disability nursing, in Ireland, has not needed to make the same journey as its counterpart in the UK and Northern Ireland. This is evidenced by the absence of any formal community intellectual disability nursing and the continuation of alliances between institutional settings and nurse education, whereby students' experience is largely based in campus or village settings. There is also evidence, however, that some services are changing and that new options, such as supported living, are being considered. This may have serious implications for the future role and functions of intellectual disability nursing. Although few educational establishments in the Republic of Ireland appear to be addressing these implications, with most post-graduate courses focusing on challenging behaviour, one course in community intellectual disability nursing is being offered. This is, however, an initiative of the college rather than of An Bord Altranais.

1.3.2 Intellectual Disability Nursing

In Ireland, the discipline of intellectual disability nursing has only been a reality since the early 1960s, when An Bord Altranais commenced its Mental Handicap Nursing Register. In forty years the discipline has grown to its current status as one of the main divisions of Irish nursing, with 3860 persons on the active register (Nurse Register Statistics 2004 – An Bord Altranais 2005a). There has, however, over the past few years, been some discussion and questioning regarding the role of intellectual disability nurses (Barr 1996). This has been, to some degree, driven by changes, that have seen services move from being primarily segregational and reductionalist to what are now more integrational and holistic (Government of Ireland 1998), with the paradigm-shift in such services resulting in a move from a medical to a humanistic model (Mercer 1992). It is clear that such a move represents a significant deviation from the traditional biomedical approach (Gates and Wilberforce 2003), which focused on the physical processes of disease and its management within the context of pathophysiology, and which was the basis upon which much of intellectual disability nursing practice had been built.

Furthermore, intellectual disability nursing had, since its inception, been strongly identified with medicine-led, institutional care. The dissonance that was developing between service and nursing philosophies led to the adoption of the bio-psycho-social model (Engels 1977), as the basis for intellectual disability nursing provision (Eastern Regional Health Authority 2003). This model, albeit innately medical, considers the mind and body as interlinked aspects of the person, and distinguishes between illness and disease.

The dilemma which Irish intellectual disability nursing has been facing is not a unique one, for it was similarly encountered by British nurses in the 1970s and 1980s, following the release of the *Report of the Committee of Enquiry into Mental Handicap Nursing and Care* (Department of Health 1979). Amongst the many important recommendations the this report proposed was a suggestion that intellectual disability nurse training be discontinued and that all those involved in the provision of residential care be amalgamated into one generic, commonly trained “residential care staff” (p.86). The effect of this report was to stimulate intellectual disability nurses to examine what their role was so as to be able to argue for the retention of what they considered to be their unique input into the care of people with intellectual disabilities. This was to lead again to a point whereby intellectual disability nursing was to be restructured as a post-registration course. The decision to retain pre-registration nurse education was made finally in 1994 by the Department of Health, but with the implied caveat that courses of preparation be responsive to the changing service requirements (Department of Health 1994). As a result of this process, the face and direction of intellectual disability nursing in the United Kingdom was radically changed, with greater emphasis on developing the role of the nurse working in the community setting (Barr 1996). Although this was initially grounded in a revised 1982 syllabus, it was also a reflection of the realisation that, whereas the majority of nurses were working in residential centres, the majority of people with intellectual disability were located outside of them. It was also a response to the changing character of service provision, which the *Report of the Learning Disability Nursing Project* (Department of Health 1995a) identified as being “now based on the belief that people with learning disabilities should lead an ordinary life in community settings" (p.7).

The Learning Disability Nursing Project (Department of Health 1995a) attempted to provide some insight into the role of the nurse in this discipline. In doing so, it examined it in relation to the needs of people with learning disability (Figure 1.1).

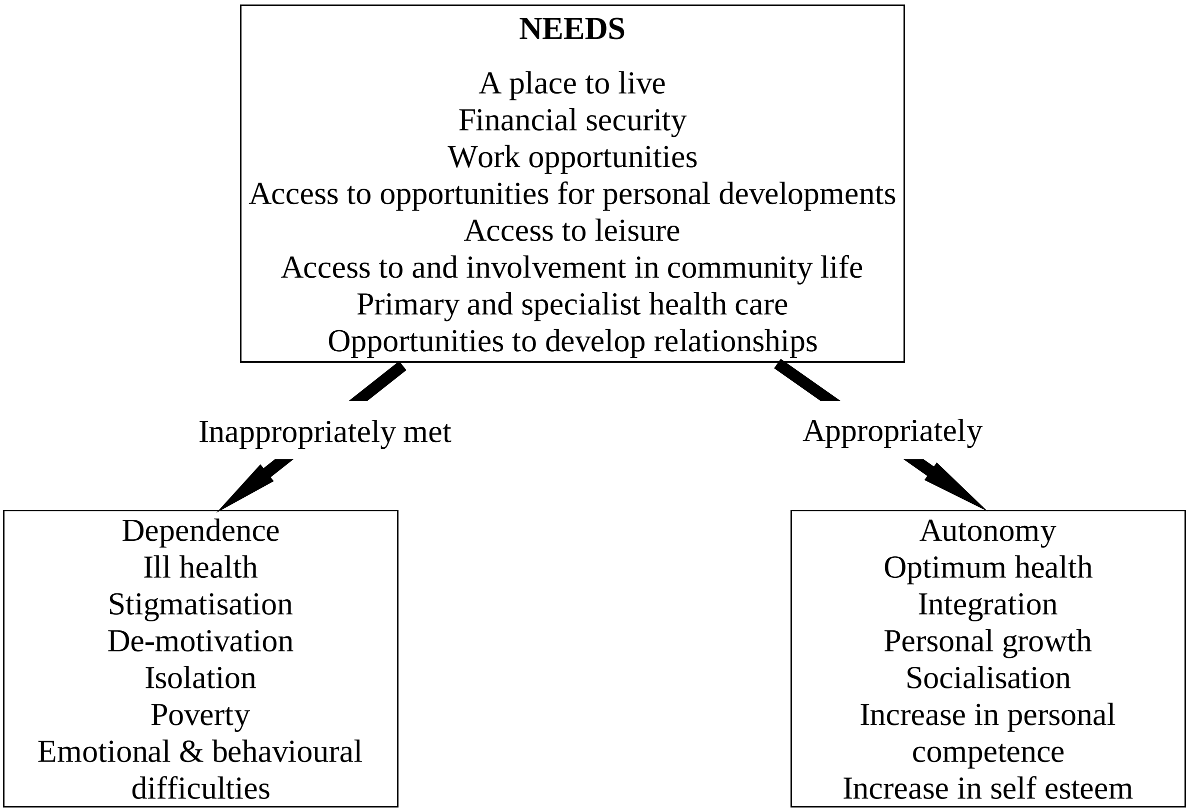


Figure 1.1 The needs of people with learning disability and the consequences of appropriate or inappropriate support (from Department of Health 1995a. p.10)

Within the above context, the authors broadly identified the learning disability nurses' role in relation to:

- Assessment of need
- Health surveillance and health promotion
- Developing personal competence
- The use of enhanced therapeutic skills
- Managing and leading teams of staff

- Enhancing quality of support
- Enablement and empowerment
- Co-ordinating services.

Whilst these give some basic direction as to what the role of the nurse in UK learning disability services is seen to be, it must be noted that the report has been criticised for its lack of guidance regarding how this role could be maintained and developed within present and future service provision (Connor 1995 cited in Barr 1996).

The professional nursing literature contains little relating to Irish intellectual disability nursing, with publications on the subject only beginning to appear after 1997. Sheerin (1998) alluded to the role of the intellectual disability nurse as an educator and skills-trainer in relation to decision-making for parents who have an intellectual disability. He has also suggested that nurses have a role in advocating on behalf of their clients, within the context of social exclusion (Sheerin 1999; Sheerin & Sines 1999).

Further understanding of the nurse's role may be drawn from the official documents that have been produced in Ireland in recent years. *The Commission of Inquiry of Mental Handicap* (Department of Health 1965), proposed the role of 'mental handicap' nursing to involve the "(a) treatment and care of the severely handicapped of all ages; (b) treatment, care and training of the lower ranges of moderately handicapped children; and (c) treatment, care and training of moderately and mildly handicapped adults" (p.136). Furthermore, it suggested that nurses' specific skills were in relation to managing intermittent illness and emotional crises. The context for these roles was suggested to be within residential centres where "those who cannot live in the community…use their limited ability to best advantage…and…lead as full and happy lives as their disabilities will permit" (p. 104). As noted in a later report (Department of Health and Social Welfare 1983), both *qualities* of kindness, humanity and dedication, as well as *expertise* in relation to training and skills were necessary characteristics of nurses.

This report on the *Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland* (Department of Health and Social Welfare 1983) made no contribution to describing the actual role of the intellectual disability nurse, but, rather, set out parameters for the proposed role of educationalists in meeting the educational/training needs of these clients, the implicit assumption being that nurses would not contribute to these needs.

The *Needs and Abilities* report (Department of Health 1990) continued the educational strand of its predecessor and redefined what had been termed ‘mental handicap’ in the context of ‘intellectual disability’, thus moving the framework away from the biomedical and indeed bio-psycho-social models towards a psycho-socio-educational one. This reflects the manner in which service philosophy in the UK changed some ten years earlier (Sines 1995), and in Scandinavia and the United States twenty years previous to that (Nehring 1994). In considering the living requirements of people with intellectual disabilities, *Needs and Abilities*, similarly to the *Report of the Committee of Inquiry into Mental Handicap Nursing and Care* (Department of Health 1979) in the UK, proposed community based residences. It also proposed the need for some common training amongst those who would work in such residences, with an emphasis on practical home making skills. It is unclear as to whether the authors of this report saw a role for a specialised intellectual disability nurse in these areas.

The first Irish official document to explicitly examine the intellectual disability nurse - *the Report of the Working Group on the Role of the Mental Handicap Nurse* (Department of Health 1997) - reaffirmed the place of the specialist nurse in services for people with intellectual disabilities. It is of concern, though, that the philosophy which the working group employed was that which has underpinned a syllabus of nurse training (An Bord Altranais 1993), which, although revised, was initially set out in 1985, and appeared to reflect a strong biomedical bias, as evidenced by the inordinate content of biological subject matter. The report's linkage to this philosophy and absence of any functional definition of the nurse's role decidedly reduces its contribution to the overall debate.

With respect to the changing character of service provision, and with the continued move towards community based residences, it is unclear as to whether or not the current syllabus actually prepares the nurse to meet the competencies as outlined above. This is anecdotally supported by the fact that only 7619 (30%) of people with intellectual disabilities are located in residential services (Barron and Mulvany 2004), whilst the Department of Health (1997) suggests that 1561 (81%) of intellectual disability nurses work in residential care settings. If this is the case, then it appears that the skills and knowledge of the intellectual disability nurse may be seen to be most appropriate to meeting the needs of those intellectually disabled people who are in residential care settings. This is further supported by the increasing tendency of service providers to address community-based provision in more generic terms, and to employ a variety of personnel in these posts (Government of Ireland 1998).

1.4 Identifying the Focus for Research

In view of this, it appeared that any research study aimed at identifying the focus of intellectual disability nursing should be carried out within the area in which the majority of such nurses are working, that is, residential services. This may, however, be a somewhat simplistic and myopic view, for it does not take account of the possibility that there may be a radical change imminent. The re-focusing of nurse education programmes on community, rather than hospital-based services that occurred in the United Kingdom has not yet occurred in the Irish context. This may be due to the structure of the nurse training system here, where schools of nursing have remained strongly linked to traditional residential services. Whereas the An Bord Altranais has designated specific clinical placement experiences for student nurses, the schools of nursing have sought to have these fulfilled within their associated service areas.

Thus, the vast majority of student nurses' clinical experience is within residential care, and may be seen by employers to be of limited relevance to the community situation (Government of Ireland 1998). The recent realisation of the *Commission on Nursing* recommendation (Government of Ireland 1998) that pre-registration nursing education should enter into third-level institutes, may result in a similar re-focusing of nurse education programmes on community care as was the experience in the Northern Ireland situation when, in 1997, nurse education moved from the colleges of nursing to higher education. Mindful of the demographics mentioned above, it would appear that, with the continued shift towards providing intellectual disabled people with community based living, the role of the nurses in this field will be further called into question unless the relevance of their contribution is explicated and is found to be responsive to the changing demands of the client group.

It is clear from what has gone before that there is an immediate need for defining the essence of intellectual disabilities nursing, through the identification of the specific phenomena that are the focus of nursing intervention in that area. These interventional foci will represent a base upon which to conceptualise that discipline.

1.4.1 Aims

The aim of this thesis is to explore the usefulness of employing standardised nursing terms to describe current clinical nursing practice in Irish residential intellectual disability services.

The research section is prefaced by comprehensive accounts of the literature on nursing terminology and related fields, and on the development of intellectual disability nursing practice. This will provide a contextual perspective within which the terminological description of nursing may take place.

The research section attempts to answer the following questions:

1. ***What are the interventional foci of nursing in residential intellectual disability services?***

There have been a number of attempts to describe the role of intellectual disability nursing in Ireland (Department of Health 1997, Eastern Regional Health Authority 2003, Bruton 2003). These have, however, tended to result in generalised statements which added little to the understanding of what the actual contribution of nursing is in intellectual disability services.

2. ***What is the current contribution of nursing in residential intellectual disability services?***

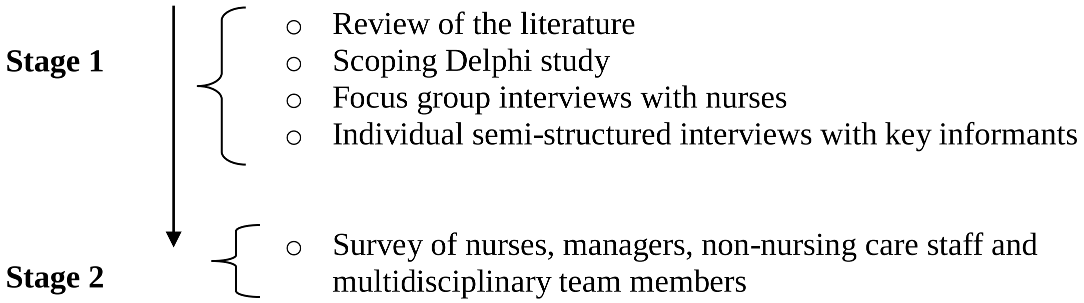
No studies as yet have addressed the description of intellectual disability nursing from an empirical perspective. The use of standardised language as a tool for describing the actual interventional contribution of nursing may provide a basis for a clearer consideration of the potentially unique role of this branch of the profession.

3. Is the nursing terminological approach useful for describing the unique contribution of nursing?

The use of standardised language to describe the contribution of nursing in intellectual disability services may provide a means for describing the foci of nursing across care settings. This may prove to be an invaluable tool in the development of a discipline of nursing that responds meaningfully to a dynamic health service across institutional and community residential services.

In answering these questions, the study involves a two-stage design (Figure 1.2). The first stage is qualitative in methodology and investigatory in nature, seeking to provide a grounding upon which the second, quantitative survey may be based. The rationale and specific methodologies employed are discussed separately in chapters 3, 4 and 5. Findings will also be presented in their respective chapters, with the analysis and findings from the pan-organisational survey presented in chapters 6, 7 and 8. The overall findings will be discussed in the final chapter, chapter 9, with recommendations made for nurse education, service provision, nursing practice and future research.

Research Design



Stage 1

- Review of the literature
- Scoping Delphi study
- Focus group interviews with nurses
- Individual semi-structured interviews with key informants

Stage 2

- Survey of nurses, managers, non-nursing care staff and multidisciplinary team members

Figure 1.2: Research design for the study.

CHAPTER 2

Literature Review and Rationale for the Study

This chapter will discuss the professional nursing literature that is pertinent to the questions that are being addressed in this study. It will first examine the development of terminology-based approaches to describing nursing and will then proceeds to examine the interventions of intellectual disability nursing practice as well as those client issues which these interventions seek to address. The literature will be examined for evidence of any prior usage of standardised terminology in relation to these issues/interventions.

This review will form the basis for describing current knowledge of the unique contribution of nursing to residential intellectual disability service provision. It will also inform further stages of the study.

Three databases were searched – Medline, the CINAHL and PsychInfo – spanning the period 1982-2005. Official documents and other published materials were also employed in this review.

2.0 Introduction

There have been, throughout the past 40 years, dramatic developments within nursing, with the advent of clinical nurse specialist (Bousfield 1997, NCNM 2004a) and advanced nurse practitioner roles (Sutton and Smith 1995, NCNM 2004b); expansion of practice (An Bord Altranais 2000); movement from apprenticeship-type training to degree-based education (An Bord Altranais 2005b); and initiation of a research agenda (Department of Health and Children 2003a). These developments have seen nursing move from being a largely subservient, practice-oriented, discipline towards being a profession with a balance of both practical and academic endeavour (Savage 1998).

One focus has remained constant throughout the ages of nursing however, and indeed, may be traced back to Nightingale and beyond: that nursing must be describable (Nightingale 1860). Amongst the rationales for this is that if nursing cannot name the issues with which it is concerned then it can never achieve autonomy or recognition for what it contributes to care (Clark and Lang 1992), and that the identification and classification of nursing diagnoses are key criteria along the road to full professional recognition (Carpenito 1995).

This literature review examines the development of standardised language and terminological systems in nursing. It then considers the role of nursing in relation to the care of persons with intellectual disability, and explores the employment of standardised language to describe intellectual disability nursing.

2.1 Using Standardised Language to Describe Nursing

The 1947 opinion that nurses diagnose was a milestone in the realisation that there was more to nursing than subservience and that nurses did not only follow others' decisions, but, rather, made decisions themselves (McGuire 1991). Furthermore, these decisions were *diagnostic* in nature, implying that nurses possessed a specific body of knowledge that was pertinent to the specific problems that they encountered (Carpenito 1995). The focus of academic investigation honed in on two questions regarding nursing diagnosis: 1) what do nurses diagnose; and 2) how do nurses diagnose?

2.1.1 Diagnosis as a Part of Nursing

The concept of diagnosis, within health care, and to a degree in general usage, is casually identified as being synonymous with the medical decision-making process. Indeed, the Oxford Paperback Dictionary (2002 p.222) defines diagnosis as “a statement of the nature of a disease or other condition made after observing its signs and symptoms”. Outside of health care, however, diagnostic tools are employed routinely by technicians and others for the identification of problems with various equipment and systems. Within health care, there appears to be some acceptance of the fact that many of the professions allied to medicine do diagnose, but only within their specific area of competence. The combination of the terms ‘nursing’ and ‘diagnosis’ is, however, fraught with political undertones, for it appears to challenge the diagnostic role of the medical profession (Gordon 1994). The reasons for this are unclear, but may be rooted in the fact that the scope of nursing practice has, historically been poorly defined, and has often coincided with that of medicine. This reality has been acknowledged in the evolution of nurse practitioners who are, in fact, carrying out ‘medical interventions’, but from a nursing perspective, and, it has been suggested, with more satisfactory outcomes than junior doctors (Sakr et al 1999).

The nursing diagnosis movement was formalised by the creation, in 1973, of the National Conference Group for the Generation and Classification of Nursing Diagnoses, which held its first annual conference that year. Later, in 1982 this was to combine with its Canadian counterpart to form the North American Nursing Diagnosis Association (NANDA), aimed at defining, refining, and promoting a taxonomy of nursing diagnostic terminology. This has been the focus of NANDA’s work for 28 years and has resulted in the development of an expansive and widely-used nursing taxonomy. There have, however, been criticisms of NANDA’s approach, and of the concept of nursing diagnosis, itself. Specific criticisms of the NANDA taxonomy came from Kim and Camilleri (1984) (cited in Clark et al 2000), and related to: 1) inadequate scope; 2) need for greater clarity of diagnosis concepts and definitions; 3) issues related to reliability and validity; 4) concerns regarding clinical utility; 5) absence of wellness diagnoses; 6) inadequacy of the conceptual model. Clark et al (2000) concur that the taxonomy does not meet the criteria for internal and external validity, but note that the Nursing Diagnosis Extension Classification (NDEC) project is addressing these issues. Further criticisms that the work of NANDA is based on an American view of nursing (Lützén and Tishelman 1996,Hogston 1997) is, again, being addressed by the NDEC project through the provision for satellite sub-projects to be run on, an international basis, with populations not readily provided for under the United States health care system. The evolvement of NANDA International is also an attempt to increase cross cultural diversity.

2.1.1.1 What Do Nurses Diagnose?

Nurses make diagnoses and assign diagnostic labels to decisions regarding phenomena that are the focus of nursing interventions (International Council of Nurses 2001). This is of particular importance as such diagnoses are the basis for choosing appropriate therapeutic outcomes and interventions (NANDA 2003).

Early attempts to describe the boundaries of nursing, within which the phenomena of interest are contained, were conceptual in nature, and led to descriptions of the four-part metaparadigm of nursing – person, nursing, health, environment (Fawcett 1995). Such descriptions were, however, grounded in theory and were defined only in the context of what nursing theorists believed about the key concepts. A more practical approach to explicating what the phenomena of interest to nursing were, emerged within the context of scope of practice.

Scope of nursing practice may be best understood within the context of the definition of nursing in use in a specific geographical region (An Bord Altranais 2000; ICN 2001). Thus, some of the earlier attempts to define the phenomena upon which nursing interventions were based were heavily influenced by Abdellah (1959) and Henderson (1966). Later attempts focused on the human responses to actual or potential health problems as seen in the functional health patterns (Gordon 1993), the human response patterns of Taxonomy I (NANDA 1992) and the International Classification for Nursing Practice (ICN 2001). These have reflected the shift in the focus of nursing away from nursing activities and towards clients' problems (Gordon 1994), a shift expressed in the 1987 definition of nursing promulgated by the International Council of Nurses:

> Nursing, as an integral part of the health care system, encompasses the promotion of health, prevention of illness, and care of the physically ill, mentally ill, and disabled people of all ages, in all health care and other community settings. Within this broad spectrum of health care, the phenomena of particular concern to nurses are individual, family, and group responses to actual or potential health problems. These human responses range broadly from health restoring reactions to an individual episode of illness to the development of policy in promoting the long-term health of a population.
>
> (ICN 1987 cited in ICN 2001 p.ii)

In the context of the above, it may be deduced that nurses make clinical judgements about those "individual, family or community responses" (NANDA 2003 p.263) that are pertinent to "the area of attention as described by social mandates and professional and conceptual frameworks of professional nursing practice" (ICN 2001 p.iii). This is, therefore, subject to regional and cultural variability.

2.1.1.2 How Do Nurses Diagnose?

Early models of decision-making in nursing involved the systematic identification and naming of the essential parts of nursing – problems, interventions and goals (Hunt and Marks-Maran 1986). It has been observed above, however, that the parts of nursing which are identified and named at any one time, are largely determined by what is considered to be important at that time. Thus, until recently, descriptions of nursing centred on what nurses did, with particular emphasis on conformity in relation to the actual activities that were employed (Savage 1998). This task-oriented, biomedical, approach is considered to have been "reductionist, mechanistic, and dualistic" (Savage 1998 p. 2), leading nurses to focus on a set group of activities which were to be used in a ward or hospital in relation to the presentation of a generalised problem. It is, however, not unanimous that the biomedical model was inappropriate for nursing. Indeed, McKenna (1996) recognises its importance "in the battle against illness and disease" (p.29), a view cautiously shared by Arementout (1993).

The consequence of the traditional relationship between nursing and medicine was that modern nursing developed within the context of a model, which emphasised diagnosis, treatment and cure (Holden 1990, Reed and Watson 1994). Health care was thus viewed from an illness, or problem focused perspective, and was addressed using the scientific deductive methodology inherent in the nursing process (Gordon 1994) (Figure 2.1).

The similarities between this four-part problem-solving approach to nursing care (Hunt and Marks-Maran 1986, Gordon 1994, Pesut and Herman 1998, Aggleton and Chalmers 2000) and that which is found within the illness-oriented medical model (Hope et al 1989) are evident from Figure 2.2.

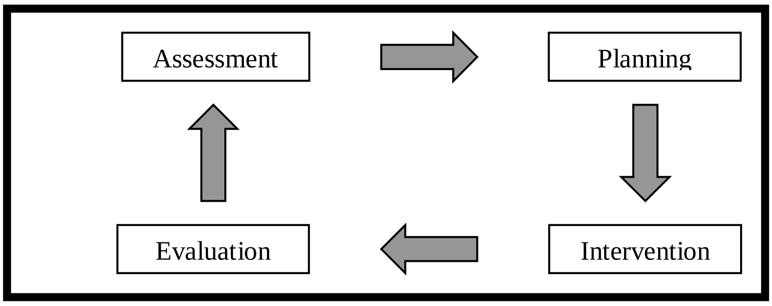


Figure 2.1: Diagrammatic representation of the nursing process
(Aggleton and Chalmers 2000)

This scientific approach, which became popular in the mid-twentieth century, could be viewed as an attempt to formalise the cognitive process of problem solving, and by doing so, to improve the professional profile of nursing within the nurse-doctor relationship. However, as is reflected within the literature, the written evidence of this cognitive process – the care plan – was frequently not properly completed and, thus called into question the appropriateness of such an approach to nursing care (Henderson 1982, De la Cuesta 1983, Brider 1991, Gwozdz and Del Togno-Armanasco 1992, Howse and Bailey 1992, McCrae 1993, Davis et al 1994, Fonteyn and Cooper 1994). Henderson (1982) suggests that a major shortcoming of the process of nursing was that, as a rational approach, it did not take account of the often irrational, intuitive aspects of nursing care, and so, created a dissonance between clinical nurses' conscious and unconscious perceptions of what they did.

Medical Model	**Nursing Process**
Assessment of Illness	Assessment of Therapeutic Problems
Planning of intervention	Planning
Treatment	Intervention
Evaluation	Evaluation

Figure 2.2: Two approaches to addressing health care

This determination to demonstrate the cognitive process that underpinned the application of nursing was further expressed by Bonney and Rothberg (1983), who used nursing diagnosis, in the 1950s as a client-evaluation tool. And although these appear to be amongst the first persons to employ nursing diagnoses, Fry (1953) is widely accepted as having been the instigator of the term.

2.1.2 Terminological Classification Systems and Data Sets

The identification and labelling of phenomena that are of concern to nursing has facilitated the development of standardised terminologies which, when sorted by rules, allow for the formation of classifications (ICN 1996). The relationship between initial concepts, terms, classifications, the data set and the ability of this information to link into documentation and other systems is presented in Figure 2.3.

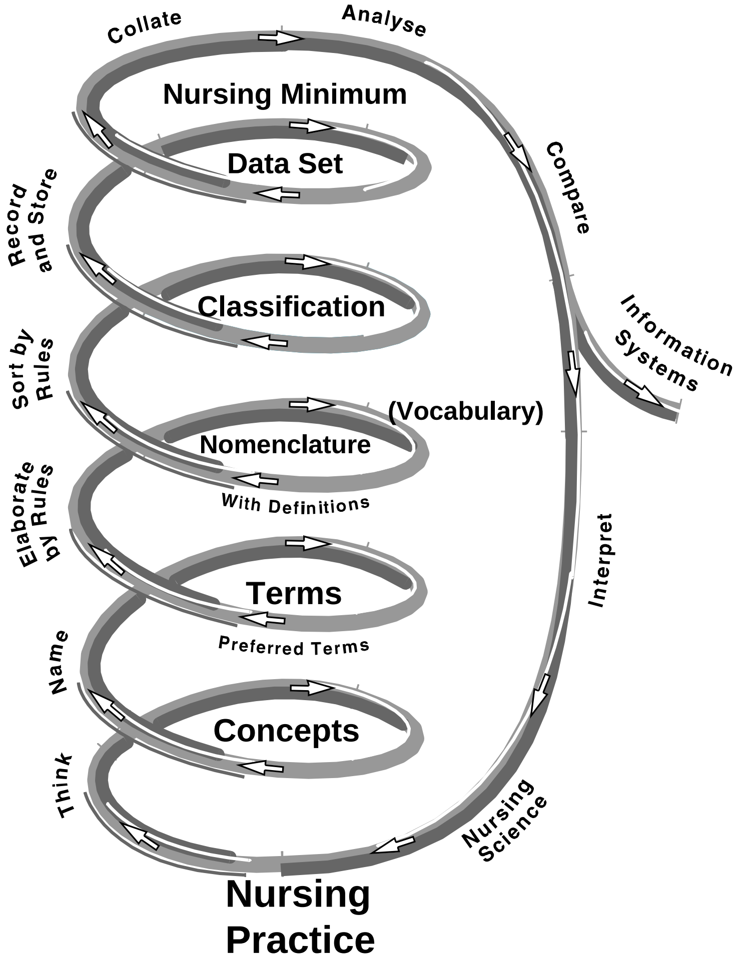


Figure 2.3: Relationship between nursing terms, vocabulary, classification and data set (reproduced from ICN 1996 with permission)

Classification systems have, for many years, been employed in healthcare as a means of categorising data according to specified groups and classes. Perhaps the longestextant example is the International Classification of Diseases (WHO 2005a), which has its origins in the 1850s, and which codes and classifies diseases and other health problems for general epidemiological and health management purposes. Another largely medical example (Christensen 2003) is the International Classification of Functioning, Disability and Health (WHO 2001), which classifies health and health related domains that describe body functions and structures, activities and participation. The potential for interaction between classifications and clinical terminologies has been identified as crucial for future work, particularly in the perspective of a growing automation of information processing (WHO 2005b).

It is suggested that the development of such terminologies and subsequent classification of same along a taxonomic structure will address the issues raised by Clark and Lang (1992), as well as presenting other advantages to nursing. Thus, Hardiker (2003) suggests that this will help to meet the “increasing and conflicting demands placed on nursing information” (p.279). It is also proposed that it will lead to “greater expressiveness and more extensive reuse of data from heterogenous sources” (Hardiker and Rector 2001 p.212), as well as improved communication with others and decision making (Hardiker et al 2002, Hwang et al 2003). Finally, the capacity for such development to generate new nursing knowledge is posited by Hardiker et al (2002) and Thoroddsen and Thorsteinsson (2002).

2.1.2.1 Terminological Developments

Whilst the original terminologies listed terms alphabetically (Gordon 1994), or hierarchically (Christensen 2003), this was considered to be an inadequate representation of the complex reality of nursing practice. Hardiker (2001), Hardiker and Rector (2001) and Hardiker et al (2002) identify two types of terminological classification systems: 1) enumerative systems and 2) combinatorial systems.

Enumerative terminology systems group terms together under a codified numerical system according to hierarchic and other pragmatic relationships. They contain terminological phrases that are pre-arranged and coordinated (for example: *impaired verbal communication*). NANDA Taxonomy 1, Nursing Interventions Classification (NIC) and Nursing Outcomes Classification (NOC) are examples of enumerative systems (Henry and Mead 1997, Hardiker et al 2002, Hardiker 2003). Bakken et al (1994) suggest that this approach to classification may not be able to represent the detail of the information that is present in clinical reality. Combinatorial terminology systems, unlike their enumerative counterparts, do not prescribe pre-arranged phrases, but allow complex terminological phrases to be developed from basic concepts. The Omaha System, International Classification for Nursing Practice (ICNP) and the Home Health Care Classification System (HHCC) are examples of such systems. The ICNP incorporates a multi-axial approach breaking down nursing phenomena and activities into seven axial components: focus of nursing practice; judgement; means; action; time; location; and client (Figure 2.4) (ICN 2005).

Figure 2.4: ICNP Seven Axis Model (from ICN 2005).

Such an approach facilitates the development of an immense number of possible combinatory phrases (Hardiker et al 2002), and is in tune with the standards for terminological models as set out in the ISO reference terminology models for nursing diagnoses and actions (Figures 2.5 and 2.6) (International Standards Organisation 2003).

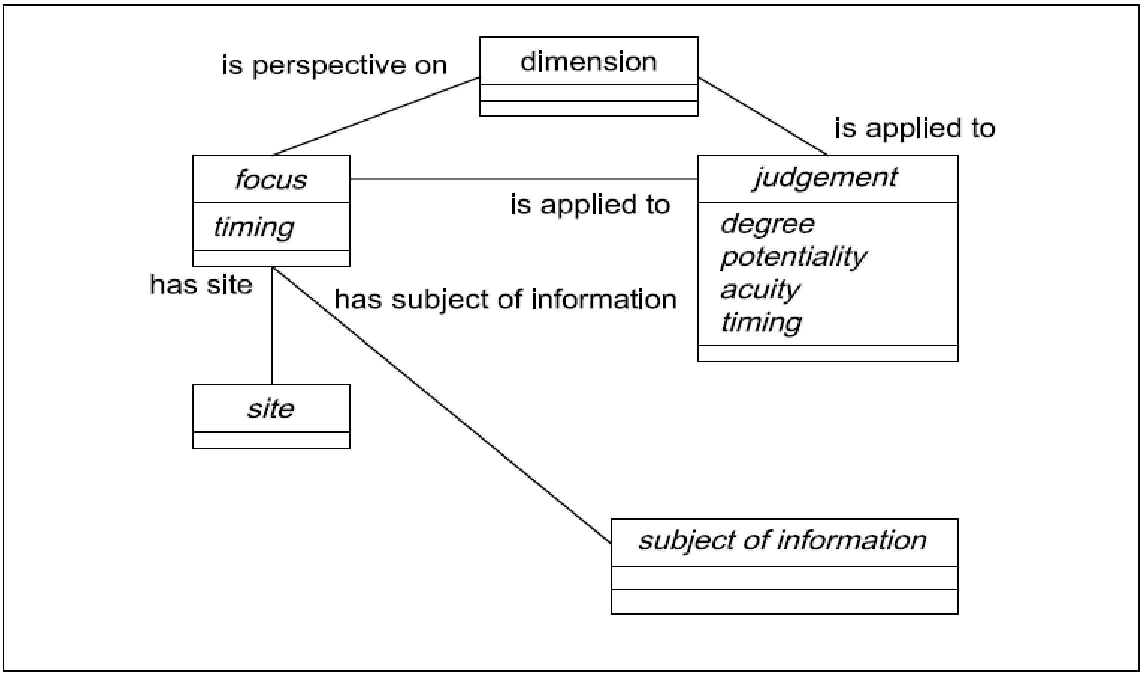


Figure 2.5: ISO reference terminology model for nursing diagnoses (from ISO 2003).

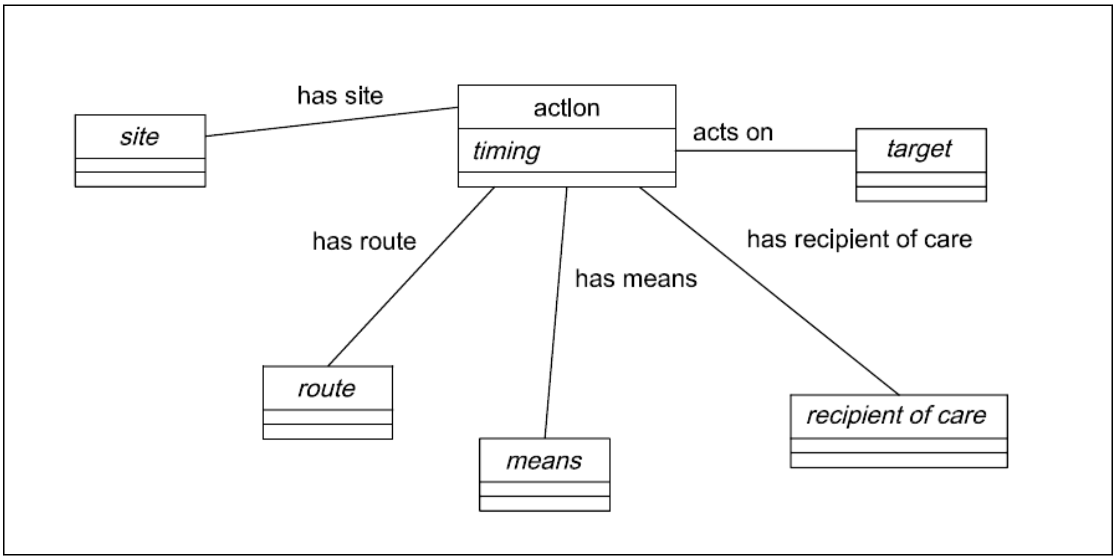


Figure 2.6: ISO reference terminology model for nursing actions (from ISO 2003).

The development of such a reference terminology model provides a basis for communication of terminological classification systems across time and geographical expanse (Hardiker et al 2000, Moss et al 2003).

Bakken et al 2000 enumerate the terminological classification systems which incorporate nursing concepts as:

- Home Health Care Classification (HHCC)
- International Classification for Nursing Practice Beta Version (ICNP)
- National Health Service Clinical Terms (NHS Read Codes)
- North American Nursing Diagnosis Association Taxonomy I (NANDA)
- Nursing Interventions Classification (NIC)
- Nursing Outcomes Classification (NOC)
- Omaha System
- Patient Care Data Set
- Perioperative Nursing Data Set
- Systematized Nomenclature of Medicine Reference Terminology (SNOMED RT)

This list has been added to, in recent years, by:

- SNOMED Clinical Terms (amalgam of NHS Read Codes and SNOMED RT) (SNOMED 2005)
- ICNP Version 1 (ICNP 2005)
- NANDA Taxonomy II (NANDA 2003)

The nursing terminology developed by NANDA, despite taxonomic criticisms, has achieved widespread usage throughout the United States and other countries (Clark et al 2000). Whilst it was developed as a classification of nursing diagnoses (NANDA 2003), its relationship to the NIC and NOC classifications has, over the past few years, been explored and developed under the NANDA-NIC-NOC linkage programme (Johnson et al 2001, McCloskey et al 2003). This has facilitated the creation of research-based links between diagnoses, interventions and outcomes.

2.1.2.2 Nursing Data Sets

The development of nursing terminological and classification systems has facilitated the establishment of nursing minimum data sets. A nursing minimum data set (NMDS) is “a minimum data set of items of information with uniform definitions and categories concerning the specific dimension of nursing, which meets the information needs of multiple data set users in the health care system” (Werley et al 1991 p.422).

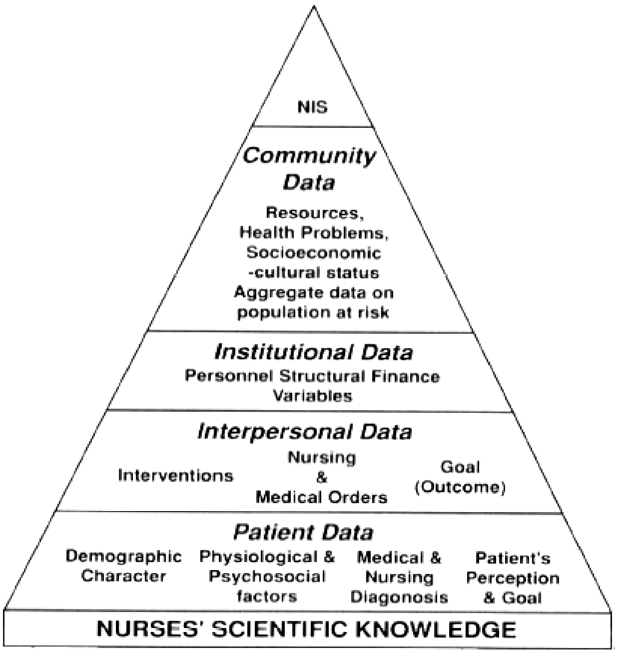


Figure 2.7: Categories of a basic nursing data set (Werley et al 1991 p.422).

Werley et al (1991) suggest that the principal categories of data in a nursing information system are as in Figure 2.7 and that the identification of such *minimum data* has the capacity to demonstrate cross-population comparisons, forecast client dependencies and plan workforce requirements (Boer and Delesie 1998). It may also stimulate nursing research and describe nursing care across settings and populations (Goossen et al 1998).

Despite the perceived advantages, the NMDS has only been operationalised in three countries, U.S.A., Belgium and France (Goossen 2002). Other countries, such as Hungary and Finland (Turtiainen et al 2000) have tested the Belgian NMDS, whilst testing of the Netherlands NMDS is ongoing (Griens et al 2001, Goossen 2002). Development work is being undertaken in a number of other countries. One of these countries is the Republic of Ireland, where a five-year collaborative study is ongoing to identify the Irish NMDS in general and mental health areas. The research literature yielded no specific information on the identification of the minimum data set for nursing persons with intellectual disability in any country.

2.1.3 Outcomes of Nursing Diagnosis

The nursing diagnosis approach developed at a time when the relevance of clinical judgement was being examined, and the need for its explication was being expressed. This was also within a context of the written evidence of this cognitive process – the care plan – not being properly completed. This is a problem that remains a concern in nursing (Henderson 1982, De la Cuesta 1983, Brider 1991, Gwozdz and Del Togno-Armanasco 1992, Howse and Bailey 1992, McCrae 1993, Davis et al 1994, Fonteyn and Cooper 1994). Apart from this improper use of documentation, "no clear and consistent language was available for use in clinical settings" (Gordon 1994 p.3). Statements of judgement or diagnosis were frowned upon within the profession, as they were seen to be within the ambit of the medical diagnostician (Gordon 1994). The introduction of a nursing terminology countered the negativity with which nursing judgement had been viewed, and provided a platform for the development of a shared language across nursing (Hyun and Park 2002).

The commencement of the language work also set the scene for further taxonomic developments, as, for example, the identification of diagnostic labels, in stating what were clinically judged to be the foci of nursing care, suggested a need for a similar identification of what were the desired outcomes of such care. Thus, the classification of nursing-specific patient outcomes was formally addressed (Johnson and Maas 1997, ICN 2001). The natural progression of the work, in providing a complete description of nursing, was to describe and classify nursing interventions (McCloskey and Bulechek 2000, ICN 2001).

Thus, nursing diagnosis has had potentially positive outcomes for supporting the documentation of nursing practice (Cho and Park 2003). It has also provided a basis for objectively addressing professional practice, by focussing *nursing* intervention on the *nursing* issues, rather than directly on the *medical* diagnoses which provide the focus for *medical* care. This has provided for the documentation of nursing accountability (Warren 1983) through the recording of nursing decisions and interventions that are grounded in research-based data. Some authors have even suggested that the evasive linkage between theory and practice may be bridged through the use of nursing diagnoses (Krenz et al 1989, Gordon 1996), thus providing a complete understanding, and *description,* of what nursing actually is.

2.2 The Contribution of the Nurse in Intellectual Disability Services

The discipline of intellectual disabilities nursing has been a reality, in Ireland, since the early 1960s, when An Bord Altranais (the Irish Nursing Board) opened the mental handicap division of the Nursing Register. Some of the main historical aspects relating to service development and to the introduction of specialised nursing have been considered in chapter 1. This section examines the phenomena of interest to nurses as well as the interventional components of the nursing role, as evidenced in the literature, and as described using both standardised and non-standardised language.

2.2.1 Describing the Issues of Concern to Intellectual Disability Nurses

The developmental work that has been carried out in an attempt to identify and classify the issues that are of concern to nursing in general has been described in the first part of this literature review. The description of such issues as 'nursing phenomena' or 'nursing diagnoses' (Gordon 1997, ICN 2005) have been based on the premise that there is a problem that requires nursing intervention, the outcome of which will represent a development, that will be perceived, by both the patient and nurse, to be positive (Beyea 1999). Whilst it is evident, from the quantity of literature on the topic, that this approach has received a generally positive response within acute general and chronic long-stay situations, it does not seem to have met with such a response amongst intellectual disability nurses. Thus, out of over 8661 references on the subject of 'nursing diagnosis' in the CINAHL, Medline and PsycInfo databases, spanning the period 1982-2005, only seven relevant papers were found in response to combining the keywords 'developmental disabilities', 'mental retardation' and 'learning disability' with the term 'nursing diagnosis' (Miller et al 1987, Hochberger 1993, Brown and Roth 1994, Gabriel 1994, Mann 1994, Chambers 1998 and Chambers 2003). It could be deduced from this that the integration of nursing diagnoses into intellectual disability nursing practice has received scant attention. If this is the case, we should first consider the reasons. Firstly, it may be related to intellectual disability nurses’ perception that their branch of the discipline is far removed from those within which nursing diagnosis and other conceptualisations of nursing arose (Turnbull 2004). Secondly, it may be due to the fact that much of the nursing diagnostic work has come from the U.S.A. where the speciality of developmental disabilities nursing was not recognised, by the American Nurses Association, until 1997 (Nehring 2004). Thirdly, as has been noted above, Mercer (1992) suggests that there has been as a progressive movement of nursing away from a medical, problem-focused approach to a more holistic, developmental one. If this is the case, the paradigmatic shift that has occurred in intellectual disabilities nursing may be of sufficient importance that it could be considered to represent a basic conceptual variance in relation to that of those disciplines of nursing in which current nursing diagnoses arose (Sheerin and Sines 1999).

Albeit lacking in quantity, the literature that is extant regarding nursing diagnosis in the field of intellectual disability does go some way towards identifying diagnoses that are relevant to that field. Chambers (1998) examined the application of nursing diagnoses, as classified under NANDA Taxonomy I, to the care planning documentation at an intellectual disability adult training unit. In this he identified a number of frequently occurring diagnostic labels. These diagnoses, which were applied to the care plans of 26 conveniently-sampled clients with severe or profound intellectual disability, are presented in Table 2.1.

Table 2.1 Frequently occurring nursing diagnoses in intellectual disability nursing (Chambers 1998)

Response Category	**Diagnostic Label**
Exchanging	Alterations in nutrition: eating less than required. Functional incontinence High risk of suffocation trauma Altered protection
Communicating	Impaired verbal communication
Relating	Self-care deficit: toileting
Perceiving	Sensory-perceptual alteration
Feeling	High risk of violence directed at self or others

This exploratory paper is limited in scope as it was carried out, with a convenience sample in one centre in the United Kingdom. Over a two-year period, the researcher introduced NANDA terms into the nursing care plan process. Westbrook (2003) has highlighted the importance of ensuring that terms, developed and used in different cultures, have the same conceptual meaning. It is not clear if any attempt was made, in this study, to explore staff’s understanding of the NANDA terms, prior to their employment. Whilst twenty-six nursing diagnoses were identified in the care plans during the data collection period, Chambers concludes that there is a need for further terms to be researched to address such areas as 'non-verbal communication'. In a later paper, Chambers (2003) expands on this specific issue to propose a new nursing diagnosis of the same name. The importance of this client problem is supported by

Mann (1994), who identifies this as an area of nursing interest in his care plan for an intellectually disabled client who was unable to take control in his daily life.

Miller et al (1987) addressed the effects of using nursing diagnoses in the care plans of a population of intellectually disabled clients in a long-term care setting. Their audit of 659 nursing care plans indicated that 66% of nurses were using complete or incomplete NANDA labels. Five frequently-occurring labels emerged from this study:

- Ineffective breathing pattern;
- Alteration in bowel elimination: constipation;
- Alteration in nutrition: less than body requirements;
- Fluid volume deficit;
- Impairment of skin integrity: actual-potential.

(Miller et al 1987)

Whilst the above diagnoses are largely related to a body systems approach, the authors did acknowledge that this would be altered by a movement away from such a viewpoint, which was being facilitated by the revision of intellectual disabilities nursing standards, which had commenced in 1985 (Miller et al 1987).

A further insight into the use of nursing diagnosis in intellectual disabilities nursing is provided by Gabriel (1994), who discussed the care of a client with developmental disability and mental illness. Although this is a non-generalisable case study, focussing specifically on dual diagnosis of developmental disability and mental illness, it is suggested that the prevalence of such illness is as high as 39% (Deb et al 2001) among adults and 42-50% (Strømme and Diseth 2000, Cormack et al 2000) among children with intellectual disability. Gabriel (1994) identified 12 NANDA diagnoses that are suggested to be relevant in the care of this client. The identified diagnoses are:

- Ineffective individual coping;
- Potential for violence, directed at self and others;

- Diversional activity deficit;
- Sleep pattern disturbance;
- Altered growth and development;
- Knowledge deficit;
- Altered thought process;
- Fear/Anxiety;
- Social isolation;
- Impaired verbal communication;
- Rape trauma syndrome;
- Impaired adjustment.

(Gabriel 1994)

Hochberger (1993), in an opinion paper, discussed the psychiatric and nursing diagnoses that are most commonly associated with intellectual disabled persons with concomitant mental illness. Eight diagnoses are identified:

- Potential for violence: self-directed or directed at others;
- Alteration in thought processes;
- Self-care deficit;
- Potential for injury;
- Alteration in nutrition: more than body requirements
- Impaired verbal communication
- Sensory-perceptual deficit.

(Hochberger 1993)

Doenges and Moorehouse (1998), in their general pocket guide to nursing diagnoses, identify diagnoses commonly associated with intellectual disability. No indication is given, however, as to how these diagnoses were arrived at. The proposed nursing diagnoses are:

- Impaired verbal communication;
- Self-care deficit;
- Risk for altered nutrition: more than body requirements;
- Impaired social interaction;
- Ineffective family coping;
- Impaired home maintenance management;
- Risk for sexual dysfunction.

(Doenges and Moorehouse 1998)

The dearth of information from the nursing literature supports the suggestion that there may be reluctance to using nursing diagnostic terminology in intellectual disability nursing documentation and parlance. Despite apparent reservations, however, it may be shown that such terminology can actually relate quite well to the nursing phenomena that are inherent in the field of intellectual disability nursing. Indeed, Brown and Roth (1994) have demonstrated clearly how they might be employed by examining their use in relation to fictitious clients. Some examples of such scenarios are provided in Figure 2.8.

Example 1	
Client:	Rita is a 25-year-old woman, who lives in a residential unit with three other women. She is very active but has no concept of danger. She is independent in meeting her own hygiene needs and is capable of feeding herself, without assistance. She has recently absconded from the unit on two occasions, but was quickly found within the locality.
Nursing diagnoses:	High risk for injury related to lack of awareness of environmental hazards (NANDA 2003, Carpenito 1995).
Nursing intervention:	The nurse will instigate environmental management: safety initiatives, as well as educational interventions (McCloskey & Bulechek 2000).
Example 2	
Client:	John is a 67-year-old man who has a very pleasant disposition, and who socialises well with those in his house and neighbourhood. Apart from having a learning disability, he also has cerebral palsy which was inappropriately managed in his youth. He has severe limb contractures and is unable to feed himself.
Nursing diagnosis:	Feeding self-care deficit, related to muscle contractures secondary to cerebral palsy (NANDA 2003, Carpenito 1995).
Nursing intervention:	The nurse will instigate self-care assistance: feeding initiatives as appropriate (McCloskey & Bulechek 2000).

Figure 2.8: Scenarios indicating the potential usage of nursing diagnoses in intellectual disability care (based on Brown and Roth 1994).

2.2.2 Describing the Interventions of Intellectual Disability Nursing

Unlike the search for nursing literature related to nursing diagnoses, the review of the literature on nursing interventions yielded a wealth of information. The reason for this may be that nursing has traditionally been a profession that has been primarily focused on ‘doing’. Thus, the nursing literature reveals much data regarding the activities that nurses carry out in respect of the problems and issues that intellectually disabled people present with. These activities are discussed within the taxonomic structure of the Nursing Interventions Classification (McCloskey and Bulechek 2000). This is a three-level structure with seven level 1 domains – physiological: basic; physiological: complex; behavioural; safety; family; health system; and community. Within each of these domains are level 2 classes under which are the level 3 interventions. For the purpose of this review, the interventions are classified under the domain structure alone.

2.2.2.1 Physiological: Basic

The physiological basic domain involves those activities of care that support physical functioning: 1) activity and exercise management; 2) elimination management; 3) immobility management; 4) nutrition support; 5) physical comfort promotion; self-care facilitation (McCloskey and Bulechek 2000). Barr (2004) and Manthorpe et al (2004) suggest that assisting clients with carrying out the activities of daily living (ADL) is a central component of the intellectual disability nurse’s role. Whilst this is a very broad focus, other authors have identified specific ADL interventions which are carried out by nurses. Issues relating to nutritional problems were highlighted in the previous section. Nurses engage in nutritional management for clients with altered nutrition (Department of Health 1995a, Bryan et al 2000, Merrick et al 2004). This may relate to the promotion and provision of balanced diets or may involve the management of anatomical or physiological disturbances through enteral feeding (Barr 2004).

Barr et al (1999), in their exploration of health screening, focused, among others, on the poor dental and oral health of people with Down’s syndrome. They identified the promotion and maintenance of good oral health as being a component of the community learning disability nurse. This study also identified other health promotional activities which contained a “physiological basic” component. Key among these were physical exercise promotion and weight management assistance (Barr et al 1999). These related to weight and cardiovascular fitness.

The report, *Continuing the Commitment*, provides further information on this interventional aspect of the intellectual disability nurse’s role (Department of Health 1995a). Amongst the interventions considered to be part of this role are sleep enhancement, managing continence, maintaining clients’ personal hygiene and ensuring physical comfort for people with physical disabilities.

2.2.2.2 Physiological: Complex

The physiological complex domain includes those care interventions that support homeostatic regulation: 1) electrolyte and acid-base management; 2) drug management; 3) neurological management; 4) perioperative care; 5) respiratory management; 6) skin/wound management; 7) thermoregulation; 8) tissue perfusion. (McCloskey and Bulechek 2000). Of the interventions that are described in the intellectual disability nursing literature two are particularly evident: managing/administering medication (Department of Health 1995a, Barr 2004, Manthorpe et al 2004, Merrick et al 2004) and management of seizures (Sines 1995, Department of Health 1995a, Mobbs et al 2002, Barr 2004, Merrick et al 2004). Medication management has been identified to comprise two components. The first of these is medication administration (Mobbs et al 2002, Barr 2004) and involves the employment of a number of routes. The second relates to the monitoring of the effects of medication, particularly anti-convulsants and tranquillisers (Department of Health 1995a; Manthorpe et al 2004). Analysis of diaries maintained by respondents in Alaszewski et al (2001) showed that activities involving medication management comprised a large component of direct care activities.

Management of epilepsy features frequently as one of the interventions that nurses employ, both from preventive and seizure management perspectives (Sines 1995, Department of Health 1995a, Alaszewski et al 2001, Mobbs et al 2002, Barr 2004).

A number of other interventions are identified in the nursing literature: measuring blood pressure (Manthorpe et al 2004); suctioning clients' airways (Barr 2004); phlebotomy (Hunt at al 2001); and pressure area management (Department of Health 1995a).

2.2.2.3 Behavioural

The behavioural domain comprises the care interventions that support psychosocial functioning and facilitate life-style changes (McCloskey and Bulechek 2000), and has as its classes: 1) behavioural therapy; 2) cognitive therapy; 3) communication enhancement; 4) coping enhancement; 5) patient education; 6) psychological comfort promotion. The intervention in this domain that emerged repeatedly from the literature related to behavioural management or, more specifically, employing behavioural techniques for the management of behaviours that may be challenging or the result of emotional difficulties (Department of Health 1995a, Gilbert et al 1998, Gates et al 2001, Mobbs et al 2002, ERHA 2003, Barr 2004, Manthorpe et al 2004, Slevin 2004, Hawkins et al 2005, Slevin and Sines 2005). It is apparent, from this, that challenging behaviour and its management is considered to be an important component of nursing practice. This is challenged by the Irish College of Psychiatrists (2004) who identify problematic behaviour to be "an important component of psychiatric disorder" (p.10) requiring management by psychiatrist-led mental health teams. Considering their view that "consultant psychiatrists in intellectual disability work in isolation, without the skilled expertise and back-up that such teams would provide" (p.13) and that "most staff in intellectual disability services do not have training in mental health" (p.13), it is implicit that intellectual disability nurses are not judged to be competent in the management of challenging behaviour.

Other interventions related to this domain were counselling clients (Hunt et al 2001, Mobbs et al 2002), management of mental illness (ERHA 2003, Barr 2004, Manthorpe et al 2004), alleviation of anxiety (Hunt et al 2001).

2.2.2.4 Safety

The safety domain includes those care interventions that support protection against harm (McCloskey and Bulechek 2000), and has as its classes: 1) crisis management; 2) risk management. One intervention emerged strongly in the nursing literature in this regard – health screening (Rose and Kay 1995, Sines 1995, Barr 1996, Department of Health 1995a, Barr et al 1999, Glasby 2000, Hunt et al 2001, Mobbs et al 2002, Hart 2003, Manthorpe et al 2004). This is a broad interventional area which incorporates many interventional components. These are not explicated in the literature, but Barr et al (1999) employed monitoring of weight and blood pressure as indicators of cardiovascular status; examination of testes and breasts as indicators of sexual health; assessment of sight, hearing and touch as indicators of sensory health; assessment of skin; assessment of mobility; and assessment of oral and dental status. The need for intervention in relation to this latter aspect has recently been confirmed in the Republic of Ireland (Department of Health and Children 2005). These were complemented by phlebotomy, where indicated. Barr et al (1999) found that the majority of clients/carers considered that community nurses for people with intellectual disabilities should conduct these screening tests. The importance of physical and mental health screening is reaffirmed by Hunt at al (2001) in their study into the effectiveness of a health screening tool. Health facilitation is also suggested as a role for intellectual disability nurses (Department of Health 2001).

Interventions related to the maintenance of client safety during epileptic seizures (Department of Health 1995a, Mobbs et al 2002, Barr 2004) and general maintenance of safety (Merrick et al 2004) were included in this domain. These have been discussed previously.

Other interventions related to safety were personal safety management (Department of Health 1995a), crisis management (Mobbs et al 2002, ERHA 2003), preventing violence towards self or others (Barr 2004) and providing first aid (Barr 2004).

2.2.2.5 Family

The family domain comprises the care interventions that support the family, and incorporate the classes: 1) childbearing care; 2) childrearing care; 3) life-span care (McCloskey and Bulechek 2000). Much of the interventional focus in the literature is on family and caregiver support (Department of Health 1995a, Department of Health 1995b, Sines 1995, Barr 1996, Jules 1996, Alaszewski et al 2001, Barr 2003, Barr 2004, Nehring 2004, Slevin and Sines 2005). Most of these papers, however, relate to the role of community intellectual disability nurses and there is little regarding this intervention with regard to persons in institutional residential care. Indeed, McConkey et al (2005) reported that families have fewer contacts with their relatives who live in campus or institutional settings than those in community residences provided by the same service agency.

Intellectual disability nurses are also reported to employ interventions for sex education (Hunt et al 2001, ERHA 2003, Hart 2003) and family planning (McRae 1997, Wilkins 2004, Morse and Roth 1994).

2.2.2.6 Health System

The health system domain comprises those care interventions that support effective use of the health care delivery system (McCloskey and Bulechek 2000) and has three classes: 1) health system mediation; 2) health system management; 3) information management. It has been recognised that people with intellectual disabilities experience difficulties in accessing health care (Department of Health 2001, Department of Health and Children 2001a, Barr et al 1999). The operationalisation of providing access to such health care has fallen, amongst others, on the shoulders of intellectual disability nurses (Turnbull 1997, Barr et al 1999, Sweeney 2004). This may take on the form of assisting clients to access services, as well as referring them on to appropriate specialists (Hunt et al 2001). Prior to referral, though, there is a need for adequate assessment to be carried out. Rose and Kay (1995) Mobbs et al (2002) and Glasby (2000) suggest that assessment of need is a key component of the nurse's interventional complement.

Other interventions associated with nursing relate to the system management aspect of practice. In this regard, some authors consider that intellectual disability nurses have a management and coordinating role, including that of leading teams of staff (Department of Health 1995a, Glasby 2000, Manthorpe et al 2004). Mobbs et al (2002), ERHA (2003) and Slevin (2004) also consider there to be nursing interventions whereby they advise other professionals regarding health care and challenging behaviour. This is supported by Sweeney (2004), and by Alaszewski et al (2001) who identified a number of axes of liaison activities between nurses and 1) other multidisciplinary team members, and 2) outside agencies.

2.2.2.7 Community

The seventh domain, labelled community, incorporates those care interventions that support the health of the community (McCloskey and Bulechek 2000). There are two classes: 1) community health promotion; 2) community risk management. Among the interventions included here are those that contribute to health and which were discussed above – health promotion and screening. One intervention, that is shared across all health care professionals, is advocating for clients who have intellectual disability. Whilst this is not specifically identified by McCloskey and Bulechek under the community domain, it may be suggested that the health of the marginalised intellectually disabled community (Sheerin and Sines 1999, Gannon and Nolan 2005) and indeed that of the wider non-disabled community would be supported by interventions that promote social inclusion (Department of Health and Children 2003b, Jenkins et al 2003, Scottish Executive 2002). One of these interventions is advocacy aimed at reducing marginalisation of intellectually disabled people (Blackmore 2001, Jenkins and Northway 2002), thus maximising their presence and participation in community (Department of Health 1995a).

Nurses also intervene to promote client independence through empowerment (Sines 1993, Sines 1995, Turnbull 1997, Scullion 1999, Barr 2004, Slevin and Sines 2005). This presupposes, though, that nurses are, themselves, empowered to perform such interventions, which may place them in conflict with other interests in healthcare (Jenkins and Northway 2002). A recent study into Irish nurses' and midwives' experiences of empowerment, would, however, suggest that this is not the case (Department of Health and Children 2003c).

In a survey of organisations representing specialty nursing groups in the U.S.A. (McCloskey et al 1998), the Developmental Disabilities Nurses Association identified

30 core interventions that are suggested to define the nature of the specialty (Table 2.2).

Table 2.2: Core interventions of developmental disabilities nursing (McCloskey et al 1998)

- Abuse protection support
- Anxiety reduction
- Aspiration precautions
- Behaviour management
- Behaviour management: self-harm
- Behaviour management: social skills
- Bowel management
- Communication enhancement: hearing deficit
- Communication enhancement: speech deficit
- Communication enhancement: visual deficit
- Developmental enhancement
- Documentation
- Environmental management: safety
- Health education
- Health screening
- Incident reporting
- Infection control
- Medication administration
- Medication management
- Multidisciplinary care conference
- Normalisation promotion
- Nutrition management
- Patient rights protection
- Seizure management
- Seizure precautions
- Self-help assistance
- Staff supervision
- Teaching: prescribed medication
- Telephone consultation
- Weight management

The nursing literature provides an insight into interventional foci and interventions that are of concern to nursing intellectual disability care. The wide range and variety of interventions is quite striking and presents nursing as a profession that can be employed within any aspect of service provision. Whilst some very specific interventions have been identified (for example measuring blood pressure), many are broad interventional headings, which would incorporate more specific activities (for example anxiety reduction). Despite the attempts of the Developmental Disabilities Nurses Association, it is not possible, however, to identify a definitive core of interventions without reference to the setting in which the nurses work and the clients that they serve.

2.3 Use of Standardised Terminology in Intellectual Disability Nursing

It has been suggested, in this review, that standardised language may have application within the branch of intellectual disability nursing, and that the employment of clear, shared terminological labels may assist in the description of the core diagnoses, interventions and outcomes around which such nursing care operates. Whilst the problem-oriented conceptual variance remains, it may be possible to address this by moving towards a more health-oriented understanding of the term 'nursing diagnosis'. Gordon (1976) had originally asserted that nursing diagnoses "made by professional nurses, describe actual or potential health problems which nurses by virtue of their education and experience are capable and licensed to treat" (p.1298). It is clear that this definition encompasses a problem-oriented approach. A more recent definition that has been employed by NANDA describes a nursing diagnosis as "a clinical judgement about individual, family or community responses to actual or potential health problems/life processes." (NANDA 1999 p.149). This approach is more inclusive than that of Gordon, focussing, not only on problems, but also on life processes. Despite its adequacy of meaning, however, the retention of the term 'diagnosis' could be perceived to be inappropriate, for, whereas Gordon (1994) asserts the need for nursing to reclaim the fact that it uses the cognitive process of diagnosis, intellectual disability nurses are increasingly identifying themselves as being essentially different from other nurses (Government of Ireland 1998, Turnbull 2004). This may be grounded in the fact that intellectual disability nurses are most frequently engaged, not in the management of illness *per* se, but rather “in social change, health promotion and public education” (Turnbull 2004 p.10). This suggests a need to move away from terminology that may be construed to be biomedical in nature.

An alternative term to ‘nursing diagnosis’ and one which will be employed interchangeably in this study is ‘interventional focus’ (Sheerin 2002, 2004). This term solely describes the identification of the issues that are to be the focus of the nursing intervention, and makes no presupposition regarding the nature of those issues in respect of functionality or dysfunctionality.

Nursing diagnosis, as an extension of the 'nursing process', grew out of a desire to explicate the cognitive processes that are at play in nursing (Gordon 1994). As such it may be argued that it has been instrumental in moving nursing on from being seen as a 'rote job' comprised of ritual tasks, towards being identified as a complex activity, encompassing very many aspects of humanity and human life, and drawing together the many and varied strands associated with such life, with the aim of reaching interventional decisions about how to address these same aspects to the benefit of their clients and humanity as a whole. It was noted by the *Learning Disability Nursing Project* that, whereas a decision-making process is employed by intellectual disability nurses, it has not lent itself to the job of describing what it is that nurses uniquely offer to intellectual disability services (Department of Health 1995a). Thus, nurses were unable to identify their contribution to such services. Nursing diagnosis provides a clear, objective approach to making decisions about client care. It also provides a clear record of such care which provides "evidence of care required, intervention by professional practitioners and patient or client responses" (UKCC 1993, 4.3). This is vital in the protection of both client and nurse from a legal perspective. It is also important for the on-going development of intellectual disability nursing, for it provides a source of information on best practice that can be disseminated among the nursing profession (Barr 1996). This is further developed in the person of the advanced nurse practitioner, who is concerned with expanding the boundaries of nursing for the development of future practice in order to enrich professional practice as a whole (UKCC 1994). This is assisted by the passing-on of practice-related knowledge both through role modelling and in recorded data. Through this, nursing diagnosis assists in the process of "identifying the discrete role played by nurses...in care" (UKCC 1993, 5.2), and thus in identifying the unique contribution that specialised nurses offer to intellectual disability services, for it serves to demonstrate the outcomes for clients (Barr 1996, Department of Health 1995a).

2.4 The Context of Care in Irish Intellectual Disability Services

Intellectual disability service provision in Ireland, has, historically, been met by voluntary organisations. These services were complimented by the development of state-run services in the 1980s. Whilst, in keeping with the practice of segregation, many of the older services were located away from urban centres, newer services have tended to be driven by a philosophy of inclusion, and have developed in urban areas with smaller residential units – community group homes (Department of Health 1990, Eastern Regional Health Authority 2003). This movement has been mirrored by some of the traditional services, which have sought to move away from the institutional model.

Various service types have developed throughout Ireland over the past century. Some of the voluntary services developed within the context of a specific religious ethos, whereas others evolved from a philosophy of inclusion and normalisation. State services derived originally from the old mental health institutions, where many people with intellectual disabilities had been located. For the purpose of this study, these were considered to be significant differences that might have resulted in variances in the role of nursing in those settings.

Following the publication of key *Report of the Commission of Inquiry on Mental Handicap* (Department of Health 1965), the diversification of services occurred at pace within the Republic of Ireland. Thus, an increase was seen in the number of day and training services for persons with moderate or severe intellectual disabilities. This focus, which was developed and continued in later reports, has resulted in a broad system of residential and day services.

Barron and Mulvany (2004) indicate that the majority of people with intellectual disability, in Ireland, do not avail of residential services, but rather live within a home setting (n=15731, 61.9%). Of the remaining people with intellectual disability, 3462 (35.8%) live in community groups homes, 3444 (35.6%) live in residential centres and 741 (7.7%) live in independent settings. Over half of the final 2038 people live in other full-time residential settings, with data not available in respect of the remainder.

There are a variety of day services provided by Irish intellectual disability services, spanning from home support, through preschool, primary and secondary education, rehabilitation and training, sheltered employment, vocational training and generic day services. *The National Intellectual Disability Database* (NIDD) indicates that these services are attended by 23645 people, 7936 of whom receive residential services too. The remaining 15709 people are day attendees (Barron and Mulvaney 2004).

The NIDD indicates that residential need will increase significantly over the period 2005-2009, with the greatest increase being in community group home placements (n=1780). In contrast, it is estimated that only a further 376 residential centre places will be required over the same period.

2.5 Conclusion

This literature review has examined the developments which have led to the standardisation of terminology employed to describe nursing and to facilitate communication between nurses and other professionals. It has been explained that, of the various terminologies, that developed by NANDA is most evident in the English-language literature. For this reason, and on account of the linkages that have been developed between NANDA and NIC, the labels incorporated in these terminologies would be employed in this study.

It has been noted that, although there is some evidence for the transfer of such developments to the intellectual disability nursing literature, this has been very limited. In order to explore the core interventions and interventional foci of intellectual disability nursing it was required to perform a broader examination of the nursing literature. This yielded thirty foci for nursing intervention and fifty-eight interventions. Whilst these provided a basis for development of a survey tool in a later part of the study, it was considered that initial exploratory work was required in order to develop a more representative list that was applicable to Irish intellectual disability services.

CHAPTER 3

Exploratory Delphi Study

3.0 Introduction

One of the principal aims of this study was to describe the interventional foci of nursing in Irish residential intellectual disability services. The literature yielded some information on where these foci might lie, but this was generally quite inadequate as a beginning point. In the absence of a body of knowledge it was decided that an initial exploratory study would be required in order to provide direction to the next qualitative and later quantitative stages of the study. In the light of this, it was considered that such a study should be conducted within a tight timescale and with minimal resource implications. The Delphi technique was chosen for this purpose as it removed the requirement for bringing persons physically together in one place and allowed for the development of a consensus-based perspective on the initial foci of nursing in this specialised field.

3.1 The Delphi Technique

The Delphi technique, which was developed by the RAND organisation in California in the United States in the late 1940s and early 1950s, has had a somewhat chequered history as a research tool. It takes its name from the mythological Apollo Pythias' Oracle at Delphi by which the Greeks were able to predict the future. The technique was originally used in a U.S. Air Force sponsored project attempting to predict the view of the Soviet Union leadership on the potential bomb requirement to neutralise strategic U.S. targets (Linstone and Turoff 1975).

There have been many attempts to define the technique, the seminal text defining it as 'a method for structuring a group communication process so that the process is effective in allowing a group of individuals, as a whole, to deal with a complex problem' (Lindstone and Turoff 1975, p.3). This raises some key points about the process: it is structured in that it systematically allows for the distribution, feedback and redistribution of information and knowledge among a group of individuals. The manner in which it achieves this, by maintaining panellist anonymity, facilitates the group in dealing with a problem that 'does not lend itself to precise analytical techniques but can benefit from subjective judgements on a collective basis' (ibid p.4). Reid (1988) furthers this definition and identifies that the panellists are usually 'experts' on the specific issue and, therefore, can offer 'informed judgements' with the aim of increasing the knowledge on that issue or to establish priorities (Bijl 1992). The technique, which has seen widespread application within the spheres of social policy development (Critcher and Gladstone 1998), forecasting and decision-aiding (Rowe and Wright 1999) has been criticised for its lack of scientific rigor. It is however considered to be best suited to investigating those issues that do not lend themselves to such empiricism and has been likened to a structured brainstorming session (Sackman 1975), permitting the development of consensus between the participants (Reid 1988). Taking all of the above concerns into account, it may be summed up as being a method of obtaining the most reliable consensus opinion of a group of experts by a series of intensive questionnaires interspersed with controlled feedback (Dalkey and Helmer 1963).

Building again on what has been stated above, the professional literature reveals a number of characteristics that are considered to be central to a classic Delphi technique.

- A panel of experts is employed as a source for obtaining the desired information (Strauss & Zeigler 1975; McKenna 1994; Beretta 1996; Keeney et al 2001). Many studies suggest that these 'experts' should be: informed individuals (McKenna 1994); specialists in their field (Goodman 1987); individuals who have knowledge about the specific subject (Davidson et al 1997; Lemmer 1998; Green et al 1999); proven track record in professional practice with considerable experience (Williams and Webb 1994). The use of such persons has, however, been queried by Strauss and Zeigler (1975) who posit that knowledgeable experts my present a biased perspective on the subject in question. They further put forward the idea that non-experts might be less subjective.
- Delphi studies are invariably conducted in writing, with sequential rounds of questionnaires interspersed and summarised results of the previous round being communicated to, and evaluated by, panel members (Strauss & Zeigler 1975; McKenna 1994; Beretta 1996; Keeney et al 2001). The presentation of the summarised group results, rank-ordered or frequency distributed, facilitates the identification of patterns of agreement (McKenna 1994).There is, therefore, a systematic attempt to produce a consensus of opinion and to identify opinion divergence (Strauss and Zeigler 1975; McKenna 1994; Beretta 1996). Consensus is, however, not an easy concept to define and has been variously set at 51% (Loughlin and Moore 1979; McKenna 1995), 55% (Payne et al 1976), 70% (Green et al 1999; McKenna and Hasson 2002) and

75% agreement among respondents (Rogers and Hector 1997). Williams and Webb (1994) suggest that, in their evaluation of published Delphi studies, the level for consensus was frequently set *in the light* of data analysis.

- Anonymity is a central tenet of Delphi techniques. Traditionally, this involves the anonymity of both panel members as well as of their statements (Strauss and Zeigler 1975; McKenna 1994; Beretta 1996; Rowe and Wright 1999; Keeney et al 2001). Some modified Delphi approaches have, however, veered away from total anonymity and have settled solely for anonymity of statements (McKenna 1989; Hayne and Pollard 2000; LeClair et al 2001; van Steenkiste et al 2002)
- Each round of the process involves a computational or analytic or iterative approach followed by a controlled feedback of analysed information (Strauss and Zeigler 1975; Beretta 1996; Rowe and Wright 1999), often with statistical aggregation of the group response (McKenna 1994).

The typical procedure for the enactment of the technique are set out by Linstone and Turoff (1975) as consisting of the questioning of a panel of experts on specific questions or issues through the use of written questions which are presented individually and simultaneously to selected respondents to answer. Panellists should have no contact with each other and will usually remain unknown to one another; these features are suggested to represent two advantages of the technique over focus groups (Reid 1988; Jairath and Weinstein 1994; Williams and Webb 1994; Beretta 1996). First round answers are scrutinised, collated and aggregated into a preliminary consensus by the researcher and this is then presented individually to the same respondents in the second round in which they are again asked to respond to the same questions. Whilst the cycle may be repeated through several rounds until an acceptable degree of consensus has been achieved, it is suggested that significant consensus may be attained during the first two or three rounds (Critcher and Gladstone 1998; Rowe and Wright 1999).

Although there were, initially, strict criteria for defining what constituted a true Delphi technique, various modifications have been made with regard to structure and focus. A perusal of the literature yields an array of labels but the main ones are listed herein:

- The *classical Delphi* comprises the four distinguishing aspects of anonymity, iteration with controlled feedback, statistical group response and expert input (Goodman 1987). It is essentially a forum for the establishment of facts (Stewart 2001).
- The *numeric Delphi* employs the essential characteristics in order to specify a single or minimum range of numeric estimates or one that makes forecasts in respect of a problem (Strauss and Zeigler 1975; Reid 1988).
- The *policy Delphi* allows one to define a range of possible answers or alternatives to a current or anticipated policy problem. In this, it is a forum for generating ideas (Stewart 2001).
- The *decision Delphi* assists with the process of reaching decisions (Rausch 1979; Stewart 2001).
- The *historic Delphi* allows an explanation of the range of issues that underpinned a specific decision or identifies the range of possible alternatives that could be posited against a certain past decision (Reid 1988).
- The *reactive Delphi*, rather than generating lists of items, explores reactions to previously prepared information (McKenna 1994).

- The *real-time Delphi* facilitates the immediate generation and distribution of responses to the panellists through the use of computer technology (Beretta 1996).
- The *modified Delphi* is an umbrella term that represents those techniques that encompass most of the key characteristics, or focus on the development of new ideas by panellists (McKenna 1994). Thus, for example, Rausch (1979), McKenna (1989) and Baldwin et al (1999) employed only anonymity of ideas, not of panellists; and Endacott et al (1999) discarded statistical summarisation between rounds.

There is an abundance of comment on the relative advantages and disadvantages of the Delphi technique. This is summarised in Table 3.1.

Table 3.1: Advantages and disadvantages of the Delphi technique.

Advantages

- Removes interpersonal factor (Reid 1988; Jairath and Weinstein 1994; Williams and Webb 1994; Beretta 1996)
- Efficiency and cost effectiveness compared with personal interviews (Polit and Hungler 1987; Davidson et al 1997)
- Useful for difficult areas which can benefit from subjective judgements on a collective basis but for which there may be no answer (Lindemann 1975)
- Ability to guide a group towards consensus and a final decision (Loughlin and Moore 1979; McKenna 1994; Williams and Webb 1994)
- Can be highly motivating for participants (McKenna 1994)
- High content and face validity on account of use of panel of experts and quest for consensus (Polit and Hungler 1987; Goodman 1987; Williams and Webb 1994)
- Can reach a large number of individuals concerning decisions (Loughlin and Moore 1979)

Disadvantages

- Lack of agreed minimum sample size (Beretta 1996).
- Absence of usual representative sampling techniques (Beretta 1996).
- Poor response rate for later rounds (McKenna 1994; Keeney et al 2001).
- Provision of too much info on first questionnaire may bias responses or limit available options (Keeney et al 2001)
- No evidence of reliability (Williams and Webb 1978; Walker and Selfe 1996)
- Illusion of expertise (Linstone and Turoff 1975).
- Lack of accountability for views expressed as anonymity is maintained (Sackman 1975).

The Delphi technique has been used extensively in many fields, including education (MacPhail 2001), walking (Tolley et al 2001) and forecasting (Slaughter 2002) among others. Whilst nurse researchers were originally slow to adopt the method as a research procedure (McKenna 1994), it has now achieved wide usage within the profession: manual handling (Love 1997); cancer care (Hitch and Murgatroyd 1983); professional development needs (Gibson 1998); priorities for nursing research (Bond and Bond 1982, Goodman 1986); seeking out the characteristics of optimum practice (Butterworth and Bishop 1995); nurse education (Twycross 2001) and psychiatric nursing (Armstrong et al 2000).

This study marked the initial investigation into the diagnostic and interventional components of the nursing role in residential intellectual disability services. As such, it was not a stand-alone study, but rather was an idea-generating exercise, aimed at feeding into the subsequent stages of the overall research. It was considered that this would be most readily and cost-effectively addressed through the use of a modified Delphi approach. In this approach anonymity was maintained between panellists and between researcher and panellists. This was achieved through the employment of an intermediary through whom all correspondence passed. He was responsible for the initial contact with panellists and for coding questionnaires, with the result that the researcher received coded, but anonymous, responses. Whilst iteration and controlled feedback remained as a central component of this approach, the qualitative nature of the responses did not permit statistical analysis, but rather was addressed through rank ordering of items. Group response was achieved through the collation and representation of questionnaires to the identified experts. Issues in relation to the identification of appropriate experts will be addressed in the next section.

3.2 Sampling Procedure

There is much discussion regarding the ideal panel size. In their review of Delphi studies Rowe and Wright (1999) identify group sizes ranging 3 to 98 panellists. Whilst Reid

(1988) describes studies with panels of 10 to 1685 individuals, Turoff (1975) recommends that the ideal group size be between ten and fifty persons.

In this exploratory study a group of eight individuals with expertise in intellectual disability nursing practice was identified. Expertise was defined on the basis that participants be registered intellectual disability nurses, have extensive (>5 years) experience of nursing in residential services, and have a strong knowledge base grounded in relevant theory or practice, evidenced by completion of or participation in appropriate graduate or postgraduate courses. The final criterion for selection was that participants be proposed by their nurse manager.

For the purpose of this preliminary study, a convenience sampling approach was employed to identify two residential intellectual disability services from which the sample would be drawn. One of these services had a long history of service provision and provided institutional residential care whereas the other had been developed, more recently, along a community-based residential model. The population, therefore, spanned the nursing staff of these two services. Correspondence between the author and each service nursing management requested that four individuals be identified who met the above inclusion criteria, and that their details be forwarded to the research assistant. This led to the development of an anonymous, purposive sample of eight individuals who were invited to participate in the study. All of the candidates opted to participate on the panel and completed consent forms (see Appendix A). An overview of the eight respondents is provided in Table 3.2.

The group of experts had a mean of 11 years in practice (range 5-15 years). The average age was 34 years (range 28-38 years). 87.5% (n=7) were female whilst 12.5% (n=1) were male.

Table 3.2: Profile of participants in Delphi study

Participant	Number of Years Since Registration	Highest Qualification	Post
1	6	Bachelors Degree (MSc Student)	Clinical Placement Coordinator
2	5	Bachelors Degree (MSc Student)	Clinical Placement Coordinator
3	13	Masters Degree	Clinical Nurse Manager 2
4	12	Masters Degree	Senior Nurse Manager
5	13	Masters Degree	Clinical Nurse Manager 1
6	9	Bachelors Degree in Nursing	Senior Staff Nurse
7	14	Bachelors Degree in Nursing	Clinical Nurse Manager 1
8	15	Masters Degree	Nurse Practice Development Coordinator

3.3 Methodology

The process of enacting a Delphi study comprises a number of stages, two of which precede the actual distribution of questionnaires and collation of responses. As Rowe and Wright (1999) have suggested that much of the consensus is achieved in the first two or three rounds, it was decided that a three-round approach would be employed (Figure 3.1).

Round 1

The first questionnaire consisted of one question which sought to elicit a listing of the phenomena upon which nursing interventions in residential services are focused. This questionnaire, therefore, simply asked the question, “What do you consider to be the issues upon which nursing interventions in residential mental handicap nursing focus?” The following example was provided as guidance: wound care nurses may focus on infection as one of their issues.

Whereas the phenomena upon which nursing interventions are based are usually described as ‘nursing diagnoses’, it was decided not to use this term, for, whereas Gordon (1994) states the need for nursing to reclaim the fact that they use the cognitive process of diagnosis, intellectual disability nurses have frequently identified themselves as being philosophically distinct from other nurses (Government of Ireland 1998), with a focus on the psychosocial aspect of care rather than the biomedical. The employment of a term such as ‘diagnosis’ which is heavily weighted in biomedics was adjudged to be inappropriate.

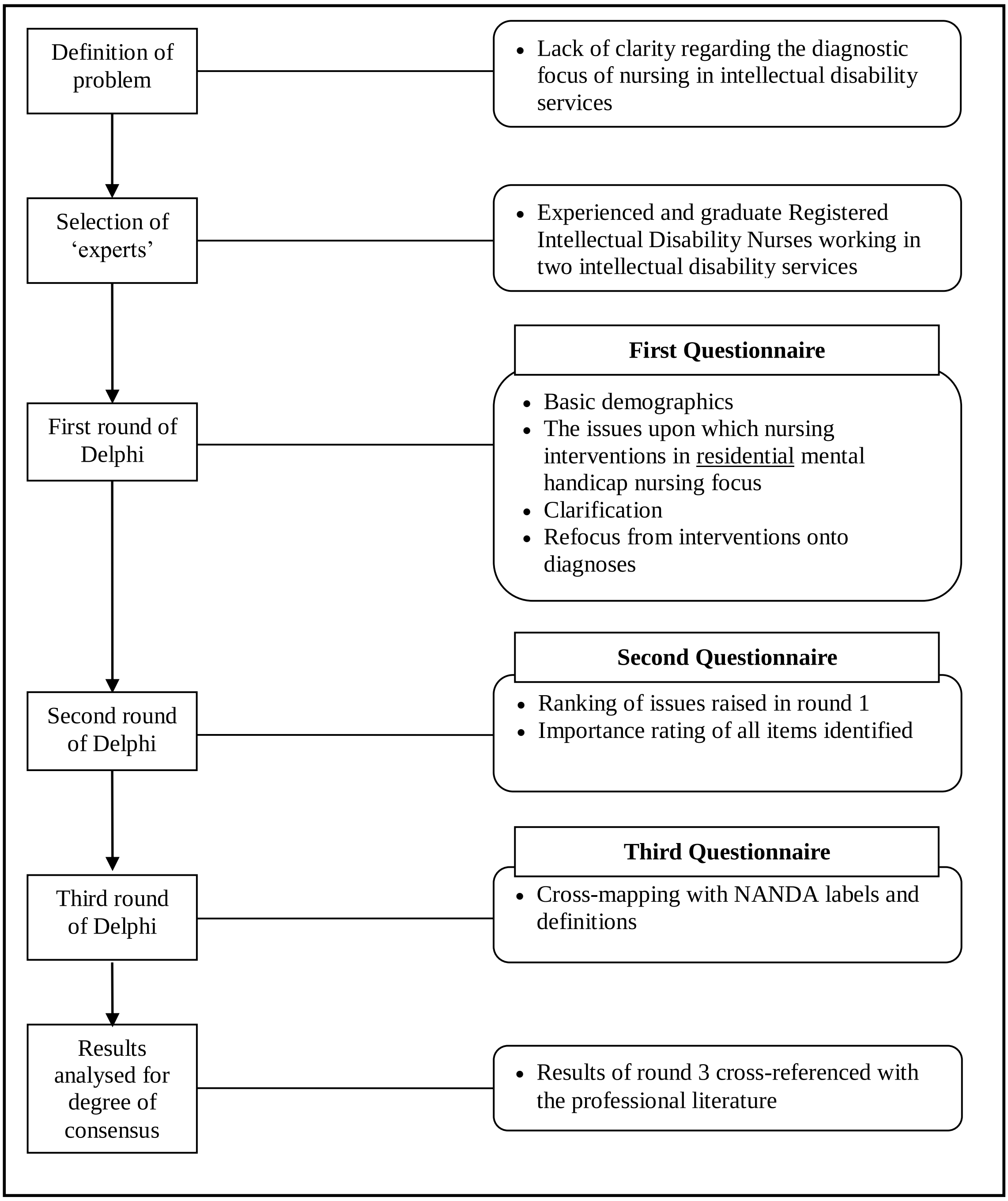


Figure 3.1: Diagrammatic representation of the three round Delphi technique employed (based on Broomfield and Humphris 2001)

In light of the conceptually biomedical nature of the term ‘diagnosis’- diagnosis, noun, is defined as ‘the identification of the nature of an illness or other problem by examination of the symptoms’ (Oxford University Press 2002, p.395) - it was considered that there was a need to move away from terminology that may be construed to be biomedical in nature. Accordingly, a new term 'interventional foci' was employed, for it solely centred on the identification of the issues that are the focus of the intervention (Sheerin 2002).

Upon receipt of the completed questionnaires, it became clear that a process of clarification was needed. This was because the participants, rather than identifying the issues that led to the employment of specific nursing interventions, instead identified the interventions themselves. The participants’ intervention-based terms were examined and broad interventional foci labels were posited by the researcher (Table 3.3). The responses to round 1 along with their associated clarifying descriptors were returned to the panellists for clarification. In this they were requested to confirm whether or not these clarifying descriptors were adequate representations of their initial responses. Upon receipt of clarification by participants a comprehensive list of all clarified descriptors identified was compiled.

Table 3.3: Round 1 responses with the researcher’s clarifying labels

Participants’ Responses	**Clarifying Descriptors**
• Basic nursing care; e.g. washing, feeding, dressing. • General Nursing • Development of living skills – bedmaking – cooking – shopping. • The ordinary activities involved in 24 hour care: bathing, feeding, cleansing, etc. promoting independence throughout same. • Looking after patients’ personal hygiene needs.	(Risk for/Actual) Inability or Reduced Ability to perform Activities of Daily Living (specify level of ability & reason)
• Promoting skin integrity.	(Risk for/Actual) Impaired Skin Integrity.
• Infection control.	(Risk for/Actual) Infection
• Identifying dietary requirements. • Looking after patients’ dietary needs, including special dietary needs.	(Risk for/Actual) Nutritional Imbalance/Altered Nutritional Need (specify reason)
• Physiotherapy; promoting use of walking aids etc. • Caring for the non-mobile and those confined to bed or wheelchair bound.	(Risk for/Actual) Impaired Mobility (functional, environmental, motivational) (Risk for) Complications of Reduced Mobility
• Identifying pre-seizure (epileptic) activity/behaviour. • Management of epileptic seizure.	(Risk for/Actual) Impaired Safety (related to seizures)
• Management of challenging behaviour. • Dealing with aggressive outbursts/ behavioural problems e.g. smearing, bullying, self-injurious behaviour. • Education and training of the client in socially acceptable behaviours etc.	(Risk for/Actual) Violence to self/others (related to Challenging Behaviour) (Risk for/Actual) Isolation and/or Rejection (related to Challenging Behaviour) (Risk for/Actual) Lack of Cooperation
• Observation of clients’ general health and maintenance of same. • Continuous observation of clients for signs of illness, distress, apathy.	(Risk for/Actual) Altered Health Status (related to specific clinical manifestations)
• Adherence to normalisation principles. • Attitudes towards people with a mental handicap. • Community integration – access to local facilities. • Provision of a happy, safe and comfortable environment, and includes staff education and training re the principles of normalisation.	(Risk for/Actual) Isolation and/or Rejection (related to Social Isolation/ Institutionalisation) (Risk for/Actual) Abnormal Living Patterns (related to Social Isolation/Institutionalisation) Lack of/Requirement for Knowledge (society)
• Dealing with those who have sight or hearing difficulties	(Risk for/Actual) Isolation related to Impaired Communication
• Meaningful engagement with clients. • Communication; verbal and non-verbal. • Dealing with those who have sight or hearing difficulties	(Risk for/Actual) Impaired Communication (intrinsic or extrinsic)
• Swimming for a small number of clients i.e. recreational pursuits. • Walks around the grounds. • Passive recreational activities – primarily T.V. • Limited social activities outside of the hospital. • Leisure needs. • Organisation of social/recreational activities in line with individual ability and preferences.	Lack of/Requirement for Exercise. Lack of/Requirement for Recreation.
• Spiritual needs.	Lack of/Requirement for Spiritual Support
• Correspondence with parents, siblings/guardians and…guidance and counselling and inclusion of parents in all decision making regarding their child.	Lack of/Requirement for Knowledge (client/family)
• I would act as spokesperson for the individual and represent the individual, family and staff concerns.	(Risk for/Actual) Inability to self-advocate (client/family)

Round 2

The second questionnaire, which comprised a list of the twenty clarified descriptors, was sent to the panellists who were asked to indicate the importance of each of the twenty interventional foci to intellectual disability clinical nursing practice. This was facilitated through the use of a three-point Likert scale, where 3 indicated ‘important to practice’, 2 indicated ‘neither important nor unimportant’ and 1 indicated ‘unimportant’. This was the basis for defining consensus. In order to distinguish those items that were considered to be important, from those that were not, a group mean of 3.00 was selected as the cut-off point. Any response item with a score equal to 3.00 and with a standard deviation (SD) of less than 1 would be included for further consideration. As a measure of variability, the standard deviation is also an indication of consensus (Broomfield and Humphris 2001). Additionally, and separately, the panellists were requested to rank order all of these interventional foci according to their relative importance in residential intellectual disability nursing practice.

Round 3

Those descriptors that had achieved the required level of consensus amongst panellists, in round 2, were used in the preparation of the third questionnaire which sought to cross-map the responses of the participants with terms from the NANDA classification that appeared to have similar conceptual meanings. These NANDA diagnostic labels and were accompanied by their associated definitions. The panellists were, therefore, requested to identify whether or not these correlated with the labels which had been allocated to their clarified responses in round 2.

3.4 Results

The responses of the participants to the round 1 questionnaire contained interesting similarities which provided a basis for immediate progress along a consensual pathway. Despite the request for interventional foci, though, most of the responses were presented in the form of nursing activities or interventions. As these were not client-focussed descriptors, the researcher attempted to clarify the inherent concepts, allowing for these to be validated by the participants. There was 100% acceptance of the clarified labels. On presentation of these clarified descriptors back to the panel, the process of rating and ranking identified those interventional foci that achieved the required level of consensus and those that were rated highly (Table 3.4). Thirteen such interventional foci were identified. These were: (Risk for/Actual) Isolation and/or Rejection (related to Challenging Behaviour); (Risk for/Actual) Isolation and/or Rejection (related to Social Isolation/ Institutionalisation); (Risk for/Actual) Violence to self/others (related to Challenging Behaviour); (Risk for/Actual) Abnormal Living Patterns (related to Social Isolation/ Institutionalisation); (Risk for/Actual) Inability or Reduced Ability to perform Activities of Daily Living (specify level of ability); Lack of/Requirement for Recreation; Lack of/Requirement for Exercise; (Risk for/Actual) Inability to self-advocate (client/family); Lack of/Requirement for Knowledge (client/family); (Risk for/Actual) Impaired Mobility (functional, environmental, motivational); (Risk for/Actual) Infection; (Risk for/Actual) Altered Health Status (related to specific clinical manifestations); (Risk for/Actual) Alteration in Eliminatory Pattern (specify bowel or bladder).

Table 3.4: Results from Delphi round 2

	Mean Score	**SD**	**Mean Ranking**	**Rank Order**
(Risk for/Actual) Isolation and/or Rejection (related to Challenging Behaviour)	3.00	.000	5.1667	1
(Risk for/Actual) Isolation and/or Rejection (related to social isolation/ institutionalisation)	3.00	.000	5.3333	2
(Risk for/Actual) Violence to self/others (related to challenging behaviour)	3.00	.000	5.8333	3.5
(Risk for/Actual) Abnormal Living Patterns (related to social Isolation/ institutionalisation)	3.00	.000	5.8333	3.5
(Risk for/Actual) Isolation (related to impaired communication)	2.87	.354	6.8333	4
(Risk for/Actual) Impaired Communication (intrinsic or extrinsic)	2.87	.354	8.0000	5
(Lack of/Requirement for) Knowledge of Intellectual Disability (society)	2.87	.354	9.0000	6
(Risk for/Actual) Inability or Reduced Ability to perform Activities of Daily Living (specify level of ability)	3.00	.000	9.5000	7
(Lack of/Requirement for) Recreation	3.00	.000	10.3333	8
(Lack of/Requirement for) Exercise	3.00	.000	10.6667	9
(Risk for/Actual) Inability to self-advocate (client/family)	3.00	.000	10.8333	10
(Lack of/Requirement for) Knowledge (client/family)	3.00	.000	11.1667	11
(Risk for/Actual) Impaired Mobility (functional/ environmental/motivational)	3.00	.000	12.1667	12
(Lack of/Requirement for) Spiritual Support	2.75	.707	13.0000	13
(Risk for/Actual) Impaired Skin Integrity	2.43	.976	13.3333	14
(Risk for/Actual) Infection	3.00	.000	13.6667	15
(Risk for) Complications of Reduced Mobility	2.87	.354	14.3333	16
(Risk for/Actual) Altered Health Status (related to specific clinical manifestations)	3.00	.000	14.5000	17
(Risk for/Actual) Alteration in Eliminatory Pattern (specify bowel/bladder)	3.00	.000	14.6667	18
(Risk for/Actual) Nutritional Imbalance/Altered Nutritional Need	2.57	.787	15.8333	19

Taking into account the contextual comments provided in response to the round 1 questionnaire, NANDA labels and definitions were suggested which would allow some degree of basic cross-mapping between the participants' responses and that terminological classification. The allocation of these terms is described in Table 3.5. The use of these terms and definitions achieved 100% agreement from the panellists.

The response rate for the study was 100% throughout, with all eight panellists completing the three rounds of questionnaires. This was surprisingly high considering the fact that such postal studies traditionally have high attrition rates (McKenna 1994; Keeney et al 2001).

Table 3.4 Suggested relativities between consensus descriptors and NANDA diagnoses (NANDA 1999)

Consensus-Based Interventional Foci	*Proposed NANDA Linkages*
(Risk for/Actual) Inability or Reduced Ability to perform Activities of Daily Living (specify level of ability & reason)	**Bathing/Hygiene Self-Care Deficit** Impaired ability to perform or complete bathing/hygiene activities for oneself. **Dressing/Grooming Self-Care Deficit** Impaired ability to perform or complete dressing and grooming activities for oneself. **Toileting Self-Care Deficit** Impaired ability to perform or complete own toileting activities. **Impaired Home Maintenance Management** Inability to independently maintain a safe growth-promoting immediate environment.
(Risk for/Actual) Isolation and/or Rejection (related to Challenging Behaviour/Social Isolation/Institutionalisation) **(Risk for/Actual) Abnormal Living Patterns (related to Social Isolation/Institutionalisation)**	**Impaired Social Interaction** The state in which an individual participates in an insufficient or excessive quantity or ineffective quality of social exchange. **Social Isolation** Aloneness experienced by the individual and perceived as imposed by others and as a negative or threatened state.
Lack of/Requirement for Recreation. **Lack of/Requirement for Exercise.**	**Diversional Activity Deficit** The state in which an individual experiences a decreased stimulation from or interest or engagement in recreational or leisure activities.
(Risk for/Actual) Violence to self/others (related to Challenging Behaviour)	**Risk for Self-Directed Violence** The state in which an individual is at risk for behaviours in which he/she demonstrates that he/she can be physically, emotionally and/or sexually harmful to self. **Risk for Other-Directed Violence** The state in which an individual is at risk for behaviours in which he/she demonstrates that he/she can be physically, emotionally and/or sexually harmful to others.
(Risk for/Actual) Inability to Self-Advocate (client/family)	**Powerlessness** The perception that one’s own action will not significantly affect an outcome; a perceived lack of control over a current situation or immediate happening. **Ineffective Role Performance** The state in which an individual demonstrates patterns of behaviour and self-expression that do not match the environmental context, norms and expectations.

(Lack of/Requirement for) Knowledge (client/family)	**Knowledge Deficient** The state whereby the client or family demonstrate an absence or deficiency of cognitive information related to a specific topic.
(Risk for/Actual) Impaired Mobility (functional/environmental/motivational)	**Mobility Physical Impaired** The state in which an individual has a limitation in independent, purposeful physical movement of the body or of one or more extremities.
(Risk for/Actual) Infection	**Risk for Infection** The state in which an individual is at increased risk for being invaded by pathogenic organisms.
(Risk for/Actual) Altered Health Status (related to specific clinical manifestations)	**Ineffective Health Maintenance** The state in which an individual has an inability to identify, manage, and/or seek out help to maintain health.
(Risk for/Actual) Alteration in Eliminatory Patters (specify bowel/bladder)	**Constipation** A decrease in normal frequency of defaecation accompanied by difficult or incomplete passage of stool and/or passage of excessively hard, dry stool. **Diarrhoea** Passage of loose, unformed stools. **Impaired Urinary Elimination** Disturbance in urine elimination

3.5 Discussion

The Delphi study was employed in an exploratory role to provide some guidance as to what the principal nursing diagnoses were in residential intellectual disability nursing care. The identification of eighteen potential nursing diagnoses and of their interventional components provided direction for the development of the interventional schedule which was later used in the focus group study.

The highest ranked interventional foci that were identified by the panellists relate to perceptions that people with intellectual disability are isolated from society and thus, experience rejection in their lives. This is compounded by the fact that the structure of service provision is often one which incorporates abnormal living patterns not in keeping with those of the mainstream society. This very point was also highlighted by the Scottish Executive (2000) in their review *The Same as You?* This situation reduces the possibility for these people to interact with others beyond their peer group and carers, and may contribute to the development of impaired communication. The emergence of challenging behaviours, expressed as violence towards self or others, to some degree, may be seen to have completed the circle, with this contributing to isolation, rejection and abnormal living patterns. It is interesting that the panellists also highly rated the lack of or requirement for society to increase its knowledge of intellectual disability. This would suggest that the group’s perception was that societal attitudes still play a role in socially segregating, isolating and rejecting people with intellectual disability (Atherton 2002). Such perceptions were similarly aired by physically disabled persons in Ireland, during the mid 1990s (Government of Ireland 1996).

The rank ordering of the interventional foci that achieved consensus maintains similar priorities, but also focuses on the self-care deficits that prevent the person with intellectual disability from achieving greater independence. These are specifically centred on the daily living activities of bathing/hygiene, dressing/grooming and toileting. Overall, the results gleaned from this study suggest that the panellists are addressing intellectual disability nursing from a social health model, with many of the issues relating, not to the condition of intellectual disability, but rather to the consequences of that state for the individual in society. This is philosophically in tune with the concepts underpinning the International Classification of Functioning (WHO 2001).

3.6 Conclusion

It is difficult to make any firm conclusions regarding the relationships between the descriptors and diagnoses as outlined above. Whilst the study was executed in a rigorous manner, this, and the generalisation of results, is significantly limited by the small sample size. The Delphi study sought to explicate the foci of nursing intervention in Irish residential learning disability nursing from the practical and theoretical knowledge of expert nurses. It has identified a number of such foci which have achieved various levels of consensus among the study participants. The thirteen that achieved a significant level of consensus were correlated by the author with validated NANDA terms, and in doing so, it achieved its aim, providing a basis of knowledge for the focus groups and key informant interviews.

CHAPTER 4

Focus Groups and Key Informant Interviews

4.0 Introduction

The Delphi study was designed to provide direction for the subsequent parts of the research study, and to provide a basis upon which a diagnostic and interventional model could be designed. It presented, however, only the perspective of eight individuals and, due to the nature of the Delphi approach, this was a consensus-based perspective which was not based on discussion or interaction.

In order to build on the tentative findings of the Delphi study, it was decided that the next stage of the research should incorporate direct contact with respondents in order to ascertain their “beliefs, attitudes…feelings, perceptions, motivations” regarding the interventional foci of nursing in intellectual disability services (Judd et al 1991. p.214).

For logistical reasons related to problems accessing respondents, this qualitative study was designed in two parts: focus groups with nurses and key informant interviews with managers.

The aim of the focus groups was to explore residential-based registered intellectual disability nurses’ perceptions of what they consider to be the foci (diagnoses/problems) for nursing interventions in residential services for people with intellectual disabilities. More precisely, this sought to find out participants’:

- understanding of the concept of ‘nursing diagnosis’ and ‘interventional focus’.
- perceptions on what the interventions appropriate to each category are,

- estimation of the relative importance of these interventions,
- judgements of what stimulates these interventions to be employed in residential intellectual disability nursing.
- experience of using diagnosis-intervention-outcome approaches in clinical practice.

The key informant interviews aimed to explore service and nursing managers' perceptions of what they consider to be the most important interventions for nurses in residential intellectual disability services, and what they perceive to be the foci (diagnoses/problems) for such nursing interventions in those services. In view of the anecdotal evidence that nursing may not have developed along the same philosophical direction as had services, this study also aimed to explore if service and nursing managers consider the *actual* foci of intellectual disability nursing to be in tune with the philosophy underpinning such services. These aims were addressed by seeking managers':

- understanding of what philosophy underpins the current direction in service provision;
- perspectives on what the principal interventions of nurses in residential intellectual disability services are;
- perspectives on what the actual principal foci of nursing in intellectual disability residential services are;
- consideration of the current relevance of nursing to residential intellectual disability service provision;
- consideration of how residential services will develop in the next 5-10 years;
- perspectives on the future relevance of nursing to residential intellectual disability service provision;
- understanding of how future residential services will be staffed.

The design and operationalisation of these qualitative studies will be presented in this chapter.

4.1 Focus Groups

The focus group has been used widely as means of obtaining “perceptions on a defined area of interest in a permissive, non-threatening environment” (Krueger 1994 p.6). It has found broad usage within healthcare (Cahill 1997, Fulton 1997, Bruce et al 1999) as well as in other fields, as diverse as rural studies (Pini 2002), information management (Parent et al 2000) and ergonomics (Bruseberg and McDonagh-Philp 2002). Its initial employment was within marketing, where it was used as a means of eliciting opinions on products, with the goal of enhancing marketing strategies. It is suggested that the focus group is useful means of gaining in-depth understanding of people’s thoughts, feelings and perceptions about issues (Basch 1987, Carey 1994, Macleod Clark et al 1997, Torn and Nichol 1998, Wallace et al 1999), and it is further argued that it has a high face validity due to credibility of comments from the group members (Nyamthi and Schuler 1990, Torn and Nichol 1998). Content validity is based on the evidence that no new ideas emerge as additional focus groups are conducted. It is also influenced by a moderation style which reduces the possibility of opinions being overtly influenced by group interaction (Carey 1994, Twinn 1998, Wallace et al 1999). As a qualitative technique, the focus group has been found to be particularly useful for exploring the complexities of a particular study topic (Basch 1987, Carey 1994, Torn and Nichol 1998).

The central tenet of focus groups is that they are conducted on the assumption that attitudes are not formed in isolation, but rather are the result of social interaction (Lankshear 1993). The focus group employs that social interaction as a means of drawing out the attitudes of a homogenous group of individuals who have undergone a common or shared experience (Fealy et al. 2000). The group interaction brings to the fore a rich body of qualitative data representing the thoughts, feelings and opinions of the participants (Holloway and Wheeler 1996). Morgan (1998) suggests that, although the group perspective is important, one must not ignore the fact that individual members of the group also have an effect on the perspective. In this, he warns against ‘psychological reductionism’.

Typically a focus group is a group interview, which brings together four to twelve key informants on a particular topic (Krueger 1994, Grbich 1999), and which takes place over a 60-90 minute period (Grbich 1999). It is usually recommended that the focus group should form part of a series of such interviews, as the conduct of a single group session may, on account of particular group dynamics, lead to atypical results (Krueger 1994).

An important characteristic of the focus group is that homogeneity is maintained within the group. Homogeneity may refer to gender (Krueger 1994), race, grade (Twinn 1998), or to study-determined key characteristics, and can be achieved by the conduct of several focus groups involving a variety of informants. The importance of homogeneity resides in the requirement for participants to be able to interact without fear, thus generating data that may be otherwise unobtainable (Kitzinger 1995, Morgan 1998, Twinn 1998). Allied to this characteristic is the consideration that participants should not know each other (Basch 1987, Stewart and Shamdasani 1990), as it is suggested that this may lead to a narrowing of the group’s perspective and may even inhibit disclosure. Morgan and Krueger (1993) and Krueger (1994) acknowledge that this characteristic is increasingly being challenged.

Whereas no previous studies, using focus groups as a means of exploring nurses’ perceptions on the focus of nursing in intellectual disability services were identified, many were located which explored perceptions on a wide range of professional issues: nursing education needs (Ayer and Smith 1998); nurse managers’ perceptions of diploma level preparation regarding skill competency (Carlisle et al 1999); implications of third level nurse educational developments on nurse teachers (Kirk et al 1997); pre-registration clinical placements for P2000 students (Jones and Akehurst 1999); exploration of the role and concept of the nurse practitioner (Torn and McNichol 1998); perceptions of the philosophy and practice or nursing (Macleod Clark et al 1997); influence of care plans on nursing (Mason 1999); and perceptions of care and services (Wallace et al 1999).

The use of skilled moderation in association with an accurate and reliable means of data recording can elicit a quality of subject perspectives that may be difficult to obtain using other forms of questioning (Krueger 1994). The method's principal weaknesses lie in its inherent group effects, which can influence the content of the discussion, and thereby threaten the validity of the data. The tendency of individuals to conform to group opinion may prevent full expression of the true attitudes and feelings of individual group members (Carey and Smith 1994, Holloway and Wheeler 1996). Group effects may also be expressed through group compliance with the views of dominant individuals (Holloway and Wheeler 1996). In the absence of skilled moderation, there may be limited control over the discussion and difficulty in managing and focussing the debate.

This study marked a continuation of the exploratory work that was initiated in the Delphi study. It, therefore, sought to further identify the foci of nursing interventions in intellectual disability service provision, but through the direct identification and exploration of the nursing interventions, instead of the diagnoses. The rationale for this refocusing was grounded in the tendency of Delphi respondents to identify interventions rather than diagnoses. This is probably related to the fact that nursing has traditionally been a profession of 'doing' rather than of 'rationalising'

(McNamara 2005). The second aim of this study was to assist in the development of an interventional questionnaire which would form the survey tool in the final stage of the research; the primary aspect of this being that a list of interventional terms would be identified and contextualised. The usefulness of the focus group in the generation of survey items is widely recognised (Hughes and DuMont 1993, Ashbury et al 1997, Ayer and Smith 1998). Indeed, Morgan (1998) specifically identifies that 'focus groups can contribute to the creation of survey items…by providing item wordings that effectively convey the researcher's intent to the survey respondent' (p.25).

4.1.1 Sampling Procedure

It is suggested that the selection of participants should be concerned with the minimisation of sample bias rather than with the generalisability of results (Krueger 1994, Morgan 1998). This is reflected in the approach used for selecting the sample, as it indicates a 'shift from random sampling toward theoretically motivated sampling' (Morgan 1998 p.35). In consideration of this, and of the fact that the target group was registered nurses working in residential intellectual disability services, it was decided that the sample would be drawn from this group. As with the Delphi study, it was decided to seek participants from both of the residential service models already identified: institutional and community. Two initial focus groups were held, one with staff from each model of service. Furthermore, as it was considered that the outcomes of this study could have had implications for nursing education, an extra focus group was held with a group of nurse educators. Although the difficulties of conducting focus group interviews with existing groups have been highlighted in the literature (Krueger 1994), it was decided that the cost involved in bringing strangers together in a neutral venue was prohibitive, and compromise was needed (Krueger 1994). Three focus groups were, therefore, conducted; one in each of three intellectual disability establishments, involving participation by nursing staff (clinical or educational) from those establishments.

There is much debate regarding the appropriate number of focus groups that should be held. It is generally suggested that this is dependent on the available time and resources (Hughes and DuMont 1993, Krueger 1994). Morgan (1998) indicates, though, that it is normal practice to hold only three to five groups, as it has been found that theoretical saturation often occurs at this stage (Glaser and Strauss 1967). The decision to undertake only three groups was taken in the light of the homogeneity of participants, a characteristic that is associated with more rapid saturation (Morgan 1998).

The initial stage of sampling involved the random selection of the two services. One of these services was located in Eastern Region of the HSE whilst the other was in the North-Western Region. A nursing school outside of Dublin was similarly selected. Having sampled the source units from which the participants were drawn, a purposive sampling approach was employed in relation to the selection of nurses within the two services. The chief executive officer was requested to organise the identification of eight individuals who matched the inclusion criteria. In order to maintain control over the sampling process, strict criteria were set regarding the selection of participants. It was indicated that the participants:

- be registered on the active Register of Nurses in the division of Intellectual Disability;
- be entered onto the Intellectual Disability division of the Register for a period of not less than five years prior to the focus group interview;
- be employed in the residential part of the service (including respite units);
- be employed in different units to other focus group participants;

- be a staff nurse (Focus Group 1);
- be a clinical nurse manager (Focus Group 2).

Selection of the source unit for the final focus group with nurse educations was similarly executed by randomly sampling one of the seven schools of intellectual disability nursing. Permission was obtained from senior management to approach the nursing tutorial staff. The criteria for inclusion for this focus group were that the participants:

- be registered on the active Register of Nurses in the divisions of Intellectual Disability and Nurse Tutor;
- be entered onto the Intellectual Disability division of the Register for a period of not less than five years prior to the focus group interview;
- be employed in the school of nursing as a nurse tutor.

All of the persons identified as prospective participants received a formal invitation to participate in “a 90-minute discussion session, aimed at exploring what the focus of nursing in residential intellectual disability services is”. Details of the meeting time and location were provided and individuals were requested to return a completed consent form to confirm their willingness to attend. One week prior to the focus groups, a reminder letter was sent accompanied by the interventional schedule that would be the focus of much discussion during the actual interview. It was hoped that, if this schedule was completed prior to the group interview, the results would be less influenced by group effects.

The first focus group involving staff nurses was attended by only six persons, as two of those who had agreed to participate did not attend on the day. All eight of the expected participants attended the second focus group which involved unit heads, whilst the third meeting with nurse tutors was attended by the four tutors in the selected school of nursing.

Characteristic	n	%
Gender		
Female	14	77.8%
Male	4	22.2%
Age Profile		
20-30 years	8	44.4%
31-40 years	5	27.8%
41-50 years	4	22.2%
>50 years	1	5.6%
Employment Role		
Unit Head	8	44.4%
Staff Nurse	6	33.3%
Nurse Tutor	4	22.2%
Experience		
5-10 years	11	61%
11-15 years	2	11%
16-20 years	2	11%
>20 years	3	16.7%

Table 4.1: Profile of focus group sample

The three focus groups elicited the responses of 18 nurses with a mean of 12.2 years post-registration experience in intellectual disability nursing. Whilst all had extensive experience of residential intellectual disability service, the mean for continuous years for those currently in such services was 4.8 years (Table 4.1).

4.1.2 Methodology

Each of the focus groups was conducted in accordance with a topic guide (see Appendix B). It has been suggested that the topic guide is a useful approach to imposing structure on the discussion and allowing for comparisons to be made between groups during the analysis (Morgan 1998). Furthermore, Krueger (1994) considers that the flexibility of such a guide allows for the moderator to react spontaneously to discussion that emerges. The topics on the guide related to the express aim of the study in exploring registered intellectual disability nurses' considerations of what constitute the foci (diagnoses/ problems) for nursing interventions in residential services for people with intellectual disabilities.

Operationalisation of the topic guide was closely allied to the use of an interventional schedule which was developed based on the interventional findings of the Delphi study, the professional literature and, in particular, the work of Kastermans and Oud (2000). The interventional schedule took the form of an initial investigation into previously identified nursing interventions in the field, with a subsequent refocusing on the issues that elicited such interventions. It presented the participants with a list of thirty interventions, which were identified as being associated with nursing in residential intellectual disability service provision, alongside a list of corresponding definitions (see Appendix B). In advance of the focus group, participants were requested to indicate the level of importance that they associated with each of the interventions on a three-point nominal scale where 3 indicated ‘important to practice’, 2 indicated ‘neither important nor unimportant’ and 1 indicated ‘unimportant’. In order to distinguish those items that were considered to be important from those that were not, a group mean of 2.75 was arbitrarily selected as the consensus cut-off point. Any response item with a score greater than or equal to 2.75 and with a standard deviation (SD) of less than 1 would be included for further consideration.

Prior to their administration, and in order to examine them for validity and reliability, the topic guide and interventional schedule were submitted to a senior nurse manager and a nurse academic, both of whom were experienced in the discipline of intellectual disabilities nursing. Two individuals with experience in the moderation of focus groups were identified and procedures were agreed between in order to ensure consistency in the conduct of the groups. These individuals were also knowledgeable in respect of the topic under examination, something that Krueger (1994) considers to be a desirable trait.

The researcher took on the mantle of assistant moderator. The responsibilities of both moderator and assistant were clearly demarcated in accordance with Krueger’s (1994) recommendations. Thus, the moderator was concerned with chairing and directing the discussion. This involved the introduction of the topic under discussion, the explanation of the group’s remit, the facilitation of discussion and the closure of the session as set out on the topic guide. The assistant moderator was responsible for the preparation and control of the environment within which the focus group took place. He also controlled the recording devices and took copious notes as well as writing participants’ comments on the flip-chart. If appropriate, and at the invitation of the moderator, the assistant engaged in the discussion on a particular aspect of the topic.

The focus groups were conducted at the three sites during July and August 2000, and proceeded according to the topic guide. Each focus group lasted a minimum of 90 minutes and elicited a rich quality of discussion. A central component of the focus group meetings was that participants would rank and rationalise ten of the interventions which they considered to be of particular importance in their work. They were also asked to identify the diagnoses that might lead to the identified interventions being employed. At the completion of each focus group there was an opportunity provided for participants to make final comments and to identify any further issues that they considered may have been pertinent to the discussion. The focus group interviews were recorded using analogue tape recording devices with hi-gain microphones. The use of this equipment was agreed by the participants and was made as unobtrusive as possible. Data was transcribed manually after the interviews.

4.1.3 Data Analysis

The analysis of qualitative data obtained during the focus groups was undertaken using a thematic content analytical approach guided by the structure imposed on the whole process by the interventional schedule. Thematic content analysis is “a procedure for analysing written, verbal, or visual materials in a systematic and objective fashion” (Polit and Hungler 1987). This was achieved through manual identification of themes pertinent to those interventions that achieved the consensus level applied to the study.

The purpose of content analysis is to develop knowledge and insight into the concept under investigation from the contextual data gathered (Krippendorff 1980). This task involves the application of a staged approach to analysis of the data collected in the focus group interviews. This consists of the selection of concepts and unit of content to be recorded; the development or adoption of a category (coding) system for classification of the units of content; revisiting of the data and refinement of coded themes in the light of contextual detail (Polit and Hungler 1987).

As this was a study of interventions, it was decided that these would be the thematic concepts which would be recorded. Rather than devising a wholly new system of classification, the NANDA Taxonomy II was chosen as the categorical structure within which the themes would be classified (NANDA 2003). This three-level system of domains, classes and nursing diagnoses was consistent with the reverse chaining of the NANDA, NOC, and NIC linkages that would provide a means of extrapolating nursing diagnoses from context-based interventions.

The transcribed interview data were placed into thematic interventional categories to allow for analysis of content. These were categorised according to similarities and differences that were noted from an analysis of the transcripts in relation to the interventional schedule. This permitted the development of ‘conceptual clarity’ in developing a perception and understanding of the data (Cavanagh 1997) thus allowing the principal themes to emerge from the data.

Further analysis was applied to the transcripts to aid in the assignment of extrapolated nursing diagnoses. The process mirrored some aspects of the diagnostic reasoning process proposed by Carnevali and Thomas (1993) with contextual cues being employed for the purpose of reaching a diagnostic judgement – the categorical output of the process.

4.1.4 Findings

The focus groups elicited a wealth of information regarding the interventions which were considered by the participants to be of importance in residential intellectual disability service provision. Discussion on each of these interventions produced further data about the problems/diagnoses which led to them being employed.

In advance of the focus group, participants were requested to consider the importance of the interventions which were presented on the interventional schedule. The results of this allowed for further consideration of the interventional foci that brought about these interventions. Eleven of the thirty interventions achieved the group mean of ≥ 2.75 (Table 4.2). These were communication enhancement, medication management, anger control assistance, shift report, seizure management, safety enhancement, emotional support, self-care assistance, documentation, nutrition management and infection control.

These interventions were further examined for contextual meaning, based on the taped and noted responses, and the potentially related interventional foci were then applied. This involved backward chaining along the nursing diagnosis-nursing intervention pathways set out by Johnson et al (2001) in their NANDA, NOC and NIC linkage work. The contextual aspect of the interventions was obtained through the key questions in the topic guide whereby participants were asked to identify the foci for the listed interventions. The relationship of interventions to interventional foci is demonstrated in Table 4.3. This relationship will now be further explored.

Table 4.2: Group means of interventions rated by participants

	Mean Score	*SD*
Communication Enhancement	2.94	.236
Medication Management	2.89	.323
Anger Control Assistance	2.88	.332
Shift Report	2.83	.383
Seizure Management	2.83	.383
Safety Enhancement	2.83	.383
Emotional Support	2.82	.393
Self-Care Assistance	2.82	.393
Documentation	2.78	.428
Nutrition Management	2.78	.428
Infection Control	2.78	.428
Communication Enhancement: Active Listening	2.72	.461
Infection Prevention	2.67	.485
Sleep Enhancement	2.61	.502
Self-Care Assistance: Toileting	2.61	.502
Self-Care Assistance: Bathing/Hygiene	2.61	.502
Medication Management: oral	2.61	.502
Presence	2.61	.502
Skin Surveillance	2.59	.507
Humour	2.56	.511
Socialisation Enhancement	2.56	.511
Security Enhancement	2.56	.511
Recreation Therapy	2.56	.511
Perineal Care	2.56	.511
Oral Health Promotion	2.53	.514
Self-Care Assistance: Dressing/Grooming	2.50	.514
Exercise Promotion	2.44	.511
Spiritual Support	2.41	.618
Teaching: Prescribed Medication	2.24	.664
Home Maintenance Assistance	2.17	.618

Table 4.3: Interventions and their corresponding diagnoses

Communication Enhancement Impaired social interaction Social isolation Altered thought processes Impaired verbal communication	***Medication Management*** Challenging behaviour Physical illness Mental illness Risk for Poisoning
Anger Control Assistance Need for communication Ineffective coping	***Shift Report*** Need for communication Need for continuity of care
Seizure Management Risk for injury Risk for trauma Altered protection Altered thought processes Self-esteem disturbance Personal identity disturbance Impaired social interaction Knowledge deficit (safety) Risk for suffocation	***Safety Enhancement*** Altered protection Knowledge deficit (safety) Risk for self-mutilation Risk for injury Risk for violence: self-directed Risk for violence: directed at others Altered thought processes Altered health maintenance Risk for trauma
Emotional Support Ineffective individual coping Social isolation Risk for loneliness Dysfunctional grieving Anxiety Impaired adjustment	***Self-Care Assistance*** Self-care deficit Altered thought processes
Documentation Need for communication Need for continuity of care Need for monitoring condition Requirement for accountable practice	***Nutrition Management*** Altered nutritional status Requirement for adequate nutrition Requirement for choice of foods Feeding self-care deficit
Infection Control Risk for infection Ineffective individual coping Toileting self-care deficit Bathing/hygiene self-care deficit	

4.1.4.1 Communication Enhancement

Communication enhancement is defined as ‘assistance in accepting and learning alternate methods for living with impaired/diminished hearing/speech/vision’ (McCloskey and Bulechek 2000. p.222-224). Many authors have identified that communication may be altered for persons with intellectual disability and may require the employment of approaches other than the verbal route (Doyle 2004, Ferris-Taylor 2003, Rooney 2002). This was similarly reflected by the participants in this study. One participant noted that:

> *...sometimes they might not be able to communicate, you know, there might be a communications problem, especially people with severe and profound learning disabilities. It's probably the most frustrating thing not to be able to communicate.*

It was suggested that this may be due to a disorder of communication, either cognitive or functional, leading to an 'inability to communicate effectively'. The presence of such communication problems results in a situation whereby needs and wants cannot be related. This may be associated with the development of other problems, including isolation, challenging behaviour and marginalisation. It was widely recognised that communication between clients and staff was vital.

4.1.4.2 Medication Management

Medication management is defined as "facilitation of safe and effective use of prescription and over-the-counter drugs" (McCloskey and Bulechek 2000. p.451). Persons with intellectual disability may, just like any other human being, need to take medications for physical and mental health conditions, such as diabetes mellitus, arthritis, epilepsy, depression, schizophrenia etcetera. Participants also identified that they may also require medications to manage acute behavioural problems. The qualitative effect of medication on a person's life was noted by one participant:

> *...medications can play a very important role in a person's life and should be reviewed on a regular basis...it can either enhance a person's life of it can take from a person's life...*

The aspect of professional accountability associated with medication management was also highlighted and it was noted that there is a "need for monitoring medication use and effectiveness" and to "regularly review medications".

4.1.4.3 Anger Control Assistance

Anger control assistance is defined as “facilitation of the expression of anger in an adaptive non-violent manner” (McCloskey and Bulechek 2000. p. 143). Anger itself may be expressed in many ways. The participants frequently cited incidents of aggressive behaviour and violence towards self or others. It was felt that, for many clients, there was an inherent inability to express anger positively, and that there was ‘a need for clients to be able to express anger and control violence’ and ‘to be able to manage anger outbursts’:

> *…we have to make it possible for them to be able to express anger in a controlled environment…is the only way they can do it.*

Central to the management of inappropriately expressed anger was the realisation that there was a need to prevent volatile situations by ‘defusing them before they start to erupt’.

4.1.4.4 Shift Report

The shift report is defined as the “exchanging of essential patient care information with other nursing staff at change of shift” (McCloskey and Bulechek 2000. p. 585). Participants were adamant that this was an important intervention, but were not able to detail the need for its employment, other than stating that there was a need for communication between staff/shifts, and that the shift report facilitated information-sharing between the staff on different shifts. It also was seen to be central to the continuity of care.

4.1.4.5 Seizure Management

It is estimated that approximately 21% of persons with intellectual disability will also have epilepsy (Frank 1994). Many of the participants indicated that they cared for clients with active epilepsy and that this resulted in the need for seizures to be managed safely as there was a risk for injury. This linked in closely with proper medication management and monitoring of the effectiveness of medications, as well as with communication enhancement as this facilitated the identification of ‘tell-tale’ signs and so was seen to increase the potential of identifying the potentiality of a seizure occurring, thus allowing safety measures to be instigated in advance of the seizure.

4.1.4.6 Safety Enhancement

Safety enhancement involves “intensifying a client’s physical and psychological safety” (based on McCloskey and Bulechek 2000. p. 571). The participants in the focus groups related the need for safety enhancement to the occurrence of intrinsic issues such as self and other-directed violence, as well as to extrinsic factors, including obsession with electrical equipment. The requirement to maintain a safe environment was particularly highlighted, especially in the light of epilepsy, challenging behaviour, pica and risk of absconding. One participant focused on the issue from the perspective of rights:

> *…it’s everybody’s right to live in a safe environment…safety from other clients without fear of assault…*

This tied in with what was described by others as the legal requirement for staff to meet their duty of care to the clients

4.1.4.7 Emotional Support

Emotional support involves the “provision of reassurance, acceptance, and encouragement during times of stress” (McCloskey and Bulechek 2000. p. 300). The reality of stress for persons with intellectual disability in residential services was repeatedly raised during the interviews. For some the stress was associated with the experience of loss following admission to residential care:

> *…a lot of the clients we work with are moving out from home for the first time…and it's a big change in their lives and they're living with nine other people that they don't know… they may not be sure of the reason why they're here…*

Others related it to the lack of opportunity for friendships within residential services:

> *… sometimes people with LD don't even get the opportunity* [for friendships]*…they live in a residential unit…they meet the staff in that unit…they go to the day service and meet the staff in that day service…they go to a social club organised by the organisation and meet volunteers there, and then come back home to the residential unit.*

Many other issues were identified as being factors in the causation of emotional stress: significant changes in person's life; bereavement; loss of items important to person; poor home contact. The common thread running through all of these was that clients were often not able to cope with the stress that they imposed on their lives.

4.1.4.8 Self-Care Assistance

Self-care assistance is defined as "assisting another to perform activities of daily living" (McCloskey and Bulechek 2000, p. 575). All of the participants identified that their clients required assistance in one or more of the self-care areas: bathing/hygiene; toileting; dressing/grooming; feeding. It was recognised that a key role of the nurse was to help the client to increase his independence in self-care.

> *It is very important for the clients to be able to do as much as they can for themselves.*

This focus on independence was linked to the development of self-esteem and also to the increased potential for integration and acceptance by others in society.

4.1.4.9 Documentation

Documentation entails the "recording of pertinent patient data in a clinical record" (McCloskey and Bulechek 2000. p. 260). This intervention was set within the same context as ‘shift report’. Thus, it related to consistency and continuity of care in environments where communication channels may not be ideal. The importance of documentation in the development of a patient record was noted by one participant:

> *It’s necessary to look at the client’s past to let it guide what you’re doing at the moment…point you in a particular direction.*

This, therefore, helped to build up a record of care. It was suggested, though, that many nurses considered there to be too much emphasis on documentation, and that this was taking up a significant proportion of nurses’ time. This had to be balanced, though, against the legal and professional requirement for record keeping.

4.1.4.10 Nutrition Management

Nutrition management involves “assisting with or providing a balanced dietary intake of foods and fluids” (McCloskey and Bulechek 2000, p.474). The requirement for nutritional management was stated to stem from two main directions: the dietary requirements of the person’s body and the functional inability of some clients to take in food. Thus, for some people there is:

> *An inability to feed self due to physical disability…*

…whereas for others:

> *…particularly people that you wouldn’t know, they may be finicky eaters and it’s very important that they have their nutrition needs met*

The risks of inappropriate nutrition were identified as including constipation, malnutrition and obesity. Medical conditions, such as diabetes mellitus and phenylketonuria also determined the nutritional makeup of the diet.

4.1.4.11 Infection Control

McCloskey and Bulechek (2000) define infection control as “minimizing the acquisition and transmission of infectious agents” (p.398). The reality of having a large number of clients living in close proximity was considered by participants to increase the potential for infection spread. This was accentuated by poor hygiene standards among some clients. The need for proper screening of clients was highlighted:

> *…if you have 5 individuals coming in; you could have 5 children coming in from home…so first its very important to note, to check on everyone as they come in…*

Allied to screening was the need for “good hygiene standards” among staff in order to prevent outbreaks and to protect both clients and staff.

The contextual information provided in relation to the employment of the above eleven nursing interventions allowed for the identification of thirty-three potential nursing diagnoses (Table 4.4). The definitions and locations of each of these diagnoses under NANDA Taxonomy II structure (NANDA 2003) are provided in Appendix B.

4.2 Key Informant Interviews

This study sought to explore both nurses and managers’ ideas of what they considered to be the most important interventions for nursing in residential intellectual disability services, and what they perceived to be the foci for such nursing interventions. Whilst it was relatively easy to organise focus groups with nurses and nurse educators from specific institutions, it was not readily possible to bring service or nurse managers from various services together in a single venue without significant costs being incurred. It was also identified that the commitments related to such positions would deter from them being able to come together at one point in time. For this reason, therefore, it was decided that key informant interviews would be conducted with service managers and clinical nurse managers who had responsibility in residential intellectual disability service provision.

Table 4.4: Nursing diagnoses extrapolated from the identified nursing interventions

Nursing Diagnoses

Ineffective Health Maintenance
Risk for Imbalanced Nutrition: Less than Body Requirements
Risk for Imbalanced Nutrition: More than Body Requirements
Constipation
Risk for Constipation
Dressing/Grooming Self-Care Deficit
Bathing/Hygiene Self-Care Deficit
Feeding Self-Care Deficit
Toileting Self-Care Deficit
Knowledge Deficit (Safety)
Disturbed Thought Processes
Impaired Verbal Communication
Disturbed Personal Identity
Risk for Loneliness
Risk for Situational Low Self-Esteem
Risk for Chronic Low Self-Esteem
Interrupted Family Processes
Impaired Social Interaction
Anxiety
Dysfunctional Grieving
Impaired Adjustment
Ineffective Coping
Risk for Infection
Risk for Injury
Risk for Trauma
Risk for Suffocation
Ineffective Protection
Risk for Self-Mutilation
Self-Mutilation
Risk for Other-Directed Violence
Risk for Self-Directed Violence
Risk for Poisoning
Social Isolation

The individual interview with key informants offers a number of advantages over other self-report techniques such as questionnaires and focus groups. Judd et al (1991) and Polit and Hungler (1987) suggest that the former offers the interviewer the ability to manage any misunderstandings on the part of the respondent, to elicit further detail where responses are vague or lacking in detail and to allay any concerns that the respondent may have. It also gives the interviewer a greater degree of control over the order of questions and the context of the interview. The interpersonal nature of the interview encourages the development of rapport between the two parties, thus motivating the respondent, and drawing out information that might be difficult to gather by other means. Operationally, the individual interview technique can achieve very high response rates, with rates greater than 80% reported (Judd et al 1991).

Finally, Morgan (1997) suggests that it may be more effective than focus groups in obtaining in-depth understanding of a person’s opinions and understandings as it permits detailed exploration of one person’s responses, rather than those of a group.

There are, however, some disadvantages associated with individual interviews. One group of problems relate specifically to the interpersonal context of the technique. The interviewer often approaches research with expectations of what outcomes may result. Whilst such expectations may not have a significant effect on the responses of persons who are responding to a well developed questionnaire, they may profoundly influence those of respondents in the face-to-face context, which is often charged with the synergies of interpersonal rapport. Similarly, the personal characteristics of the interviewer (race, gender, professional or academic profile) may influence respondents’ answers, leading them to provide socially acceptable contributions to meet the perceived expectations of the interviewer (Judd et al 1991). Individual interviews are often associated with high cost. This is a particular disadvantage where the respondents are scattered over a large geographical region, requiring travel and subsistence costs for the interviewer (Judd et al 1991).

In view of these factors, and conscious of the aims and objectives of the interviews, it was decided that one service manager and one clinical nursing manager would be interviewed in each of four residential intellectual disability organizations. These were chosen according the sampling procedure set out below.

4.2.1 Sampling Procedure

Participant organisations were chosen based on the division of intellectual disability residential services (NAMHI 1999) into four groups defined according to situation (rural; urban) and model of residential provision (institutional; village/community). The four resultant groups were: rural institutional; urban institutional; rural village/community; urban village/community. One organization was selected randomly from each of these groups. Initially all four organizations agreed to participate in the study. The final one, however, despite many attempts to arrange meetings, had to be abandoned at a very late date, leaving it most difficult to find a replacement organization.

The residential components of the three organizations were as follows:

Service 1: A city-based campus-style residential village complex, providing residential service for 320 clients. There is also an associated community house service providing residential service for a further 530 clients. Traditional staffing structure of multidisciplinary nature, with nursing and care assistant positions on the 'front line'.

Service 2: A rural-based service with community-based residences and supportive living programme. Minimal evidence of multidisciplinary staff structure. Significant use made of community health services. Staffed by house parents and team leaders, some of whom are nurses.

Service 3: Large city-based former residential institution with current campus-based village complex, providing residential service on site. Traditional staffing structure of multidisciplinary nature, with nursing and care assistant positions on the 'front line'.

Purposive sampling was employed in the selection of participants. The chief executive officer of each organisation was requested to facilitate the identification of one non-nursing manager and one nursing manager who matched the inclusion criteria. In order to maintain control over the sampling process, strict criteria were set regarding the selection of participants. It was indicated that the managers:

- be employed in a senior management role
- be employed in a management role for not less than five years prior to the interview;
- be employed in the management of the residential part of the service;

It was indicated that the nurse managers:

- be registered on the active Register of Nurses in the division of Mental Handicap (nursing managers)
- be entered onto the Mental Handicap division of the Register for a period of not less than five years prior to the focus group interview;
- be employed in the nursing management of the residential part of the service;
- be clinical nurse managers (grade three) or directors of nursing.

All of the persons identified as prospective participants received a formal invitation to participate in “a 1 hour discussion interview” aimed at exploring service and nursing managers' perceptions of what the focus of nursing is in residential intellectual disability care. Dates for the meetings were suggested such that both the service manager’s and nursing manager’s interviews could be held on the same day. This militated against the cost-related disadvantage of individual interviews. One week prior to the interviews, the participants were contacted to confirm arrangements. The participant characteristics are presented in Table 4.5.

Characteristic	n	%
Gender		
Female	4	66.67%
Male	2	33.3%
Age Profile		
31-40 years	3	50%
41-50 years	2	33.3%
>50 years	1	16.67%
Employment Role		
Service Manager	3	50%
Nurse Manager	3	50%

Table 4.5: Profile of personal interview sample

Key informant interviews were carried out with six persons of whom 50% (n=3) were service managers and 50% (n=3) nurse managers. All had extensive experience in intellectual disability service provision.

4.2.2 Methodology

The semi structured interviews were guided by an interview schedule (see Appendix C), which was loosely based on that used in the focus groups, with specific emphasis being placed on the interventions and foci or nurses in residential intellectual disability services. Following consultation with colleagues, however, it was decided that questions relating to the place of nursing in current and future service provision should be included. This is especially important as residential service provision and the philosophy underpinning such provision has changed considerably over the past two decades and is likely to change over the next two, with “greater emphasis on integration at school, work and in the community” (Government of Ireland 1998 p.173). Furthermore, the increasing employment of non-nursing personnel in hitherto ‘nursing’ posts is a sign of change (Government of Ireland 1998). In the light of this and conscious of the study's aim to examine nurses' and service manages' perceptions of what the foci of nursing within residential intellectual disability services are, it was considered that these additions were appropriate.

Interviews were conducted by the researcher, during the months of May and June 2001. Field notes were supplemented by the use of an analogue recording device, the employment of which was agreed, in advance, by interviewees. Data were transcribed manually after the interviews.

As a result of these interviews, data were collated on perceptions regarding, residential service provision, staff to client ratios, staffing structures, client groups and characteristics, skill mix, nurses, intellectual disability nursing and recruitment. The results of the investigative studies have been used in the development of the questionnaire to be used in the main 'pan-organisation' survey.

4.2.3 Data Analysis

Following transcription, the data was submitted to thematic content analysis as described in section 4.1.3. Seven thematic categories were identified.

4.2.4 Findings

Whereas the Delphi and focus group studies had elicited information that was specifically related to nursing diagnoses and interventions, the key informant interviews were less specific in this regard, providing more contextually important information. The tendency for interviewees to focus on these issues was noted by the researcher early in the process and, in consideration of the perceived importance of this information, it was decided that a substantial proportion of the interview time would be allocated to the discussion of these issues.

The interviews elicited a rich body of information which provided a contextual background against which to further examine the focus, and indeed, contribution of nursing within intellectual disability services. The thematic content analysis identified five key themes, namely: residential service provision; staff-client ratios; staffing structures; nursing; and recruitment.

4.2.4.1 Residential Service Provision

Interviewees were asked to comment on how, and to what degree, the residential service in which they worked had changed over the past few decades. All respondents confirmed that significant changes had occurred, but it appeared that, the developmental stage was related to what was in place when the development commenced. What emerged was a continuum of residential service (Figure 4.1).

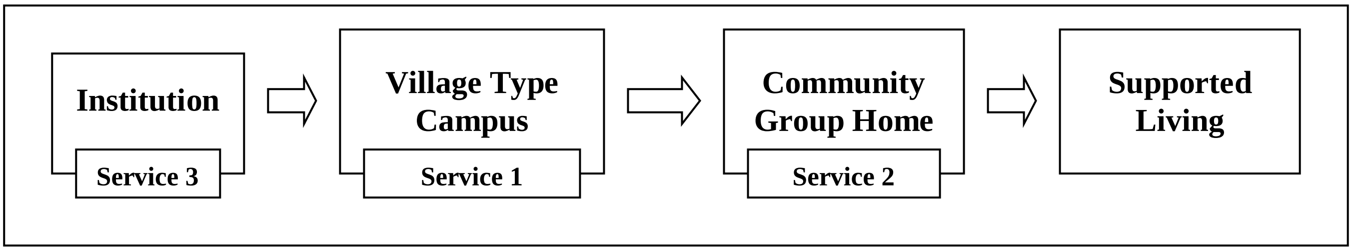


Figure 4.1: Starting point of each service on the residential service continuum.

Interestingly, each of the three services commenced from a difference starting point.

The Nurse Manager in Service 3 (NM3) indicated that the differences which she had seen in service provision had resulted in a move from group to individualised care:

> *Back then where there was a communal approach even to clothing, you know personal items - well that has now been moved on…to a more individualised form of care…things were maybe more task orientated… now we're trying to involve individualised programmes for the client given the age group that they are at now. We had a younger client population, but now it's much older.* (NM3)

The experience of an ageing population in residential care is not exclusive to this service and is identified as being a national phenomenon (Mulvany and Barron 2003). The difficulty and appropriateness of changing residential service provision for an ageing group is implied in the nurse manager's comments that they are "trying to involve individualised programmes" and it appears to have been a factor in determining the direction of development:

> *We have built a 12-bedded unit that actually is for high dependency care and palliative care… a natural progression as opposed to anything else. It's their home, and they have the supportive care here rather than in…an open general hospital.* (NM3)

This was in recognition of the fact that greater longevity may carry with it an increased dependency on others and increased morbidity.

Whereas the age profile of a client group may have an effect on service development, it was suggested by the Service Manager in Service 1 (SM1) that other client characteristics might determine the environment in which they reside:

> *Some clients, because of their challenging behaviour, inappropriate behaviour, sometimes because of sexual assaults, and again we're talking about a very small number, maybe the order of 5-10%, we have had to put back into the village-type complex.* (SM1)

The movement of clients with such characteristics to community group homes represented a service development which was noted by his nursing colleague:

> *There would have been 10 service users living in a bungalow here, and that number has reduced by 4.* (NM1)

The development of community-based residences appears to have been accelerated by an influx of clients from mental health services as a result of Irish Governmental policy (Department of Health and Children 2001a):

> *As the people came from the psychiatric hospital into the village complex, the people who were there already went into the community-based services. So, we have seen that very major shift with a very big group of people over the last 15 years or so.* (SM1)

The move to the community is argued by SM1 to have been qualitatively positive for clientele:

> *One of the questions that I ask, when they talk to me, is if they would consider moving back into village, and under no circumstances would they consider it at all; they just see it as a time of great deprivation in their lives.* (SM1)

Service 2 had, as its starting point, a community group home structure. This appeared to affect its perspective on community integration with health services being accessed within the community, unlike those of Service 3 which remained relatively centralised and specialised:

> *If people need psychiatric assessments, they go the same as you or I or anybody else would go to get psychiatric assessment…we never had the institutional identity; we never had the stringent guidelines and rules that go with institutions and I think that has been beneficial to the agency.* (NM2)

And again:

> *Why wouldn't we just use the public health nurse? I mean, there's a generic system out there. Why would you replace that?* (SM2)

This perspective facilitated movement further along the service continuum towards a goal of full integration of clients in the community, with mainstream support systems and services being accessed to meet clients' needs and personal preferences. Significantly, this development incorporated 'staffing' characteristics that were markedly different from those in the institutional and village models, with the institution of increasingly generic roles.

> *We've developed a community supportive living programme, whereby we have a community support worker who goes in and spends 'x' amount of time per week depending on the needs that the individuals have.* (NM2)

Whilst the structure of service provision varied between the three services, it appeared that there was a shared philosophical underpinning, however differently interpreted by each service. This philosophy was, at its most basic, grounded in individualisation…

> *I see an irresistible drive forward toward the individualisation of services* (SM1)

(although there was no clear explanation of what the interviewees meant by ‘individualisation’)

> *I think it’s looking at people, at individuals as individuals…person centred plans* (NM2)
>
> *…to preserve each unique individual, you know the uniqueness of each individual* (NM3)
>
> *These people require typically one-on-one support and I'm saying there's no rationale for putting them all together.* (SM2)

…at its most complex, in the five service accomplishments as expounded by O’Brien and Tyne (1981) cited in Race (2002).

> *To enable the clients to achieve their best potential…quality of life is the actual philosophy underpinning that…O'Brien's 5 values is at the core of this.* (SM3)

One interviewee was adamant that a number of central concepts underpinned quality service provision. Amongst these were inclusion, choice and rights.

> *We need to work much harder from an inclusive perspective.* (SM2)
>
> *To me best practice in the field is not about sticking everybody in group homes from a residential perspective. It is about having a range of options; allowing people to be as independent as they possibly can be.* (SM2)
>
> *The days of any of us with professional qualifications and expertise being able to dictate how the service is to be provided is gone...people will vote with their feet, and people will have the rights and they'll have the legal system, and the country will and already has the resources to be able to ensure that people really do have a choice.* (SM2)

These concepts are key, recurrent themes in the professional literature (Jenkins et al 2003, Northway and Jenkins 2003, Race 2002, Department of Health 2001, Richardson 2000). Placing these qualities at the core of care provision was argued to lead to greater discernment and potential within services:

> *So, once you do that with one aspect of the service I think then…you start to question other areas.* (SN2)

The significance of the paradigm shift that has taken place in intellectual disability services is evident from the direction that these services are expected to take in the medium-term, for at the core of the interviewees' forecasts is greater individualisation, choice and human rights.

> *Looking at our supported living programme in 10 years time you'd be as likely to see someone with a most significant disability living in their own apartment, with tailor-made individualised supports, as you would be a person with a mild intellectual disability…it's already on our agenda to say 'why aren't we looking at supported living for people with challenging behaviour, even for people with significant medical difficulties'.* (SM2)
>
> *Very many of us are still stuck if the idea of a 5-bedded group home is as innovative as we can be. Within the next 10 years…we will move away into supporting people living in individual apartments with support going into them, and maybe in, couples, I would say increasingly couples, getting the level of support they need, which might be someone going in to cook their dinner, or might be someone to help them to phone the pizza parlour in order to get the pizza sent in or whatever. (SN1)*
>
> *Residential services would be much more about supports to individuals rather than programmes, like group-homes programmes, or even a supported living programme, and that they'd be much more individualised, tailor-made.* (SM2)
>
> *I feel that complex services like this are going to become redundant by default.* (NM1)
>
> *I think we're going to have a lot more people out in supportive living, and I think we're going to be a lot more innovative in how we deliver that service.* (NM2)

The importance of persons with intellectual disability staying within their own family unit was also highlighted, but it was noted that services would have to change to provide support to these families.

> *I think we're probably going to get into in-home support in general in a bigger way and I think the other thing that probably needs to be developed is a better support network in general for families.* (NM2)

It was further suggested that, when it is not possible for people to remain with their families, the family model should be maintained as much as possible.

> *We will see more family-based alternatives…alternative family-like scenarios for people.* (SM2)

It is interesting to note that the interviewees within the institutional residential service saw the possibility of supported care developing in their service, albeit in the longer term.

> *I would see people and partners in, maybe, apartments, where people might be able to transfer out to that, and eventually maybe go to their own place. I have no doubt, a lot of the clients that we have in the community at the moment could actually be supervised from afar in their own homes, in a different setting.* (SM3)

The major developments that were forecast for the following ten years were centred on moving clients from converted institutional units to bungalows on a village-type campus, and from those units out into community group homes.

> *The long term plan is to build smaller type bungalow settings for smaller residential groups, so its more smaller groups and more individualised care.* (NM3)
>
> *I have no doubt that people even from the challenging behaviour unit here will go out into the community, have a trial period, see how they get on, maybe transgress back in again.* (SM3)
>
> *Maybe the ideal situation might be that there'd be two houses together; one might have direct supervision and the other one would have it from afar. And I mean this is where I can see someone with challenging behaviour realising their potential, is to have their own space, their own apartment, and who knows what. Care is there if its required, but from afar.* (SM3)

Within one part of the service, the client profile demanded that elderly care facilities be developed centrally.

> *I would see more respite, palliative care, and possibly Alzheimer day care.* (SM3)
>
> *We have to plan the bungalows around care of the older person.* (NM3)

4.2.4.2 Staff-Client Ratios

The movement from institutional units to group homes, whether campus-based or in the community, has implications for staffing, for, whereas it was noted that institutional unit with up to thirty clients might be staffed, during the morning time, by only six carers, the smaller bungalows or community houses had a much more favourable client staff ratio.

> *We have five houses at present, and the maximum number* [of clients] *in any house is five, the average is four. And each house has its own transport and each house has two staff members.* (NM1)
>
> *Each house has an allocation of 4 nurses for six clients and that is a very high allocation of nurses in any community house because we are going to move forward into the community, but we cannot change the present needs of our service users.* (NM1)
>
> *When I started first there was only 6 residential houses and there were six people in each house. Since that we have obviously acquired much more property and we've reduced the numbers within the houses, and the most we have in any house is five, and that's in only one house now, and with two staff. All the other houses have 5 or less.* (NM2)

The development of community based residential services has led to a change in the staffing characteristics with more flexibility being required in caring roles and a movement away from traditional ‘nursing’ activities in favour of more normative home-building work. This has resulted in a situation whereby there are now more care staff than nurses working in community residential services.

4.2.4.3 Staffing Structures

The issue of how services are and might, in the future, be staffed raised interesting perspectives that suggested a variance between nursing and non-nursing managers. It was recognised that some services had historically developed along a more medicalised model:

> *I think that there is a difference between our service and other services that would have a lot more input by Health Boards and who have traditionally trained nurses…they would have a huge focus on nurses within their service.* (NM2)

In the village campus setting, however, nurses were also considered to be central to the provision and supervision of care within newly introduced care structures:

> *There has been the introduction of 'autonomous teams' with team managers taking responsibility for certain areas within the complex itself. At the moment there's five autonomous areas within the complex one specific to people with challenging behaviour, one to people who have physical-sensory disabilities, one in relation to our community houses, one in relation to a training-prevocational unit, and the other in relation to our respite services.* (NM1)

Non-nursing care staff were seen to work within the context of nursing care and referred back to nursing as their ‘point of reference’:

> *In social and recreational activities,* [care staff] *would work by themselves...but they know the nurse is only two doors down…in the sitting room or whatever. In the residential bungalows…it’s very much care practices, good nursing care.* (NM1)

It was noted that these two groups of staff were engaged in shared activities that were not performed by other grades of staff. Within this relationship, care staff worked in a supportive role to nurses who were responsible for maintaining standards of care:

> *It’s…a mixture of nurses and care staff...* (NM3)

…with nursing…

> *...more about…directing client care.* (NM3)

It was suggested, though, that the perceived need for front-line nurse leadership could be related to the client group or the fact that nurse training occurred at that centre.

> *Always a staff nurse is working alongside a care assistant, and maybe two care assistants and one staff nurse, and all team managers are actually nurses. But I would have to add that within this complex we are dealing with*

> *people who have severe learning disabilities - all of our population have a severe learning disability. I think that's one of the reasons why we have so many nurses as well as the fact that* [the centre] *started off as a school of nursing.* (NM1)

The proposed relationship between the primacy of nursing care and severity of clients' intellectual disability is interesting and, if it could be shown that clients with more significant disability were located in institutional and village-type services, it would provide some explanation for the apparent centralisation of nursing around these services.

There was general agreement amongst informants that some degree of skill mix was required:

> *Yes, I fundamentally agree that we have to have skill mix.* (SM3)
>
> *I think it'll be staffed more non-nursing, with a supervisory role, yet at the same time keeping the watchful eye on it so that still things will be going according to plan, with less nurses and more care assistants.* (SM3)
>
> *Less supported and more integrated, much more integrated into the 'normal' environment, with the preschools, primary schools...So maybe the nurse mightn't be so involved with those group. My visualisation would be the community learning disability nurse visiting them.* (NM1)

Nurse managers, however, expressed some concern regarding what they saw as a movement away from nursing in residential services, with suspicions that this move might be intentional:

> *But I think yes, in terms of the generic service I do think that it is going to move that way. I think that it will be people with relevant qualifications. I'm not sure if they're creating generic posts because it's so difficult to get nurses, or whether they just don't want nurses.* (NM2)
>
> *I think the diversity of people working in the areas…on a personal basis I don't think its good, and I feel that the new methods for advertising for posts…carry no clarity whatsoever and I feel that that's one of the reasons why nurses are not applying.* (NM1)

Further insights into this perceived deviation away from nurse-led care emerged during discussion on the topic of nursing.

4.2.4.4 Nursing

Specialist registered intellectual disability nurses (RMHN/RNID) have been of crucial importance to the provision of care throughout the past forty years providing " a range of services across a wide variety of locations to meet the particular, complex and difficult needs of their clients" (Government of Ireland 1998 p.171). Despite its purported aim, the Report of the Working Group on the Role of the Mental Handicap Nurse (Department of Health 1997) did not provide any detailed insight into what these nurses actually do contribute in terms of interventions. The suggestion that nursing was central to service provision did not meet with unanimously agreement amongst informants. A number of core nursing skills were identified (Table 4.6).

Table 4.6: Core skills of intellectual disability nurses

Management	*Coordination and organisational skills* *Arranging clinical appointments* *Observation* *Setting and maintaining standards* *Leadership* *Knowledge* *Planning* *Programme planning, development and evaluation* *Innovative* *Staff management* *Workload management* *Advocacy*
Communication	*Liaising with interdisciplinary team* *Counselling* *Ability to listen* *Intuition*
Care Provision	*Maintain client personal hygiene* *Prevention of pressure sores* *Maintaining dental and gum hygiene* *Caring for the hands and feet* *Managing epileptic seizures* *Observing and managing physical and mental illnesses,* *Infection control* *Physiotherapy - postural drainage, suctioning* *Meeting complex feeding needs - peg feeds* *Administering medication* *Performing dressings* *Catheterising clients* *Colostomy and urostomy care*

Home Making	*Therapeutic touch* *Developing clients' skills and abilities*

It is evident from this that nurses were considered to have two main aspects to their role: management and care provision. The balance between these two areas appeared to be related to two factors: the client group and the residential model:

> *I think nurses who work in residential services would see themselves primarily as there to do the nursing duties and I think that if you're moving people to houses where there isn't a particular need for a nurse, then yes, I think they will be asking questions 'why am I going there?' but again I think this is getting back to the fact that I think, you know, if there isn't someone who needs some medical intervention, then why do you need a nurse there?* (NM2)
>
> *There are certain areas that we need nurses to provide the medical model of care, which we have got to do in certain situations. In terms of the residential services where we'd say there wouldn't be people with significant nursing needs.* (NM2)

In this latter setting, the balance would appear to rest on management with the other aspect 'home making' becoming more important. It is curious that none of the informants identified nursing skills within this area. This may be explained by the fact that nurses have, in recent years, been advised against becoming involved in 'non-nursing duties' by the main nursing union, the Irish Nurses' Organisation (INO). This development might have had a bearing on decisions about where nurses would be employed:

> *When I saw lists coming out from the INO of non-nursing duties, it would make your hair...you would turn around and ask 'what are nurses for?' you'd wonder 'are they just there for pen pushing and giving drugs?'* (SM3)
>
> *When I hear them saying 'it is not my job to lift a tray to feed a patient', I nearly cringe. I can't understand how nurses could be demarcated like that.* (SM3)

Furthermore, the unions' advice to nurses during the national strike in 1997 augmented this question for service managers:

> *I was horrified during the nurses' strike that the only thing that our nurses (and I fully supported them to be on strike - I have no difficulty with that) had to do in terms of emergency cover was to come and give medication, and I was saying to them 'are you telling me that your union has brought your level of expertise down to giving somebody a tablet - that's what I need you for - is that what you're telling me as CEO' because I think that's terrible but that was it. That was the emergency cover - go in and give the tablets and walk out the door again. And for someone like me as CEO, what's the message there? I can find other people who can give tablets and get them qualified and then I would not need nurses at all?* (SM2)

Reflecting on the list of interventions that were ascribed to nurses, informants agreed that these activities were not unique to nurses:

> *There's very little they do that another group can't do.* (NM2)
>
> *For example, catheterisation can be carried out by a non-nurse; feeding through a tube can be carried out by a non-nurse; even medication in community houses in many circumstances is now being carried out by non-nurses.* (SM1)

They did consider, though, that nurses carried these interventions out in a unique way:

> *I think it's a different way of putting things together, yeah. I think you gather it along the way, and when you know the whole being.* (SM3)
>
> *It's the ability to put all the bits of the jigsaw together and to make it all fit, if that makes sense. It's to kind of see the bigger picture.* (NM2)
>
> *I'm aware of some non-RNMH trained registered nurses, and would be aware that they do bring a kind of focus around the illness…or an undesirably regimented medication regime, for example, where it could be done much less formally and less officiously, whereas the RNMHs tend to do it in more of an holistic way.* (SM1)
>
> *The traditional* [nursing] *role is to look at the entire body of the client, be it spiritually, nutritionally, physically…the entire whole, holistic being/person*

> *and to know when they need to pull in the interventions of other people.* (SM3)

The suggestion that holism was at the core of intellectual disability nursing did not, however, meet with agreement from one service manager who considered that the biomedical model was at the very essence of nursing:

> *We've had nurses who've applied here and we would not take them because we just felt that they did not have the right attitude, they didn't have the right value system, they were rigid, they wanted to be a medical model type nurse more than they wanted to support people with intellectual disability.* (SM2)
>
> *I would have a fundamental issue with the notion of nursing because I think it reinforces the medical model and I think it sends the wrong messages. I would never allow anybody on staff to wear a nurse's uniform, for instance. I would never allow anybody on staff be referred to as 'the nurse' because again that goes against the grain, it goes against everything that this agency stands for.* (SM2)

These issues were not seen to be related to the body of skilled and knowledgeable people who hold the title ‘nursing’ but, rather, were linked, by the manager, to the professional structures within which they were formed and worked:

> *It seems to me...and I think the nursing board reinforces this...that hanging onto that title and having things like 'only a nurse can give the tablet' or 'only a nurse can give Stesolid'...I think they've so much more to offer and I think their training gives them so much more skills that to be hanging onto that stuff is just a wrong strategy.* (SM2)

This point was also raised by the nurse manager in same service who postulated that the term ‘nurse’ was becoming defunct.

> *I remember interviewing a nurse and she said 'I'm not a nurse...nurses tend to people and you know, hopefully make them well when they're sick'. You know our population...maybe the term ‘nurse’ is the wrong term anyway.* (NM2)

When asked to focus on the advantages of having intellectual disability nurses in a service, all informants agreed that they offered a quality range of skills and knowledge:

> *I think the training is a good, broad-based, focus in intellectual disability and I would prefer, as the CEO, to employ staff who had training and skills and expertise and that training is a good source of trained people.* (SM2)
>
> *They know exactly how these clients behave; how their patterns of life are. They certainly cannot be done without - they're at the core. But what makes the nurse the focal point is that they know the aetiology behind a lot of things and they can actually see things and diagnose things quicker because they're trained to do it.* (SM3)

The nurse managers, however, were more focused on what nurses brought to residential service provision:

> *People who are trained into the learning disability are more positively challenging towards our own people with learning disability and they would have greater expectations of their abilities and they tend to focus on their skills and abilities.* (NM1)
>
> *The residential service - no I can't see that surviving without nurses and nurses because they come and they're pre-educated into the field of learning disability. And they're pre-educated into all the approaches ...and the care…recreational, social and training skills that people with learning disabilities need.* (NM1)
>
> *Nurses can adapt more easily to being moved at the drop of a hat to a different location, and can fill in and can sort of, you know, can fit in very quickly into that sort of situation, and I think that's because they've had experience in various different settings.* (NM2)
>
> *I think that there's an element of professionalism in the way that nurses will deal with people and I think if you're talking about developing the services I think that as professionals I think that they have something to bring to that.* (NM2)

These positive aspects regarding the intellectual disability nurse were, however, heavily countered by a number of experiences that are contrary to the paradigm change that has resulted in more client-centred services:

> *We take a strict view that all our management positions without exception are wide open in every part of the field...and if I wish to employ a team manager…and I have a lot of nurses on a team, they say 'well, we cannot*

> *report to that person unless its a nurse, therefore we want you to employ a nurse'. If that were to go on and on, it would make it very unattractive.* (SM1)
>
> *I've spoken to An Bord Altranais for instance, some time ago about getting nurses involved in development/training for non-nursing staff and they were absolutely opposed to that, and they very bluntly told me that they don't train nurses to train other people.* (SM2)
>
> *But I do think that if you expect people to do this you should be providing training so what we're trying to do at the minute is to actually get a training package together but what we're coming up against is Bord Altranais right.* (NM2)
>
> *In some areas of our service I have seen that health care assistants have been totally dispowered because the nurses felt that they were responsible and weren't able to delegate anything down to the health care assistant.* (SM3)

The effect of issues like these on persons with intellectual disability was described starkly by NM2 and SM2 in a disturbing account:

> *You have this crazy scenario whereby there are things like the peg feed issue. I have this child who is in dire need – and I don't use that word lightly - of residential place and I cannot give it to him because I cannot find the nurses to provide the cover, and yet he's at home with his Mom who's a young mother and she's able to deal with his peg feeding so I mean its ridiculous; its actually damaging to kids and adults who need services.* (SM2)
>
> *And parents come back and say 'why does there need to be a nurse there? I look after Joe or Sammy on my own; I'm not a nurse. Why are you telling me this? Is he that sick to need nursing care?' And it is quite difficult to turn around and say 'no actually, from our own insurance perspective we have got to have nursing staff to look after your son'.* (NM2)

It was suggested that a protectionist attitude existed in nursing and that this was creating the inflexibility that was stunting the development of the profession along the lines of the new service approaches. Nurses were effectively being left behind caring for the minority of intellectually disabled persons who had the most significant physical, behavioural and mental problems.

> *I think it's a very bad strategy trying to hold onto the notion that there's something special about nursing, and that you need this medical training; it is simply not moving with the times.* (SM2)

> *This is about where are we at in terms of good services for people with intellectual disability, and, as I said, getting locked into some of these medical issues is not in the best interests of the individuals as far as I'm concerned. And I don't think it's in the interest of the nurses.* (SM2)

Paradigmatically, the social concept of the nurse was seen to be parametrically opposite to reality of intellectual disability:

> *At then end of the day people aren't sick; they have a learning problem and our job is to provide the best support systems that we can to allow those people to participate as fully as citizens...and that's not about nursing.* (SM2)

> *One of the difficulties is that the name 'nurse' is associated with nursing sick people, and people with learning disability generally aren't sick, and yet by the fact that we would associate having a nurse with them in a group home, for example, eh almost labels them as being sick. And, that is very undesirable.* (SM1)

> *So, if I could get the training that the RNMHs are getting, and if I could come up with a name that didn't label that training and that professional as a nurse - something like a homemaker or a residential worker or a residential care worker - then you would stop labelling the training and the profession as a nursing, and you would stop labelling the person with learning disability as being sick.* (SM1)

Somewhat ominously, one service manager commented:

> *And eventually, I think that we would walk away from the nursing profession, if the nursing profession, it appears is creating a huge difficulty, and they're not going to win with it in the long term.* (SM1)

It was considered that the future of nursing in more individualised residential services was unsure and would depend on significant changes occurring within the profession. These might relate to a redesignation of the role as a non-nursing, generic one, localising of nurses in health-related services and movement of nurses from the front line, into care management roles.

> *I don't think there's any need to provide a specialist learning disability 'nursing' qualification. I think the course that's there should change its name. I think it should get out from under the nursing umbrella.* (SM2)
>
> *And if people really want to be nurses, if people really have those skills, then redeploy them in community care, into the health structure and if I have clients who have health-related issues then I'll go to community care and they'll respond.* (SM2)
>
> *Nurses fear the erosion of their role…but they're not doing anything constructive to build up their role, and it's going to take a lot of time to do this. Personally I don't think that there is that time left for them to change.* (SM3)
>
> *My visualisation would be the community learning disability nurse visiting them. They'd go around the families and provide advice and liaison in relation to their child.* (NM1)
>
> *I think its in the planning and organisation; I think the role is going to be a much more community based role. I think the whole focus of the role of the nurse is going to change. You know, I think it is going to be moving away from the medical model.* (NM2)
>
> *I'd see it more about directing client care. It's going to be a mixture of nurses and care staff. But I would have concern maybe that we don't have a future.* (NM3)

In these responses it appears that there was a difference between non-nursing service managers' and nursing managers' forecasts on the future of intellectual disability nursing, for, whereas the latter considered that nursing had a future, albeit with a different focus, service managers did not appear to be confident that the nursing profession should or could be part of the developing models of residential service. Despite that, they expressed a desire to harness the skills and knowledge that nurses possess within their workforces. It was within this context that the subject of recruitment was discussed.

4.2.4.5 Recruitment

The theme of recruitment was closely allied to the issue of training and preparation for the new, generic roles in residential care. Informants indicated the skills and knowledge that they would require in applicants for such posts and these were related back to the undergraduate and diplomate nurse education programmes. Table 4.7 outlines some of the topics, content and skills which were considered to be important in the preparation of individuals for generic care posts. This list is not exhaustive and does not take account of personal qualities which were suggested by one service manager:

> *Ability to stay calm. They'd certainly want to be rational and objective. To be able to take on…to be responsible and accountable...to be flexible.* (SM3)

Table 4.7: Desirable qualities in candidates for generic care posts

Topic	*Content*	*Skills*
Philosophy of Care Provision	Values Inclusion Civil rights Advocacy Individualisation Normalisation	
Care Planning	Assessment of needs Person-centred planning Individual programme plans Personal outcome measures	Development of person-centred plans
Education	Teaching strategies	Social skill teaching Self-help skill training
Care Approaches	Early intervention Team work	
Theory in Practice	Inclusive education Inclusive employment Supported living	
Management	Organisational management Staff management Budgeting Interdisciplinary team work Unit management	General management skills Communication skills Critical thinking skills Decision-making skills Planning skills
Health Issues	Typical medical issues presenting in people with intellectual disability Treatments Side-effects First aid Infection prevention	Administration of medications by various routes Universal precautions of infection prevention First aid Behaviour management
Home Making	Cooking Hygiene management Home economics	Cooking Hygiene management

Cognizant of this body of skills and knowledge, it was acknowledged that they already exist in the form of the intellectual disability nurse:

> *It's extremely impressive, and its a wonderfully, wonderfully professional training course and its done to a very high standard; it attracts very fine people; and we hold the graduates in very high regard and as witness to that an increasing number of our senior professional appointments would come from the ranks of the RNMH trained nurse in particular and we're absolutely...it's just delivers a really well-rounded, well-trained, well-educated professional who has direct relevant information, ready to hit the ground running and we greatly prize that.* (SM1)
> *So, I see the RMHN training...I feel when I look at the training is actually a good curriculum...its very broad based...its focused in on the area of intellectual disability...it gives people a good level of expertise.* (SM2)

In view of the disadvantageous issues perceived to be related to the ‘profession’ of nursing, it was suggested that any person who was suitable to work in residential services could be provided with a similar course that could be validated by an educational establishment. Such individuals would not present with the paradigmatic conflict that was seen to be associated with nursing.

> *If you're asking me the question in the context of if I was looking for qualified staff would I select nurses above say people who have done the childcare course in Cathal Brugha Street then 'no' is probably the answer.* (SM2)
>
> *Once we make it clear that the policy of the agency is that we will allow non-nursing staff to carry out certain medical procedures and once they have been appropriately trained...the struggle at the moment is to find the most appropriate training.* (SM2)

It was accepted, however, that there would be a need for nurses to provide health-related care to persons who had health problems. It was suggested that these could be managed by a specialist community intellectual disability nurse or by a public health nurse:

> *Many of these tasks should be carried out by a person with a suitable professional qualification, certification and membership of An Bord Altranais. Some of the care that's going on is highly technical care.* (SM1)

There were also other possibilities identified which centred on the restructuring of the nursing management framework:

> *But its the business about the training...for example, if the nurse training school would recognise the role of the independent RNMH nurse practitioner who doesn't mind who he report to or who she reports to but who can support 6 separate individuals in 6 separate apartment blocks. That kind of model could make it much...nearly like a GP.* (SM1)

The nurse managers were cautious about the possibility of losing specialist nursing whilst noting that:

> *Recently there's talk of, you know, in general hospitals of training care assistants to do what would have been perceived as nursing duties, and I think if it comes in the wider general hospitals, then yeah, I think its going to filter through.* (NM2)

The experience of services that had moved away from a nurse-led approach was suggested to have been generally negative with a desire to again build up nursing numbers:

> *I think there's now a push on again to try to employ nurses, and I think that's why these people are beginning to realise that the skill mix isn't there, and its not until you lose something that you realise the asset it was and the value it brought to the agency, and I think that's what's happened here.* (NM2)

Ultimately, one service nurse manager indicated that nursing was highly valued and was viewed positively within that service, commenting that:

> *If people were interviewing for us there is no doubt that the nurse would get the job every time.* (NM3)

4.3 Conclusion

The focus groups and key informant interviews sought to elicit nurses’ and managers’ perceptions of what they considered to be the most important interventional components of nursing in residential intellectual disability services. In doing this, the group interviews identified eleven interventions and thirty-three nursing diagnoses that are considered to be related to nursing practice in this field and which represent important components of such practice. These findings are, however, somewhat ‘sterile’ when considered in the absence of contextual information regarding the situation within which intellectual disability nursing is operating. The key informant interviews addressed this contextual issue.

Whereas nurses considered that there was a body of interventions and diagnoses that were central, and perhaps unique to their practice, it emerged that service managers viewed these as being aspects of a generic role that was not tied to any specific profession. From this perspective the ‘nursing’ role was not a reality as the services had moved, or were in the process of moving away from a discipline-linked frontline caring role. It was considered that nursing had not progressed along this same path and so was in conflict with the reality of caring in the newer generic models of care. This has created a significant dissonance between service management and nursing which has been suggested to have led to an increase in the employment of non-nursing frontline staff.

Curiously, this interpretation was not shared, in full, by nursing managers who, despite acknowledging that nursing had not met the paradigmatic changes that had occurred within services, considered that the nursing role was a vital one without which clients would suffer. It was suggested that nursing could meet the challenges that were facing it and that it would continue to be a reality in disability services, albeit, perhaps, principally within those units that provide for the needs of persons with multiple disabilities, illness and severe behavioural problems.

Ultimately the focus groups and interviews were designed to build on the findings of the Delphi study, and to provide further data that would inform the development of a quantitative survey instrument. As such, their design has particular characteristics that preclude the generalisation of the findings. These limitations relate specifically to the small numbers of interviewees and informants and the sparseness of the geographical spread represented in the sample of services. In a larger study, it would have been more appropriate to extend the study across a number of services within each Health Service Executive region and to sample individuals from those services. Financial constraints limited the scope of the study and the possibility of engaging an alternative key informant interviewer. While all attempts were made to reduce the possibility of interviewer bias of interviewer effects, it is plausible to suggest that such effects may have occurred. The significance of these limitations is reduced by the fact that these studies were not summative, but were rather part of a formative research process.

CHAPTER 5

Pan-Organisational Survey: Methodology

5.0 Introduction

It has been noted that the findings of the initial investigative studies (Delphi, focus groups and key informant interviews) could not be generalised to the wider population due to the small numbers of respondents and informants. As exploratory studies, however, they were designed to provide progressively refined information that could be used as a basis for the design of a survey instrument. These were used, in association with findings from the professional literature, in the development of the questionnaire that was used for a major 'pan-organisation' survey. This was used so as to facilitate the development of an empirical model of the interventional foci of intellectual disability nursing.

5.1 Research Questions

This study sought to address the question, “what is the current contribution of nursing in residential intellectual disability services?” In view of the contextual findings of the key informant interviews, which suggested that non-nurse care staff, working in generic houseparent roles, perform the same activities as do nurses, the survey also examined the interventional foci of non-nursing care staff in similar work settings. In identifying the contributions of both staff groups, the study considered the relationships, if any, between the employment of specific interventions (the dependent variable) and three categories of specified independent variables: service factors; staff factors; client factors.

More specifically, the survey set out to answer the following questions:

1. What, if any, activities are carried out exclusively by nurses in residential services?
2. What activities are carried out both by nurses and others in residential services?
3. What do nurses, non-nurse care staff, other multidisciplinary team members and service managers, working in residential services, perceive nursing to contribute to caring in such services?
4. Are there differences in each staff grouping's perception of the above questions? Do service, client and staff characteristics have an effect on these perceptions?

This study comes at a significant time in the development of intellectual disability services, for across the country there is a blurring of role boundaries with the development of generic roles which reflect the movement of service provision towards embracement of the concept of inclusion and individualisation. The findings of the focus group and key informant studies suggest that nursing in this field has not made a similar movement. Furthermore, these findings demonstrated a dissonance between nurses' and service managers' perceptions of nursing's focus within community-based services. In view of this, and of suggestions that staff (McKenzie et al 2002), service (McConkey et al 2003) and client (Mansell et al 2002) variables affect character and/or perception of care, this study will assist in making recommendations as to how, and if, nursing should proceed.

5.2 Quantitative Research Design

The study, which is quantitative and exploratory in nature, sought to address the research questions through the employment of survey questionnaires to be administered across the various direct-care staff in Irish residential intellectual disability services.

Surveys are studies “in which information is obtained from a sample of individuals by means of self-report…for the purpose of examining the characteristics…of that population” (Polit and Hungler 1987 p.156). These authors further recognise a specific value of such a design in describing what those individuals, as representative members of the population, actually do. This perspective is supported by Parahoo (1997). Whilst the techniques employed in the preceding pages of this thesis may be employed in surveys, the most widely used technique is the questionnaire (De Vaus 2002). Irrespective of the technique employed, however, two characteristics of surveys are: 1) the structuring of collected data according to a “variable by case data grid” thus allowing comparison of cases; and 2) the examination of this data for causal relationships (De Vaus 2002).

The flexibility of surveys, in terms of design and information collected, as well as the ability of surveys to be administered across varied populations and on a wide scope of topics are considered by Polit and Hungler (1987) to be a key advantage, as is the quantity of information that may be obtained. Disadvantages of these techniques include superficiality of information, limited ability to make inferences and labour-intensiveness (Polit and Hungler 1987).

Whilst recognising that the survey design has many applications, it has been used effectively as a means of describing specific interventions of nursing: partnership interventions (Lazenbatt et al 1999); parish nursing (Tuck et al 2001); medication interventions (Glaser 2002). It has also been employed in ascertaining group perceptions: psychologists perceptions of occupational therapists' interventions (Kane et al 2005); perceptions of health care system (Wilkes et al 1998); police attitudes on people with mental illness (Watson et al 2004).

In view of this, it was considered that at survey design would be an appropriate approach for describing the interventions of nurses and others in residential intellectual disability services, as well as for exploring the perceptions of staff groups in relation to the employment of these interventions.

5.3 Sampling Procedure

The sampling process was guided by two main principles: the need to obtain a sample that represented the variety of residential intellectual disability services in Ireland, and the need to reflect the breakdown of staff groupings within services.

In defining the target population, inclusion criteria were set that sought to attract the input of nursing staff working in residential settings (label 'nurses') as well as that of other staff who are employed for the performance of duties that overlap with those of the registered nurse (label 'non-nurse care staff') . The inclusion of these and of other multidisciplinary team members (label 'multidisciplinary team members') was prompted by suggestions that emerged from the investigative studies, indicating that nursing played a role of integrating the input of other multidisciplinary team members. Finally, in the light of changing service approaches and provision, it was considered of importance that service managers (label 'service managers') contribute to the study.

The resultant criteria for inclusion are identified in Table 5.1. The criterion that nurses be 'Registered nurses' and not 'Registered Mental Handicap Nurses' (RNID) was decided upon as it had become clear, during earlier parts of the research, that many nurses working in intellectual disability services were not actually RNIDs. The decision was also influenced by the fact that logistically it would be very difficult to access those RNIDs that were actually working in residential intellectual disability services. This was an important factor because the second criterion for inclusion in the target population was that individuals must have been employed in one of the above roles in a residential service for persons with intellectual disabilities, at the time of the survey.

Table 5.1: Inclusion criteria for pan-organisational survey

- Registered nurses, clinical nurse managers and directors of nursing currently employed in Irish residential intellectual disability services (label: ‘nurses’)
- Persons currently employed in Irish residential intellectual disability posts that are open to nurse applicants (label: ‘non-nurse care staff’)
- Non-nursing service managers in Irish residential intellectual disability services (label: ‘service managers’)
- Psychologists, social workers, speech & language therapists, physiotherapists and psychiatrists currently employed in Irish residential intellectual disability services (label: ‘multidisciplinary team members’)

De Vaus (2002) suggests that there are many issues that hamper access to the target population. This was the experience in this study too, for it quickly became clear that there were major difficulties in achieving access to the staff groupings, and achieving the quota sample that was desired. Consideration had initially been given to the possibility of mailing the questionnaire to a sample of residential-based nurses on the intellectual disability section of the Register of Nurses maintained by An Bord Altranais, and to all other staff groupings identified in the inclusion criteria using databases of the Department of Health and Children and professional bodies. This was, however, rejected for a number of reasons: 1) the Register of Nurses does not reliably identify either the location of employment of nurses, or the character of that employment – residential, day service, community care; 2) many nurses working in intellectual disability services are not on the intellectual disability section of the

Register of Nurses and would, therefore, not be sampled. Similarly, there was no reliable means for identifying and accessing the other groupings of staff, and neither the Department of Health and Children nor the Health Service Executive maintained a central register of non-nurse care staff. These difficulties were acknowledged by the *Special Working Group on the RMHN* (Bruton 2003). In view of the above, it was decided that access to staff would need to be achieved via the service providers themselves. All services meeting specific inclusion criteria were, therefore, invited to include their staff in the study.

This approach resulted in significant changes being made to the sampling strategy. A two-stage sampling process was, therefore, employed. The first part of this process involved the identification of service agencies from which the accessible population was drawn. The second stage incorporated a process of availability sampling of staff according to the division of the accessible population into four strata as set out in the inclusion criteria (Table 5.1).

Sampling of the service agencies was randomly performed with only one criterion being set for inclusion: that services must have some form of residential component (whether it was an institutional, village-type, community group home and/or supported living in character). A list of Irish intellectual disability services was obtained from the service directory of the National Association for the Mentally Handicapped in Ireland (NAMHI 1999). Seventy-one services, which met the inclusion criterion, were identified. Introductory letters were sent to each of these services requesting permission and assistance in administering the questionnaire across the appropriate staff groups (see Appendix D).

In all, 42.25% (n=30) agreed, in principle, to participate in the study. Ultimately, however, only 25.35% (n=18) of services actually followed through on this agreement and allowed distribution of questionnaires, despite two further letters being sent to each service in this regard. Whilst this stage of the study was only eliciting access to service staff, the response rate is typical of postal surveys (Paxton 1995). In the case of two community-based services, it emerged that the absence of a nursing focus in those services limited their ability to contribute. One other service considered that the study would place an unreasonable strain on staff. The final service was unable to engage in the process of distributing and collecting questionnaires.

Upon receipt of confirmation that a service was willing to provide access to its staff, a breakdown of staff (according to the categories in table 5.1) was requested from the human resources department. This allowed for accurate calculation of the sample strata and, therefore, of the accessible population (table 5.2). It had been hoped that direct access to staff would have been afforded, but this was not forthcoming. A compromise was developed whereby a designated person was identified within each service who acted as a conduit for the dissemination of questionnaires.

The accessible population, to whom questionnaires were sent, comprised 1517 nurses, 784 non-nurse care staff, 44 service managers and 189 multidisciplinary team members. The variability in staff numbers between services is quite dramatic and is explained by the fact that the definition of service employed in this study was of discreet agencies of varying size, but all of which have a residential component. This separated out the regional divisions of larger agencies, leading to the identification of relatively small services, with small numbers of staff meeting the inclusion criteria.

Table 5.2 Accessible population (A= Nurses; B=Non-nurse care staff; C= Service managers; D=Other multidisciplinary team members)

	Staff Groupings				
Service Code	**A**	**B**	**C**	**D**	**Total**
0304A	45	1	2	2	50
1403B	252	0	0	2	254
0404C	15	0	2	0	17
1504D	204	63	4	32	303
1604E	13	0	0	4	17
1704F	48	240	3	13	304
1804G	4	6	1	3	14
2004H	10	12	2	6	30
1208I	498	234	6	49	787
1904J	0	3	0	0	3
2304K	26	56	0	0	82
2204L	38	0	5	2	45
2104M	6	7	2	5	20
2404N	43	0	0	2	45
3007O	9	47	2	4	62
0908P	107	0	7	26	140
1606Q	0	113	8	15	136
1008R	199	2	0	24	225
Totals	1517	784	44	189	2534
	59.9%	30.9%	1.7%	7.5%	100.0%
Mean	84	44	2	11	
Median	32	4.5	2	4	
Range	498	240	8	49	
Standard Deviation	129.5	76.9	2.6	13.7	
Pearson Skewness Coeff.	0.4	0.52	0	0.51	

Whilst it was unfortunate that probability sampling could not have been employed in this study, the use of a convenience sample, is often the only way of gaining access to groups that can not be randomly sampled (De Vaus 2002). It is interesting to note, though, that if random sampling had been employed, with a confidence level of 95% and a sampling error of ≤5% (nurses) and a confidence level of 95% and a sampling error of ≤7% (non-nurse care staff) the required samples would have been less than those that were obtained in the non-probability sample.

A total of 2534 questionnaires were distributed to the staff in the participating services. Of these, 614 (24.23%) were returned with a staff breakdown as seen in

Table 5.3. Although it has been suggested that reminder letters increase the return by up to 12% (DeVaus 2002, Fox et al 1998, Polit and Hungler 1987), no further replies were received following the posting of a reminder four weeks after the return date notified on the questionnaires. This may be attributable to the fact that these reminders were posted centrally within the services and were not distributed individually to staff – it had been made clear by some service managers that no further 'pressure' would be placed on staff to respond to the questionnaires. This resulted in a response rate that was not optimal, and which limits the ability of the findings to be generalised (Keegan and Lucas 2005). It is notable, though, that reports suggest expected mail response rates for Ireland of 12% (Brewster et al 1994) and 30.6% (Harzing 1997).

Table 5.3 Stratified sample (A=Nurses; B=Non-nurse care staff; C=Service managers; D=Multidisciplinary team members). Service code is the individual identifier ascribed to each service.

	Staff Groupings					
Service Code	**A**	**B**	**C**	**D**	**Total**	**Response Rate**
0304A	22	0	0	1	23	46%
1403B	44	0	0	0	44	17.3%
0404C	11	0	3	0	14	82.4%
1504D	24	12	1	9	46	15.2%
1604E	6	0	0	1	7	41.2%
1704F	36	64	1	3	104	34.2%
1804G	0	0	0	0	0	0%
2004H	11	5	2	3	21	70%
1208I	111	34	2	22	169	21.5%
1904J	0	0	0	0	0	0%
2304K	12	13	0	0	25	30.5%
2204L	1	0	0	0	1	2.2%
2104M	5	6	1	6	18	90%
2404N	23	0	0	1	24	53.3%
3007O	1	6	0	0	7	11.3%
0908P	21	0	3	16	40	28.6%
1606Q	21	4	2	8	35	25.7%
1008R	28	2/0	0	8	36	16%
Totals	377	144	15	78	614	24.23%
	61.4%	23.45%	2.44%	12.7%	100.00%	
Response Rates	24.85%	18.37%	34.10%	41.27%		

Whilst the characteristics of the four sampled strata will be examined in relation to those of the target population in a later chapter, it can be seen that, whereas the over all response rate was 24.23%, the response rate for non-nurse care staff was considerable lower, at 18.37%. This suboptimal response was countered by higher than average response rates from managers and multidisciplinary team members. The reason for these discrepancies is not clear, but the poor response rate of non-nurse care staff, who were almost all community-based, may have related to contemporaneous industrial relations difficulties between nurses and non-nursing care staff allied to the expressed aim of this study in attempting to describe the contribution of nursing.

It may be noted in Table 5.3 that, in some services, individual staff categories show a response of zero. Interpretation of these figures should be made in comparison with those in Table 5.3. It may be noted, therefore, that in many of these situations, there was no membership of that category in the relevant service. Whilst there is no evidence that larger services yielded higher response rates than smaller services, with the former spanning rates of 15-35%, smaller services' response rates were located at both poles with 0-11% rates and 30-90% rates. The majority of such services produced higher rates indicating that better returns were obtained from smaller services.

5.4 Questionnaire Development

There are several possible approaches to investigating the core interventional component of nursing. One might, for example, examine the number of clients with whom the intervention is used. This is, however, dependent on the number of clients that the informant has contact with, and is, therefore, potentially limiting. One might otherwise explore the time taken employing the intervention over a specified period of time. Such an approach does provide important information regarding the contribution of that intervention to the core interventional component of nursing, and was employed very effectively by Alaszewski et al (2001) in their study of the changing roles of learning disability nurses. That study, however, made significant use of nurse observation and self-reporting diaries as a means of collecting information. This was not possible with the current study, as direct access to informants was not provided. Such techniques of data collection could, however, be employed in the future as a means of validating the findings of this study. Ultimately, this study made use of the information obtained by Alaszewski et al (2001) and, by focusing on the frequency with which interventions were employed, it may provide an additional insight into their findings.

A structured questionnaire was developed from the analysis of the data obtained in the Delphi, focus group and key informant interview studies, as well as from an extensive review of the literature. The value of employing such methodologies in order to produce items for inclusion on survey instruments has been recognised by many authors (Lankshear 1993, Kreuger 1994, Straw and Smith 1995, Nassar-McMillan and Borders 2002). The qualitative studies and literature review identified three core themes that were employed in the design of the survey instrument. These core themes were 1) current contribution of nursing, 2) unique nursing role and 3) generic role. The data obtained from the qualitative studies were used to generate items within each of the identified themes.

5.4.1 Questionnaire Design

The survey instrument comprised three unmarked sections:

5.4.1.1 Demographic Information

The first section gathered information on the independent variables. This encompassed three aspects 1) service variables, 2) staff variables and 3) client variables. Service variables were placed before staff variables in line with the recommendations of De Vaus (2002). The inclusion of these allowed for consideration of the impact of each of these independent variables on the occurrence/employment of specific care interventions (dependent variables). This, therefore, provided a basis for addressing the suggestion that certain groups of staff were more likely to be engaged in particular activities, with particular clients and in particular settings.

5.4.1.1.1 Service Variables

Conscious of the unique background of service development and provision in Ireland (see section 2.4), the questionnaires employed in this survey were structured to gather information on particular characteristics. More specifically, the questions focused on:

a. Service location – Health Service Executive (HSE) Area; urban or rural;
b. Service type – state-run, voluntary or private;
c. Type of residence – community group home or residential unit.

Service location was considered to be important in the light of the historical tendency to locate intellectual disability services outside of urban areas (McLoone 1988). Some of the older residential units would have developed within the attitudinal context of segregation and it was postulated that this might have had an effect on the focus of care (McLoone 1988).

During the qualitative studies in this research it was noted that management perceptions of nursing in community-based units differed from those of managers in institutional residential units. For this reason, it was decided that this information on service variables should be collected and analysed.

5.4.1.1.2 Staff Variables

The questionnaires specifically focused on the following information regarding each respondent:

1. Gender
2. Age
3. Length of service
4. Qualifications
5. Employment role

Gender was considered to be important in the light of the fact that although the 80:20 female:male gender balance that was present in 2000 has remained unchanged, the number of males in nursing increased by 1518 (41%) between 1996 and 2001 (Department of Health and Children 2002a). The possible effect of this, if any, on the interventional foci is unknown. Inclusion of this respondent characteristic facilitated investigation of this.

The report, *Towards Workforce Planning* (Department of Health and Children 2002a) highlights the potentiality of an ageing registered nurse workforce, citing Buchan (2001), and pointing to those forces at play within the United Kingdom: “smaller intakes of new (and younger) practitioners…compounded by the attempt to encourage mature ‘returners’ to NHS employment” (Department of Health and Children 2002 p.89). With similar forces extant in the Republic of Ireland, it was considered timely to examine whether or not age of nurses and non-nurse care staff is associated with the activities that are carried out. Furthermore, anecdotal evidence obtained during visits to intellectual disability services suggested that the age profiles of registered nurses and non-nursing care staff were markedly different. It was hoped that this observation could be confirmed or refuted.

During the key informant interviews, two issues that emerged as being important in respect of nursing was the experience that nurses had, and the quality of the nursing qualification. The desire for such an effective course amongst non-nurse care staff was highlighted. In view of this, and of the fact that a number of ‘social care’ and ‘child care’ courses have developed, it was decided that the effects of experience and qualifications on the employment of interventions would be examined.

The multiplicity of role titles that have become associated with front-line caring emerged during the qualitative studies, with titles such as, houseparent, home leader, staff nurse, and care worker being used to describe what were essentially the same roles. There was a need to identify these titles and to develop workable core labels that could be used in this study.

5.4.1.1.3 Client Variables

It has previously been noted that the available data from the National Intellectual Disability Database (NIDD 1997, Mulvany and Barron, 2003, Barron and Mulvaney 2004) and from An Bord Altranais (2003, 2005a) tentatively suggested that the majority of nurses were working with the minority of intellectually disabled clients who were availing of residential services. It was postulated that these clients may have either had significant physical or behavioural needs, were challenged by multiple problems, were at extremes of age or were physically/mentally ill, thus requiring nursing intervention. For this reason, it was decided that following client information should be collated:

1. Levels of intellectual disability
2. Concomitant problems
3. Client age

Levels of intellectual disability were defined according to the ICD-10 classification which is the described as “the international standard diagnostic classification for all general epidemiological and many health management purposes” (WHO 2005a). These are presented in the glossary.

The question, on the survey instrument, relating to levels of clients’ intellectual disabilities, described the categories of mild, moderate, severe and profound intellectual disability as exclusive entities. Respondents were requested to check all of the categories that applied in respect of their clientele.

During the Delphi, focus group and key informant studies, informants identified nursing diagnoses and interventions that were related to specific client-related needs. These needs may well be consequences of the intellectual disability itself, of physical disability and/or of environmental phenomena. The suggested co-existence of such needs alongside intellectual disability, and their possible sequellae for caring staff, prompted their inclusion within the client factors to be examined in the survey. Specifically, these needs included:

1. Behavioural needs - challenging behaviour;
2. Other disabilities - physical disability; sensory disability; multiple disability
3. Technical health needs - inability to take food by mouth - enteral feeding; inability to maintain clear airway - airway suctioning

4. Self-help needs - inability to self-care; inability to mobilise independently
5. Medical conditions - active epilepsy
6. Social needs - social deficits.

The National Intellectual Disability Database (Mulvany and Barron, 2003) reported that ‘there are striking differences in the age profile of individuals in the various categories of accommodation’ (p.36). In view of this, the survey questionnaire presented respondents with five age categories, any or all of which could be checked to indicate their exposure to clients of differing age within their work environment. This approach did, however, present difficulties for interpretation, with it only being possible to report that a particular proportion of each core-care staff group cared for persons within a broad age bracket.

5.4.1.2 Perceptions of Staff Roles

The second section of the questionnaire examined respondents’ perceptions of which staff groups were responsible for the performance of specific interventions. This allowed for the designation of interventions as being unique to one group or shared between two or more groups. The interventions (Table 5.4) in this and the final section were categorised according to those identified by Alaszewski et al (2001b), and confirmed by the preliminary studies.

Table 5.4: Interventions included on the perception of staff role section of the questionnaire.

a) Direct Care
i) Administering medication
ii) Keeping medications safe
iii) Planning care
ix) Assisting clients with self-care: dressing and grooming
v) Tube-feeding
vi) Managing physical illness
vii) Suctioning of clients' airways
viii)Assisting clients with self-care: bathing, hygiene and toileting
ix) Assisting clients with self-care: feeding
x) Enhancing socialisation
xi) Managing clients' behaviour
xii) Promoting recreation
xiii) Promoting exercise
xiv) Enhancing communication

b) Management & Administration
i) Maintaining records
ii) Report writing
iii) Attending meetings
iv) Managing staff
v) Financial management/budgeting

c) Liaison Work
With
i) Multidisciplinary team
ii) External intellectual disability agencies
ii) Other external agencies
iii) Advocating for clients

d) Education
i) Developing personal competencies
ii) Training staff
iii) Teaching nursing students

5.4.1.3 Care Interventions

This final section presented a comprehensive list of forty-four interventional items that were identified in the previous studies and professional literature (see Table 7.2). The inclusion of these interventions provided a basis for addressing the second research question regarding the current contribution of nursing in residential intellectual disability nursing.

This section focused on the frequency of employment of each intervention using a 5-point Likert-type scale. The identification of frequency of employment allowed the association of particular interventions with particular staff groups to be investigated.

The definitions of the interventional items in this list were not provided for the respondents. This was on account of the fact that the terms were noted to be self-explanatory during the focus group interviews and pilot study.

The list of interventions was compared to a similar list that was identified by Alaszewski et al (2001) in their study of the changing roles and education of learning disability nurses in the United Kingdom. Many similarities were noted and, for this reason, it was decided that the activity-based role structure would transfer easily to the current study. One key difference that emerged related to the issue of family contact and the role of the nurse in facilitating this. During the key informant interviews, it was suggested that, if a client could not live with his/her family, the service was responsible for ensuring that it provided a replacement family environment. At no point, however, was there any suggestion that the active encouragement of family contact was perceived to be within the core interventional component of care. There may be a number of reasons for this. This study focused on obtaining the perspectives of staff who work within residential services. Many of the clientele within such services are of increasing age (National Intellectual Disability Database 2002) and may have been in such services for many years. There may, therefore, be less family contact. This may also be compounded by the fact that many clients were placed in services distant from their homes. Furthermore, the majority of persons with intellectual disability who live with their families were not in receipt of the services provided by staff in this study.

The interventions were, therefore, grouped under the headings: direct care interventions; management and administration interventions; liaison interventions; and educational interventions (Alaszewski et al 2001).

The key informant interviews had raised a suggestion that non-nurse care staff were carrying out many of the duties previously performed by nurses. Whereas, this study had intended to focus purely on the interventional role of nurses, it was considered that, if this role crossed over with that of non-nurses, it would be useful to examine this crossover in order to examine its effect on the unique contribution of nursing. As the focus remained on nursing, though, it was decided that there was no rationale for undertaking a parallel process of looking at non-nurses interventions and seeing if nurses undertook those as well (the flip-side of the approach). It was conceded that this approach might not fully describe all the interventions of nursing, as that was never intended, but that only the core interventions would identified.

5.4.2 Pre-Test of Questionnaire

It is suggested that pre-testing of questionnaires should involve a three-stage process (Converse and Presser 1986 cited in De Vaus 2002 p.114): question development – declared; questionnaire development – undeclared; polishing the pre-test. These stages are typically followed by cognitive interviews which allow the researcher to identify any shortcomings and ambiguities in the questionnaire. In this study, such fine honing of the survey tool was hampered by the fact there was no direct contact possible between researcher and respondents. This prevented any cognitive interviews from taking place and so, limited the development of the questionnaire. In its lieu, a pro forma that investigated respondents' views on two aspects of the questionnaire accompanied the pilot questionnaires. This was completed *following* completion of the questionnaire. The two aspects of this form were: the question development and structure; and the questionnaire development. The former of these asked the respondents to examine each question with respect to meaning, similarity to other questions, and reasons for non-response. The latter aspect focused on the flow of the questionnaire and the time taken to complete it.

The questionnaire was pre-tested among nurses, non-nurse care staff, multi-disciplinary team members and service managers in two conveniently sampled small intellectual disability services that were not used in the main study. One of these services was located in a large urban area and comprised institutional residential units. The other service was based in a rural region with community group homes. The population was determined by the numbers of staff within these services and amounted to forty individuals: fifteen nurses, twenty non-nurse care staff, three multidisciplinary team members and two service managers. There was a response rate of 65% (n=26) with 66.7% (n=10) of nurses, 55% (n=11) of non-nurse care staff, 66.7% (n=2) of multidisciplinary team members and 100% (n=3) of service managers returning completed questionnaires. Rea and Parker (1992) suggest response rates of greater than 50% to be adequate with 60% considered to be good (Fowler 1984). The response rates in this pilot study suggested that the questionnaire was well received by respondents. Although a small sample, it did, however, highlight a number of significant problems with the pre-test questionnaire:

- The wording of some questions was ambiguous.
- Two questions were suggested to be redundant.
- Two questions examining respondents' perceptions of the focus and philosophy of their services were not answered.
- One question was considered to be extremely confusing.
- Specific questions were considered to be redundant to multidisciplinary team members and service managers

Changes were made to specific questions that resulted in a nine-page, fourteen item pre-test questionnaire being replaced by a five page, ten item tool. The most significant change, however, was that, whereas a standard questionnaire had been disseminated among the pre-test sample, the redundancy of particular questions led to the development of two separate questionnaires – one for nurses and non-nurse care staff, and one for multidisciplinary team members and service managers (see appendix D). The redundant items related to the performance of activities that were deemed not to be of central importance to either non-frontline staff or service managers.

5.4.3 Further Validation

Following amendment, the two questionnaires were given to three intellectual disability nurses, one from clinical practice, one from nurse education and one from nurse management. Each of these individuals was requested to examine the survey tools with regard to their face congruity. No further amendments were required.

5.5 Distribution and Return of Questionnaire

The pre-testing stage of questionnaire development allowed for the researcher to assess the method of distribution that had become necessary. The response rate of 65% was acceptable (Fowler 1984) and the centralisation of distribution and return within the service agencies resulted in a fluid process. This process was considered appropriate and was, therefore, used in the main study.

Enveloped packs were prepared according to the numbers that were notified by the service agencies. These sealed packs included a cover letter, questionnaire and return envelope. The unopened envelopes were delivered by the researcher and similarly collected on a predetermined date. Late returns were forwarded by post.

It has been noted that the lack of direct access to respondents curtailed a number of aspects of the study. This included the ability of the researcher to send personalised reminder letters. Instead, it was necessary to send reminder posters to each of the centres to be displayed centrally and in each residential unit.

5.6 Quantitative Data Analysis

Data collected on questionnaires were transferred onto computer for analysis using the Statistical Package for the Social Sciences (SPSS Version 11.0). Descriptive and non-parametric techniques were employed in analysing and describing the data set. Parametric tests, whilst much stronger than their non-parametric equivalents, were not employed in this study as the data that was collected was of a nominal or ordinal nature. Overall, the results of the sample are reported in terms of frequencies of responses across the staff groups. Differences between staff groups' employment of interventions were analysed through use of the Kruskal-Wallis ANOVA by ranks test with post hoc analysis using the Mann-Whitney test and Holms Stepdown Procedure (Pett 1997).

Exploratory factor analysis was used in order to develop a proposed interventional model of caring in residential intellectual disability agencies. Although it is acknowledged that the sample numbers are small, the exploratory nature of the study provides a basis for other studies. Finally, prediction of the employment of care interventions was measured using binary logistic regression. This approach is considered to be particularly useful and flexible approach to examining the effect of specified independent variables on the occurrence of the dependent variable (Tabachnik and Fidell 1996). As such, it provided a test, which made no assumptions about the distributions of the predictor variables - service, staff and client variables – whilst allowing any predictive relationships between them and the employment of specified interventions to be identified (Tabachnik and Fidell 1996).

5.7 Conclusion

Significant difficulties were encountered in relation to setting up the survey, due to the problems associated with obtaining access to an appropriate sample. Central to these problems were the lack of accessible information on the location and the numbers of staff within Irish intellectual disability services. This was compounded by the fact that the only other means of accessing a sample was via service personnel departments, who were eager to maintain the confidentiality and security of their databases. These difficulties resulted in the survey development stage taking a protracted period of time to reach conclusion. They also resulted in a response rate that was not as great as had been hoped for.

Despite these problems the study, which is the first of its kind in Ireland, resulted in one of the largest samples in the intellectual disability nursing literature and provided a basis for contrasts to be made between the interventional contribution of nursing and non-nurse care staff working in the same settings. It also allowed for a multidisciplinary perspective to be obtained on the ‘professional ownership’ of such interventions.

CHAPTER 6

Pan-Organisational Survey: Description of the Sample

6.0 Introduction

A total of 2534 questionnaires were distributed to the staff in the participating services. Of these, 614 (24.23%) questionnaires were returned with a staff breakdown as seen in Table 5.3. Although it has been suggested that reminder letters increase the return by up to 12% (Fox et al 1998), no further replies were received following the posting of a reminder. This may be attributable to the fact that these reminders were posted centrally within the services and were not distributed individually to staff (De Vaus 2002). This resulted in a response rate that was far from optimal, but not unusual for anonymously completed questionnaires, and which may limit the generalisability of the findings. This sample does, however, represent the largest and most varied sample of staff to be studied in Irish intellectual disability services and is also the first attempt to systematically research intellectual disability nursing foci. As such, this study forms a knowledge base for further research into the topic.

6.1 Description of Sample

The questionnaire collected three categories of information on the sample: 1) service characteristics; 2) respondent characteristics; and 3) client characteristics. This are described separately in order to attempt to identify any possible biases in the returns received from services in the study.

6.1.1 Characteristics of Services in the Study

6.1.1.1 Service Location

The participating services represented six of the eight Health Service Executive Areas in the Republic of Ireland including, the Southern Area (HSE-S), Western Area (HSE-W), South-Eastern Area (HSE-SE), Midland Area (HSE-M), Mid-Western Area(HSE-MW) and Eastern Region (HSE-ER) (Figure 6.1).

Figure 6.1 Health Service Executive areas (source: Health Service Executive 2005)

It is difficult to obtain definitive statistics regarding the target population. Figures obtained from the Department of Health and Children (2003d) suggest that 29.5% of staff employed in intellectual disability services are nurses, 37.4% are non-nurse care staff, 10.2% are in administration and 22,8% are other members of the multidisciplinary team (Table 6.1). This is markedly different from the proportionate breakdown of these groups in the accessible population: 59.87%, 30.94%, 1.74% and 7.46% respectively. It should be noted, though, that the departmental figures refer to all types of intellectual disability service, not just residential.

Closer examination of the departmental statistics indicates, however, that the employee gradings of ‘management/ administration’, ‘health and social care professional’ and ‘other patient and client care’ are considerably broader than and not comparable with those of ‘service manager’, ‘multidisciplinary team member’ and ‘non-nurse care staff’ used in this study. Furthermore, it is evident, from the departmental figures, that not all voluntary and private services are included, thus challenging their use as a reference point. In the light of this, it was decided that data from the National Intellectual Disability Database (Mulvany and Barron 2003), regarding *client* numbers, would be employed as a proxy for the distribution of staff across the Health Service Executive areas.

Table 6.1: Breakdown of Health Service Executive personnel by region (Department of Health and Children 2003d).

	A	*B*	*C*	*D*
Eastern	1092	1581	430	954
Midland	109	287	77	113
Mid-Western	351	178	54	214
North-Eastern	319	339	85	110
North-Western	255	286	98	176
South-Eastern	198	261	56	101
Southern	352	508	133	375
Western	276	300	86	239
Total	2952	3740	1019	2282
Percentage of Total Staff	29.5%	37.4%	10.2%	22.8%

(A=Nurses; B=Non-nurse care staff; C=Service managers; D=Multidisciplinary team members)

It can be seen from Table 6.2 that the greatest proportion of respondents (43.5%; n=267) was from the HSE-ER, a region which accounts for 33.2% (n=8438) of the intellectual disability population (Mulvany and Barron 2003). The statistics for the intellectual disability population in all of the HSE regions are represented in this table

Table 6.2: Number of people included on each regional intellectual disability database (NIDD, 2004) and numbers of respondents in corresponding Health Service Executive areas

	Numbers of Persons on Intellectual Disability Database		*Numbers of Staff Respondents*	
HSE Region	*n*	*%*	*n*	*%*
Eastern	8438	33.2	267	43.5
Midland	1383	5.4	40	6.5
Mid-Western	2344	9.2	54	8.8
North-Eastern	2018	7.9	0	0
North-Western	1795	7.1	0	0
South-Eastern	3088	12.1	24	3.9
Southern	3661	14.4	72	11.7
Western	2689	10.6	157	25.6
Total	25416	100.0	614	100

A relatively unequal rural-urban divide was found among respondents, with 70.8% (n=383) describing their workplace as ‘urban’ and 29.2% (n=158) describing it as ‘rural’. This deviates from the distribution of population in Census 2002 (Central Statistics Office 2003), which reported a 60% urban and 40% rural divide.

6.1.1.2 Service Type

The emphasis on voluntary service provision which has historically developed throughout the past hundred years is represented in the sample of participating services with an 89%:11% split between voluntary and state respectively. These services include discreet services of varying size, but all of which have a residential component. This over-represents the actual situation of voluntary provision whereby the breakdown of voluntary and state service provider ratio is approximately 80%:20% (NAMHI 1999).

6.1.1.3 Type of Residence

Two models of residential unit were identified on the questionnaire – institutional unit and community group home (see Glossary). Respondents were asked to identify the model that most closely approximated to that in which they were working. The responses indicated that 246 (43.2%) were working in institutional residential units and 221 (38.8%) in community group homes. There were, however, 103 (18.1%) returned questionnaires that did not register a response to this question. This number reflects those respondents who were not working in units *per se*, but were rather linked to them – management and multidisciplinary staff.

It is interesting to compare these figures with those of the National Intellectual Disability Database (Barron and Mulvany 2004), which indicates 7619 persons availing of residential services, of whom 3462 (45.44%) were residing in community group homes, 3444 (45.2%) were living in residential centres with the remaining 713 (9.6%) located in nursing homes, psychiatric hospitals, intensive placements for challenging behaviour/profound or multiple handicap, residential support or other full-time residential service (Barron and Mulvany 2004). This suggests that the sample employed in this study was broadly comparable in terms of percentage of the clients, and maybe therefore staff, within the two types of accommodation options.

As Figure 6.2 shows, a greater proportion of nurses worked in institutional residential units (n=199; 76.5%) than in community group homes (n=61; 23.5%), whereas the opposite was observed in relation to non-nurse care staff (institutional residential unit – n=13; 8.9%; community group home – n=133; 91.1%) (χ^2 = 171.146; df=1; p<0.0001).

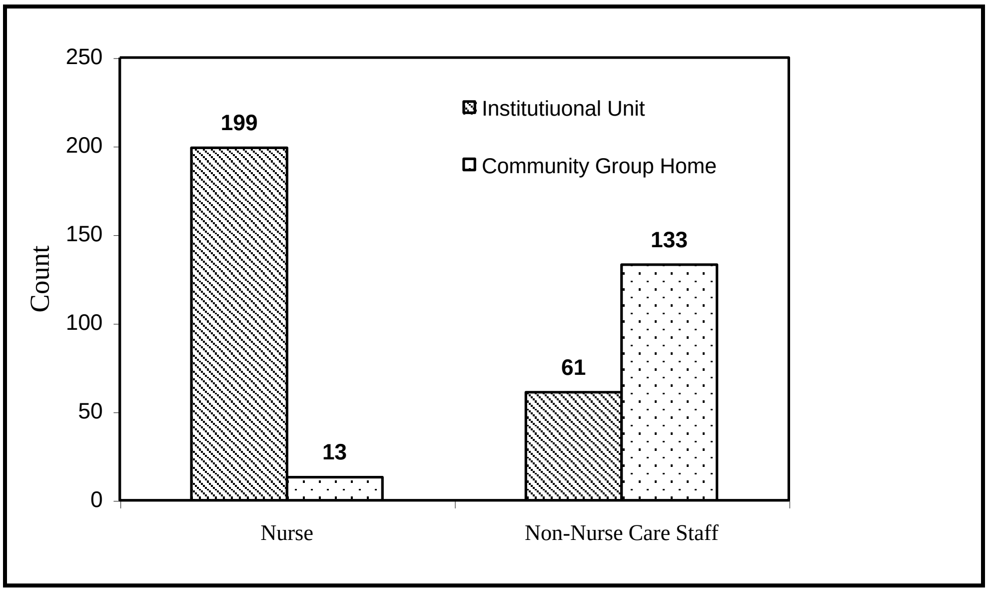


Figure 6.2: Residential employment setting of respondents.

6.1.1.4 Conclusion

This section has described the characteristics of the services that were sampled in the study. The sample appeared to be broadly representative of staff working in the two categories of residential provision but was shown to be biased towards urban services and voluntary providers.

6.1.2 Characteristics of Respondents in the Study

The data collected on respondent characteristics are presented in Table 6.3.

Table 6.3: The number and percentages of staff in three groupings broken down by gender, age and length of service.

	Nurses (N=303)	Non-Nurse Care Staff (N=150	Multidisciplinary and Service Management Staff (N=87)	Totals
Gender*				
Female	264 (87.1%)	133 (88.7%)	70 (81.4%)	467 (86.6%)
Male	39 (12.9%)	17 (11.3%)	16 (18.6%)	72 (13.4%)
Age (years)+				
20-29	59 (19.6%)	48 (32.2%)	16 (18.4%)	123 (22.9%)
30-39	98 (32.6%)	42 (28.2%)	26 (29.9%)	166 (30.9%)
40-49	92 (30.6%)	32 (21.5%)	27 (31.0%)	151 (28.1%)
>50	52 (17.3%)	27 (18.1%)	18 (20.7%)	97 (18.0%)
Length of Service (years)†				
0-9	105 (36.1%)	95 (67.9%)	42 (49.4%)	242 (46.9%)
10-19	101 (34.7%)	35 (25.0%)	23 (27.1%)	159 (30.8%)
20-29	65 (22.3%)	8 (5.7%)	16 (18.8%)	89 (17.2%)
30-39	20 (6.9%)	1 (0.7%)	3 (3.5%)	24 (4.7%)
>40	0 (0%)	1 (0.7%)	1 (1.2%)	2 (0.4%)

(*1 missing; +3 missing; †24 missing)

6.1.2.1 Gender

Of the 614 respondents, 467 (86.6%) were female, whilst 72 (13.4%) were male. These proportions were represented throughout the three main staff groupings (Table 6.3). The gender divide amongst nursing respondents, whilst slightly female-centred, is generally representative of that within the intellectual disability nursing population (89.2% female; n=3839 and 10.80% male; n=465) (An Bord Altranais 2003).

6.1.2.2 Age

Age-related data was collected nominally by requiring respondents to indicate within which of four age groupings they fell (Table 6.3). There was a significantly greater percentage of younger non-nurse care staff than of nurses or other staff with 48 (32.2%) non-nurse care staff within the 20-29 year age group, compared with 59 (19.6%) and 16 (18.4%) nurses and multidisciplinary and service management staff respectively. This trend is reversed though within the 30-39 year and 40-49 year age groups, and more markedly so within the 40-49 year age group. Thus, there are proportionally more nurses and multidisciplinary and service management staff aged 30-49 years, with all staff groups tapering off within the >50 year age group. These differences are significant ($\chi^2 = 29.338$; df=16; $p<0.022$).

6.1.2.3 Length of Service

As with the age-related data, a participant’s length of service was entered on one of five categories (Table 6.3). The main body of respondents (n=242; 46.9%) were in the 0-9 year length of service category, with a reducing number of persons per group as the service length increased. This may relate to a number of factors, including the effect of the physical aspect of care on the ageing person, expansion of services or high turnover of staff.

The trends in Figure 6.3 indicate that, whereas there was a relatively even spread of nursing experience across the 0-9, 10-19 and 20-29 years categories, a proportionately greater number of non-nurse care staff had less than 10 years of experience, with most of the remainder reporting 10-19 years of experience. Almost 50% of multidisciplinary and service management staff had less than 10 years of experience, with 23 (27.1%) and 16 (18.8%) reporting experience in the 10-19 year and 20-19 years categories respectively. These differences were significant (χ^2 = 53.044; df=16; p<0.0001). However, there are no nationally-held data sources relating to service staff with which to make comparisons.

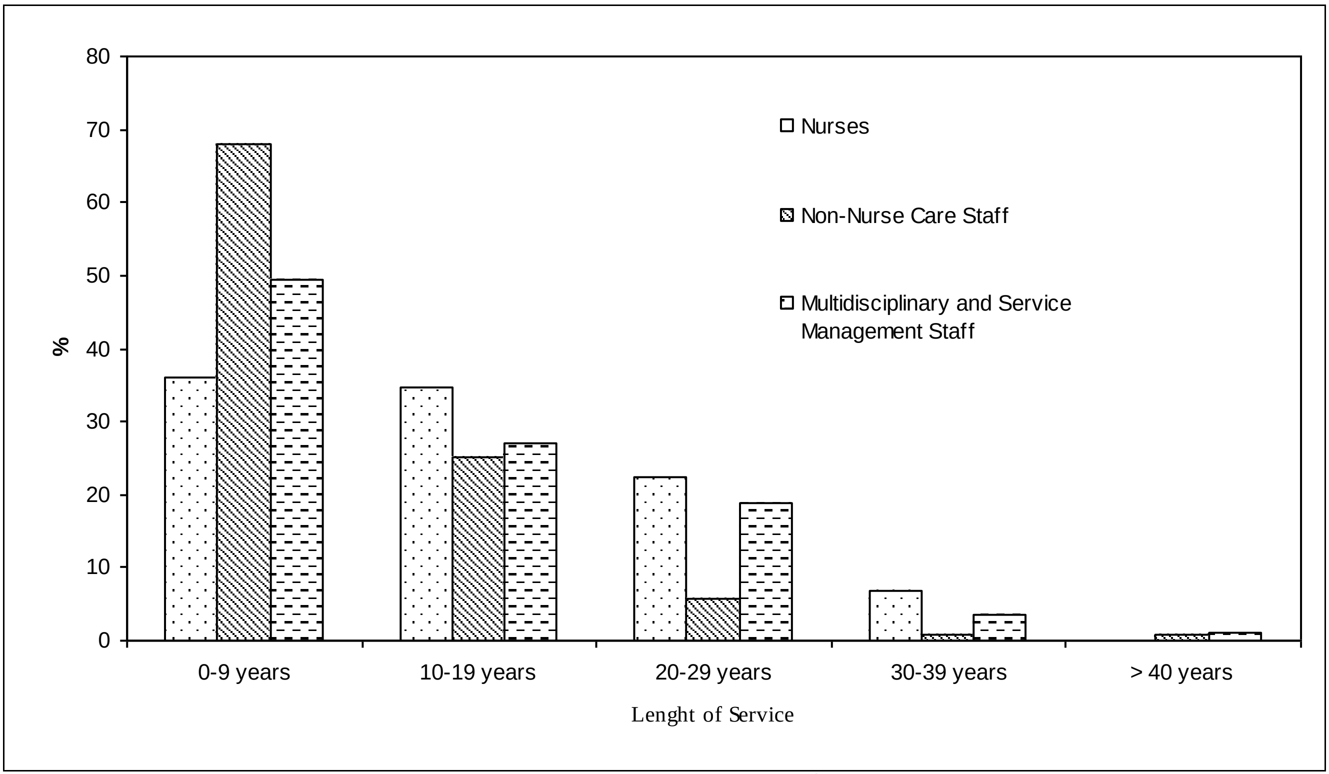


Figure 6.3: Respondents length of service – staff groupings (by category) (χ^2 = 53.044; df=16; p<0.0001).

6.1.2.4 Employment Roles

Respondents described a wide variety of job titles, which spanned both residential and day services. Many of these overlapped to some degree and so, in order to create a more useable classification of role, and following consultation with service personnel, the titles were recoded under five general categories (Table 6.4). It should be recalled, at this stage, that, although it is recognised that the nurse and, increasingly, the non-nurse-care staff, operate within the context of a team involving all professionals and others who together contribute to the care of persons with intellectual disability, the label 'multidisciplinary team' is being used in this study to refer to the members of this team other than nurses and non-nurse care staff. These two latter groups, as frontline providers or care, are a key focus of the study.

Table 6.4: Employment roles recoded

Registered Nurse	Non-Nurse Care Staff	Multidisciplinary Team Members	Service Managers
• Staff nurse • Clinical nurse manager (grade 1 or 2) • Clinical nurse manager (grade 3) • Nurse supervisor • Community nurse • Assistant director of nursing • Director of nursing • Clinical nurse specialist • Senior nurse manager	• Home leader • Houseparent/ assistant houseparent • Community support worker • Residential care worker • Social care leader/ assistant social care leader	• Physiotherapist • Psychologist • Social worker • Occupational therapist • Speech and language therapist • Educator • Psychiatrist	• Chief executive officer • Service manager • Director of service • Unit director • Respite coordinator • Area manager • Residential coordinator • Assistant director of programmes • Manager

The recoding process grouped respondents together according to the main categories identified in the inclusion criteria. Overall the final distribution of respondents showed a similarity in representative quotas when compared to that of the original sample (Table 5.3).

6.1.2.5 Qualifications

Almost two thirds of the respondents to the survey questionnaire reported themselves to be educated to an academic level below that of a primary degree (n=383; 65.1%). This figure represents those persons who had no post-secondary qualification (n=17; 2.9%) as well as those with post-secondary certificates (n=180; 30.6%) and diplomas (n=186; 31.6%). This group included 205 (54.2%) nurses who had trained on certificate and diploma courses. The remaining nurse cohort comprised 54 (18.6%)

individuals who completed a primary degree, 21 (7.2%) who completed a post-graduate diploma and 10 (3.4%) who completed a master degree. Whilst a similar pattern is seen amongst non-nurse care staff, there is a marked difference within the multidisciplinary and service management staff group, which is a predominantly graduate and post-graduate cohort. This is understandable considering the fact that many of the multidisciplinary team professions (psychology, sociology, medicine, speech and language therapy, occupational therapy, physiotherapy) have had graduate-entry status for many years. The differences between employment role and qualifications attained (Table 6.5) are significant ($\chi^2 = 137.812$; df=6; p<0.0001).

Table 6.5: The number and percentage of staff in different employment roles with highest academic qualifications attained ($\chi^2 = 137.812$; df=6; p<0.0001).

			Highest Qualification Attained				
			No Degree	Primary Degree	Post-Graduate Diploma	MSc/PhD	Total
Employment Role	Nurse	n	205	54	21	10	290
		%	70.7%	18.6%	7.2%	3.4%	100.0%
	Non-Nurse Care Staff	n	113	20	4	7	144
		%	78.5%	13.9%	2.8%	4.9%	100.0%
	Multidisciplinary and Service Management Staff	n	15	23	17	30	85
		%	17.6%	27.1%	20.0%	35.3%	100.0%
Total		n	333	97	42	47	519
		%	64.2%	18.7%	8.1%	9.1%	100.0%

More detailed examination of those respondents who reported that they had ‘no degree’ indicated that 205 (70.7%) nurses and 98 (68%) non-nurses had a post-secondary certificate or diploma.

Cross tabulation between those who have nursing qualifications and employment roles indicated that whilst the vast majority of nurses (n=302 of which 191 were Registered Nurses (Intellectual Disability) (RNID) and 111 were other-registered nurses) were in nursing roles, a sizeable proportion (n=70) were in generic residential and non-core-care roles.

6.1.2.5.1 Nursing Qualifications Held

The majority of people surveyed had a nursing qualification (n=380: 61.9%). Of those, the largest group (n=223; 59.8%) were RNIDs. It may have been expected that there would be more RNIDs working in intellectual disability services. This has not been the case since the late 1980s when services began to open intellectual disability nursing posts to any registered nurse. This is reflected by the breakdown of nursing qualifications in this survey, which shows that 39 (10.5%) respondents were Registered Psychiatric Nurses (RPN), 100 (26.8%) were Registered General Nurses (RGN), 3 (0.8%) were Registered Children's Nurses (RCN), 5 (1.3%) were RPN and RGN dual-registered and 3 (0.8%) were RGN and RCN dual-registered. Those RNIDs with other registrations were included in the RNID cohort.

A similar pattern of nursing qualifications was noted amongst nurses working in institutional units and community group homes, with no statistical differences observed.

6.1.2.6 Conclusion

This section has described the characteristics of the respondents with respect to gender, age, length of service, employment roles and qualifications. The sample has been shown to be biased towards female gender and with a greater proportion of nursing respondents in the below 39 years of age than reported in nursing registration statistics (Department of Health 2002a). Unfortunately, there are no nationally held sources of data against which to make comparisons in respect of the other variables.

This survey is, therefore, the first to provide this kind of staffing information for the Republic of Ireland and could serve as a model for future studies to monitor changes in the workforce.

6.1.3 Characteristics of Client Groups in the Study

Data collected regarding characteristics of clients, who were in receipt of care from survey respondents, related to: 1) levels of clients' intellectual disability; 2) presence of concomitant problems; and 3) clients' ages.

6.1.3.1 Levels of Intellectual Disability

It can be seen from Figure 6.4 that a greater proportion of non-nurse care staff were working with mildly and moderately intellectually disabled clients, than were nurses. The converse is true in respect of client with severe and profound intellectual disabilities. These findings were significant at the 0.001 level.

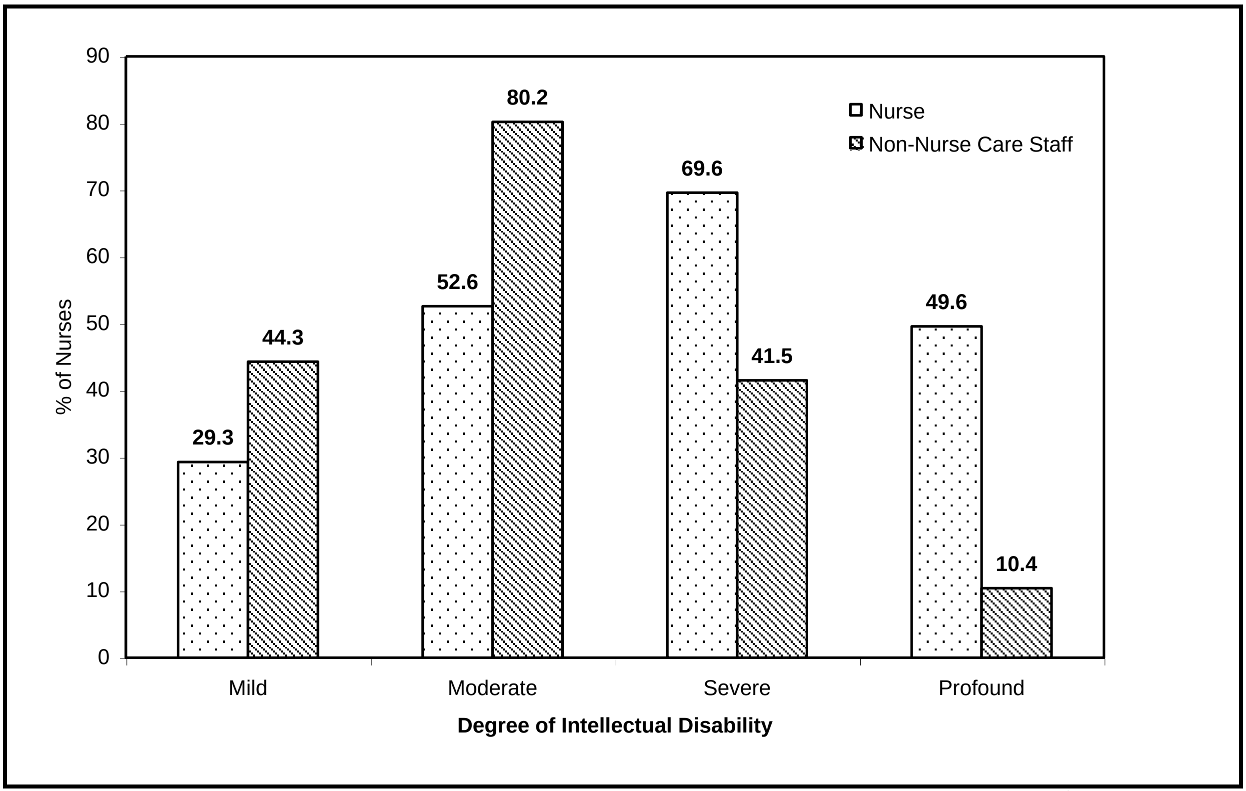


Figure 6.4 Employment roles crosstabulated with clients' levels of intellectual disability (mild - χ^2=5.774; df=1; p<0.016; moderate - χ^2=19.652; df=1; p<.0001; severe - χ^2=19.469; df=1; p<.0001; profound - χ^2=41.606; df=1; p<.0001).

Furthermore, it may be noted from Table 6.6 that a greater proportion of nurses were working with client groups that comprised a variety of intellectual disability levels. Thus, whereas 68 (45.6%) and 61 (40.9%) non-nurse care staff were working with client groups with only one or two levels of intellectual disability respectively, only a small proportion of nurses were working with such groups. The opposite trend was observed in respect of client groups with three or four levels of intellectual disability.

Table 6.6 Crosstabulations of core-caring employment roles with mixed levels of intellectual disability (χ^2=20.633; df=3; p<.0001).

			Mixed Disability Group				
			One Level	Two Levels	Three Levels	Four Levels	Total
Employment Role (role)	Nurse	N	103	96	57	43	299
		% (role)	34.4%	32.1%	19.1%	14.4%	100%
	Non-nurse care staff	N	68	61	13	7	149
		% (role)	45.6%	40.9%	8.7%	4.7%	100%
Total		N	171	157	70	50	448
		% (role)	38.2%	35.0%	15.6%	11.2%	100%

6.1.3.2 Concomitant Problems

When each of the concomitant problems - challenging behaviour; physical disability; sensory disability; multiple disability; enteral feeding; airway suctioning; inability to self-care; inability to mobilise independently; active epilepsy and social deficit - was checked for frequency of reporting within the staff groups, it was noted that, whereas both groups reported challenging behaviour, self-care and social needs to be present in their client groups, nurses reported the presence of more concomitant disabilities, as well as more medical and technical health needs (Figure 6.5). Closer examination of the components of each of these client needs confirmed this with differences being found to be significant in all except challenging behaviour and social deficits (Table 6.7).

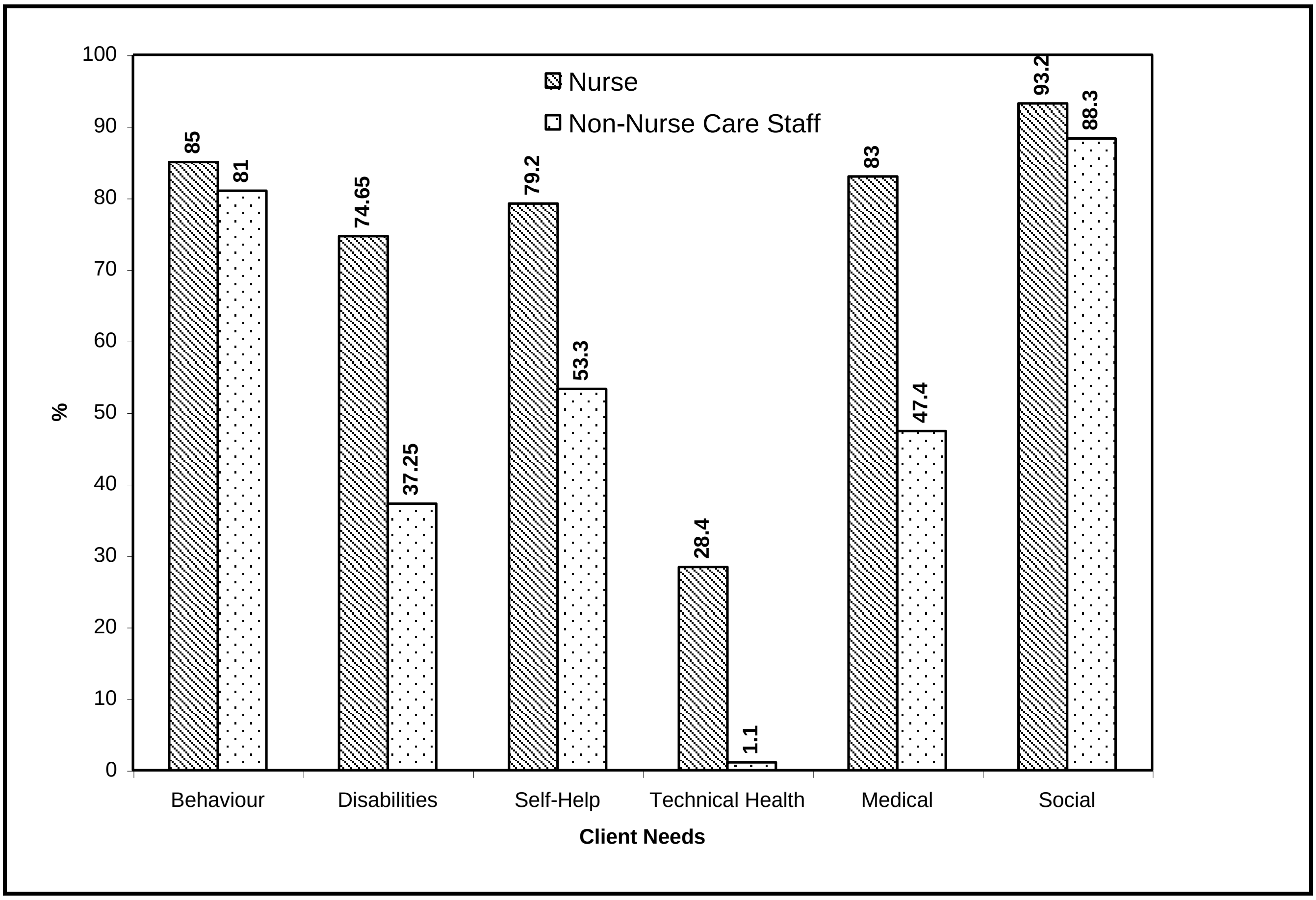


Figure 6.5 The percentage of respondents working with clients who had additional needs.

Table 6.7: Reported presence of components of concomitant needs in nurses' and non-nurse care staffs' client groups.

		Challenging Behaviour	*Physical Disability*	*Sensory Disability*	*Requires Tube Feeding*	*Requires Suctioning*	*Epilepsy*	*Multiple Disability*	*Non-Ambulant*	*Self-Care Deficit*	*Social Deficits*
Nurse	n	249	238	229	103	63	244	187	186	272	268
	%	85.3%	81.5%	78.4%	35.3%	21.6%	83.6%	64%	63.7%	93.2%	91.8%
Non-Nurse Care Staff	n	111	72	48	2	1	65	33	31	115	121
	%	81%	52.6%	35%	1.5%	0.7%	47.4%	24.1%	22.6%	83.9%	88.3%
Statistics	χ^2	1.249	38.995	76.733	57.680	31.923	60.371	59.580	62.926	8.954	1.320
	df	1	1	1	1	1	1	1	1	1	1
	p	<.264	<.0001	<.0001	<.0001	<.0001	<.0001	<.0001	<.0001	<.003	<.151

Crosstabulation indicates that nurses are more likely to be concurrently exposed to a greater number of such problems than are non-nurse care staff.

6.1.3.3 Client Age

Respondents' reported exposure to clients of varying ages indicated that there appeared to be a greater number of younger people with intellectual disability in the community than in institutional care, and that they were being cared for, to a greater degree, by nurses than by non-nurse care staff. Older clients (aged 51 to >64 years) appeared to be located, more so, in institutional settings where they were similarly cared for by nurses. The findings suggest that non-nurse care staff had greatest contact with clients within the 51-64 year and >65 year age groups. This is significant (χ^2=7.112; df=1; p<.008). The 31-50 year age group stood out as representing the largest group of clients in receipt of care from respondents. This concurs with the age profiles reported by the National Intellectual Disability Database (Barron and Mulvany 2004).

6.1.3.5 Conclusion

This section has examined the characteristics of the clients who are the recipients of care provided by the nursing and non-nurse care staff respondents. It has been shown that nurses were more likely to be working with clients who had severe or profound intellectual disability than were non-nurse care staff. Furthermore, nurses appeared more likely to be concurrently exposed to a greater number of concomitant problems than were non-nurse care staff.

6.2 Conclusion

This chapter has focused on the sample of respondents to the survey questionnaire. The rationale for the inclusion of three categories of respondents' characteristics, service, respondent and client has been discussed and explained. It has been noted that it was difficult to obtain a sample that fully represented the target population of staff. In some regards the sample employed in this study has been shown to be broadly representative. However, over and under-representation in respect of some service characteristics have also been noted.

A focus on front-line caring staff showed significant differences between nursing and non-nurse care staff, in terms of their work settings and the client groups with whom they worked. It has been shown that whilst the majority of nursing staff were working in institutional residential units, the converse was the case for non-nurse care staff, with the vast majority of them employed in community group homes, to the extent that, in this study, they may be considered to be a community-based cohort. Differences were also observed in the age profile of respondents indicating that there was a significantly greater proportion of younger non-nurse care staff than there were of nurses. The opposite scenario was noted in respect of length of time in service, with nurses reporting greater experience than non-nurse care staff. It is logical to conclude that this younger age profile and comparatively less experience are associated. More significant, though, are the differential characteristics of the clients with whom the staff were employed to support. This was elaborated by investigating, in detail, the nature of their work. These results are presented in the following three chapters.

CHAPTER 7

Pan-Organisational Survey: Conceptualisation of Care Interventions

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7.0 Introduction

This chapter addresses two issues:

i) the frequency of interventions of care by nurses

ii) the frequency of interventions of care by non-nurse care staff.

These were inherent in the first sub-aim of the study: setting out the current contribution of intellectual disability nursing in Irish residential services. The key questions focused on the interventional component of this contribution, drawing on the interventions that were identified and highlighted in the previous, qualitative work, as well as in other studies (Manthorpe et al 2004, Gates 2003, Alaszewski et al 2001a, Gates et al 2001, Bryan et al 2000, Glasby 2000, Kastermans and Oud 2000, Barr et al 1999, Chambers 1998, Gilbert et al 1998, Department of Health 1995a, Gabriel 1994, Miller et al 1987). Nursing and non-nurse care staff were asked to indicate the frequency with which they carried out each of an extended list of interventions (forty-four in all). The second key question centred on their rating as to whether or not certain interventions were performed either exclusively by nurses, by nurses *and* by others, or exclusively by other non-nurse staff.

7.1 Frequency of Care Interventions

The survey questionnaire presented respondents with forty-four interventions that were identified in preliminary studies, as well as in the nursing literature, as being important for nursing. The amalgam of these sources is presented in Table 7.1. Respondents were requested to indicate the frequency with which they carried out each intervention on an ordinal scale (Table 7.2).

It had also emerged, in preliminary studies, that there may have been differences between the roles of nurses in institutional residential units and those in community residential units. These three groups, nurses in institutional residential services (NIRS), nurses in community-based residential services (NCRS) and non-nurses in community residential services (NNCRS) became the cohorts for examining the frequency with which interventions were being employed within intellectual disability residential services. This latter group was defined as a community-based cohort as a result of the original inclusion criteria which sampled from those non-nurses who were working in roles also open to nurses. Such generic roles have developed widely in community-based residential services, but not in institutions, where nursing and care staff roles remain delineated. This provided a basis for developing a role description of caring by these three staff groups within in such services, as well as for examining the interventional contribution of each of these categories of staff to that role description. It is noted, however, that, whereas these groups account for a large proportion of core-care staff within services, other multidisciplinary team members have not been included here as their caring is of an intermittent character.

Table 7.1: Contribution of sources to the development of the interventional component of the survey questionnaire

Delphi Study	**Focus Groups**	**Key Informant Interviews**	**Kastermann & Oud (2001)**
Promoting Independence	Self-care assistance		Self-care assistance
Bathing clients		Meeting clients’ personal hygiene needs	Self-care assistance: bathing/hygiene
Attending to clients’ hygiene needs Dressing clients			Perineal care
Feeding clients		Feeding clients	Oral health promotion
Looking after clients’ dietary needs		Providing oral and dental care	
		Managing clients’ diets	
Promoting skin integrity		Preventing pressure ulcers	Active listening
Providing a happy, safe and comfortable environment	Safety enhancement	Coordinating care	Security enhancement
Advocating for clients		Organising and managing appointments	Safety enhancement
		Planning individual programmes	Humor
		Managing staff	
		Directing care	
Monitoring clients’ physical health Infection control		Caring for clients’ medical needs	
		Monitoring physical health	
		Managing illness	
		Suctioning clients’ airways	
		Performing postural drainage	
		Performing catheterisation	
		Carrying out urostomy and colostomy care	
		Carrying out physical care	
		Performing dressings	
		Performing peg feeds	
		Physical care	
		Care of hands and feet	
		Providing alternative therapeutic interventions	
Managing seizure activity	Seizure management	Managing epilepsy	
Managing challenging behaviour, aggressive outbursts	Anger control assistance	Managing behaviour	
Educating clients in socially acceptable behaviour			
Communicating with clients	Communication enhancement	Communicating	Presence
	Communication enhancement: active listening	Listening and counselling	Shift report
			Documentation
Liasing with parents/siblings and guardians		Liason work	
Providing for clients’ spiritual needs	Emotional support		
Managing immobility			Emotional support
Mobilising clients			
			Sleep enhancement
	Medication management	Administering medication	Medication management
			Medication administration: oral
			Teaching: prescribed medication

Table 7.2: Interventional component of survey questionnaire

What is the frequency with which the following interventions are carried out by you in your main place of work?

	Daily	**Weekly**	**Monthly**	**Occasionally**	**Never**
Direct Care Interventions					
Planning care					
Managing seizures					
Managing physical illness					
Managing mental illness					
Enhancing safety					
Assisting clients to control their anger					
Managing clients' behaviour					
Providing mental health assistance					
Promoting good oral health					
Managing nutritional intake					
Controlling infection spread					
Preventing infection					
Suctioning clients' airways					
Enhancing sleep					
Tube feeding clients					
Surveying clients' skin					
Promoting exercise					
Providing recreation					
Administering medications					
Keeping medications safe					
Assisting in maintaining the home environment					
Enhancing socialisation					
Providing humour					
Being present to clients					
Emotional support					
Enhancing communication					
Providing spiritual support					
Assisting clients with self-care: toileting					
Assisting clients with self-care: dressing/grooming					
Assisting clients with self-care: bathing/hygiene					
Assisting clients with self-care: feeding					
Management & Administration Interventions					
Giving verbal shift report					
Documenting care					
Managing staff - general					
Attending meetings					
Managing staff rosters					
Managing unit/house finances					
Liaison Interventions					
Liaising with multidisciplinary team					
Liaising with external intellectual disability agencies					
Liaising with other external agencies					
Advocating for clients					
Educational Interventions					
Developing personal competencies					
Training staff					
Teaching students					

The combined cohorts accounted for 74% (n=455) of the 614 respondents. Of these 48.6% (n=221) were nurses working in institutional residential units; 15.6% (n=71) were nurses working in community residential residences; and 30.1% (n=137) were non-nurse care staff working, almost entirely, within community residential services. The remaining 5.7% (n=26) of participants did not identify their working location, and were, therefore, excluded from the analysis.

The frequencies with which nurses and non-nurse care staff reported themselves to employ each of the interventions was obtained, but the level of specificity did not lend itself to robust analysis given the size of the sample obtained (see Appendix D – tables D1 and D2). In view of this, it was considered that the interventions needed to be grouped under a reduced number of items. For this reason factor analysis was employed.

7.1.1 Factor Analysis

Principal component and factor analysis are useful for analysing scores on large numbers of variables and achieving data reduction, thus developing a single composite factor from several apparently unassociated variables based on the statistical significance that exists between those variables (Tabachnick and Fidell 2001, De Vaus 2002). Factor analysis is particularly useful in theoretical modelling, producing factor-based matrices which may be used as a basis for representing reality (Nunnelee and Spaner 2000). It also provided a means of demonstrating content and construct validity of the interventional component of the questionnaire (Clark et al 2003, Considine and Martin 2005). It was employed in this study in order to reduce the number of interventional items into a set number of factors, based on the interrelationships between those interventional items.

Exploratory factor analyses with Varimax rotation were conducted using SPSS for Windows (version 11.0.1) for the combined sample as well as for each of the three cohorts separately. A loading of >.40 was applied for items on each factor. Whilst this is considered to be a fairly liberal loading, it did provide an initial perspective on the correlations between items (Tabachnick and Fidell 2001). Following consideration of the items and of their location on the rotated component matrix, it was considered that such a loading facilitated the inclusion of too wide a range of items on the factor matrix. For this reason it was decided that a higher loading of >.55 be chosen. Whilst it is the researcher's prerogative to make decisions regarding cut-off points based on an interpretation of factors (Tabachnick and Fidell 2001), it is noted that the cut-off point applied in this analysis is in line with those that are considered by Comrey and Lee (1992) to be highly appropriate.

7.1.2 Factor Analysis of Caring in Residential Services

Data from all three groups was subjected to factor analysis with Varimax rotation using SPSS FACTOR on 44 interventional items from the survey questionnaire. This allowed for content and construct validity of the interventional component of the questionnaire to be established. Principal components extraction was used prior to principal factors extraction to estimate the number of factors and presence of outliers. Suitability of the set of items for factor analysis was established by computing the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO). The KMO value of 0.873 confirmed that the correlations were sufficiently large to make factor analysis suitable (De Vaus 2002). Five factors were extracted in the unrotated component matrix (Table 7.3).

Table 7.3: Summary of factor extraction results

Factor	Eigenvalue	% Variance Explained	Cumulative % Variance Explained
1	12.624	28.7	28.7
2	4.767	10.8	39.5
3	2.978	6.8	46.3
4	2.232	5.1	51.4
5	1.876	4.3	55.6

Varimax, orthogonal rotation was chosen to maximise the variance of squared factor loadings of a factor on all of the items in the factor matrix (Nunnally 1994). As initial attempts at factor analysis had produced a large number of factors with low interventional loadings and little obvious relationship between interventional items within factors, it was decided to force the analysis into five factors. This decision was guided by the fact that these five factors accounted for greater than 50% of the variance. With a cut-off of >.55 for inclusion of an item in interpretation of a factor, 11 of the 44 variables did not load on any factor.

Table 7.4: The factor matrix for caring roles in intellectual disability services (n=455)

Factor Loading Values and Loadings of Items That Exceed 0.55

	Interventional Factor				
	Physical Health	*Psycho-Social*	*Management*	*Technical*	*Mental Health*
Assisting clients with self-care: dressing/grooming	**.759**				
Assisting clients with self-care: bathing/hygiene	**.747**				
Surveying clients' skin	**.725**				
Promoting good oral health	**.716**				
Assisting clients with self-care: toileting	**.658**				
Managing nutritional intake	**.623**				
Administering medication	**.585**				
Giving verbal shift report	**.561**				
Keeping medications safe	**.556**				
Enhancing communication		**.834**			
Providing humour		**.808**			
Enhancing socialisation		**.762**			
Emotional support		**.759**			
Being present to clients		**.756**			
Promoting recreation		**.690**			
Promoting exercise		**.659**			
Liaising with external intellectual disability agencies			**.693**		
Liaising with multidisciplinary team			**.679**		
Managing staff - rosters			**.663**		
Managing staff - general			**.657**		
Liaising with other external agencies			**.630**		
Training staff			**.613**		
Attending meetings			**.563**		
Tube feeding				**.709**	
Controlling infection spread				**.671**	
Preventing infection				**.648**	
Managing seizures				**.631**	
Managing physical illness				**.585**	
Assisting clients with self-care: feeding				**.567**	
Assisting clients to control their anger					**.693**
Managing mental illness					**.682**
Providing mental health assistance					**.677**
Managing clients' behaviour					**.677**

This indicates the heterogeneity of items on this part of the questionnaire. None of the items were shown to be complex (loading on more than one factor) at this cut-off point.

The pattern matrix for the five-factor solution, accounting for 55.6% of variance, is displayed in Table 7.4. The interventional items of the factors are ordered and grouped according to size of loading to facilitate easy interpretation. Each factor was subsequently named from the items that loaded most highly onto that factor.

It can be seen from this analysis that the first factor to emerge was termed the Physical Health Maintenance factor, which had nine high-loading items, and accounted for the largest proportion of the variance, nearly 30%. Of these, the first six, with loadings of greater than .60 related to self-care, and health maintenance.

Two of the interventions related to medication management and may be considered to relate to health maintenance. The final intervention item under this factor, related to the shift report, which enables information to be passed on to the staff on the next shift. Whilst this is not an intervention that impinges directly on the client, it does facilitate continuity of care and so promotes consistency of health management as well as being part of the evaluation role of the nurse.

The second factor, termed the Psycho-Social Health Maintenance factor, brought together interventions associated with communication, emotional support and psychological integrity, and accounted for 11% of the variance. Whilst the first five of these items were overtly supportive, the last two were interpreted within the context of psycho-social development through social and physical involvement. All of these interventions loaded above .60.

The third factor, termed the Management factor, described the key interventions that were related to wider management functions and accounted for 7% of the variance. Seven interventions loaded onto this factor and of these six rated greater than .60. The final item that loaded on this factor, attending meetings, is closely related to management, being a forum within which liaisons take place.

The fourth interventional factor, labelled the Technical Health factor, brought together interventions that related to the employment of specific clinical skills in the management or particular client/environmental issues, and accounted for 5% of the variance. The first four of these loaded highly.

The final interventional factor addressed two somewhat related foci: mental illness and challenging behaviour. It was difficult to identify an acceptable label for this factor, but, as both could be associated with mental health (Department of Health and Human Services 2001), the label ‘Mental Health Maintenance’ was chosen. This accounted for only 4% of the variance. All four interventions that loaded here scored greater than .60.

The factor matrix for caring roles (Table 7.4) was focused on the generic concept of ‘caring’ in residential intellectual disability services. Thus, the matrix was developed with reference to the amalgamated responses of the three cohorts of staff. Separate matrices were developed based on factor analysis of the responses of each of the two professional staff subgroups, namely, nursing and non-nurse care staff, as well as for the two residential settings – institutional residential care and community residential care. These matrices, which are presented in Appendix D (tables D3, D4, D5 and D6), identified if the same factors held across different settings and professional groups.

Within the amalgamated matrix, eleven interventions did not load onto any of the factors. Six of these were from the direct care section of the original interventional list and included: enhancing safety, suctioning clients’ airways, enhancing sleep, assisting in maintaining the home environment, planning care and providing spiritual support. Whereas the first four of these did load on either the community or institutional residential factor matrices, the final two did not. Five other items failed to load onto factors in any of the matrices: documenting care plans, managing unit/house finances, advocating for clients, developing personal competencies and teaching students.

Analysis of caring 1) between residential and community services, and 2) between nurses and non-nurses resulted in matrices which demonstrated some differences (Table 7.5).

Table 7.5: Prioritised interventional factors identified in factor analyses

	Interventional Factors				
	1	*2*	*3*	*4*	*5*
Generic Care (n=455)	Physical Health	Psycho-Social	Management	Technical	Mental Health
Institutional Care (n=212)	Physical Health	Psycho-Social	Management	Technical	
Community Care (n=196)	Physical Health	Technical	Management	Mental Health	Psycho-Social
Nursing care (n=304)	Bio-Psycho-Social Health	Management – Communication	Technical	Mental Health	Management – General
Non-nurse care (n=151)	Mental Health	Management – Communication	Recreation	Management – General	Physical Health

Initial comparison of these care matrices was performed through an examination of the factors: physical health maintenance, psycho-social health maintenance, management (including communication and general), technical and mental health maintenance. These will be examined in turn.

7.1.2.1 Physical Health Maintenance Factor

Physical health maintenance interventions may be described as those interventions that are employed in order to maintain a client’s physical health within satisfactory parameters. This factor, whilst emerging as the one that accounted for the greatest amount of variance in both the institutional (33.84%) and community (18.81%)

residential settings, was most prominent in the former situation where the majority of nurses were employed. The interventional components of the factor differ between both settings, with the items relating to self-care and biological system function scoring most highly on the institutional matrix, and physical integration (recreation and exercise) scoring highly on the community matrix (Table 7.6).

Table 7.6: Comparison of items on the physical health maintenance factor in institutional and community residential settings (listed in order of factor loading)

Institution (33.84% of variance)	*Community (18.81% of variance)*
Assisting clients with self-care: bathing and hygiene	Promoting recreation
Assisting clients with self-care: dressing and grooming	Promoting exercise
Managing nutritional Intake	Managing nutritional intake
Promoting good oral health	Administering medications
Keeping medications safe	Keeping medications safe
Assisting clients with self-care: toileting	Assisting clients with self-care: bathing and hygiene
Administering medication	Promoting good oral health
Surveying clients’ skin	Assisting in maintaining the home environment
Assisting clients with self-care: feeding	Enhancing socialisation
Promoting recreation	Assisting clients with self-care: dressing and grooming
Assisting in maintaining the home environment	Enhancing communication
Promoting exercise	

Important differences may be seen between nurses and non-nurses in respect of this factor. In fact, physical health does not appear as a unique factor on the nursing care matrix. Instead, it is merged with psychological and social items to form what has been termed the Bio-Psycho-Social factor. That such diverse items came together under one factor might, in some situations, be construed to be accidental and, hence, meaningless. The fact that this has emerged in relation to a profession whose members describe as having a uniquely integrated, *holistic* perspective of care may be significant (Government of Ireland 1998, Alaszewski et al 2001). In the non-nurse care staff matrix, physical health was the fifth factor and only comprised two items related to nutrition and medication (Table 7.7). Other aspects of physical health, including assisting clients with self-care: dressing and grooming loaded onto a general health factor, which included physical and mental health interventions.

Table 7.7: Comparison of items on the physical health maintenance factor in nursing and non-nurse care staff matrices (listed in order of factor loading)

Nursing (38.97% of variance)	*Non-Nursing Care Staff (4.91% of variance)*
Enhancing communication	Managing nutritional intake
Managing nutritional intake	Administering medication
Promoting exercise	
Promoting good oral health	
Providing humour	
Enhancing safety	
Keeping medications safe	
Assisting clients with self-care: toileting	
Being present to clients	
Assisting clients with self-care dressing and grooming	
Promoting recreation	
Administering medications	
Enhancing socialisation	
Assisting clients with self-care: bathing and hygiene	
Surveying client's skin	
Assisting clients to control their anger	
Assisting in maintaining the home environment	
Planning care	
Managing client's behaviour	

7.1.2.2 Psycho-Social Health Maintenance Factor

The psycho-social health maintenance factor brought together interventions that were centred on maintaining and improving the psychological and social well-being of the client, through supportive and integrating techniques. This factor emerged as the second strongest factor on the institutional care matrix, accounting for 11.4% of the variance. It was, however, only the fifth factor identified on the community matrix and explained only 4.23% of the variance there (Table 7.8).

Table 7.8: Comparison of items on the psycho-social health maintenance factor in institutional and community residential settings (listed in order of factor loading)

Institution (11.4% of variance)	*Community (4.23% of variance)*
Enhancing communication	Emotional support
Providing humour	Providing humour
Emotional support	
Managing clients' behaviour	
Being present to clients	
Enhancing safety	

Psycho-social health was, like physical health, not a unique factor in the nursing matrix but was merged with physical health under the Psycho-Social-Health Maintenance factor. It did not appear on the non-nurse care staff matrix either, but some of the items were brought together under a Recreation factor, which encompassed exercise, socialisation and humour. Supportive interventions were not included in this.

7.1.2.3 Management Factor

Management interventions are those activities that involve supervision and administration of a residential unit with respect to maintaining its daily functioning. This includes interventions related to allocation of staff, coordination of facilities, internal and external communication and budgeting. This was the third highest factor in explaining variance in the care matrices of both institutional and community residences. There is no significant difference between the items that are contained in both settings (Table 7.9).

Table 7.9: Comparison of items on the management factor in institutional and community residential settings (listed in order of factor loading)

Institution (4.87% of variance)	*Community (7.12% of variance)*
Liasing with external intellectual disability agencies	Liasing with multidisciplinary team
Liasing with other external agencies	Liasing with external intellectual disability agencies
Managing staff – rosters	Training staff
Liasing with multidisciplinary team	Managing staff – rosters
Managing unit finances	Liasing with other external agencies
Managing staff – general	Managing staff – general
Attending meetings	
Training staff	

When the management factor is examined within the context of the two staff groups, it is interesting to note that it takes on two manifestations: 1) a management communication aspect and 2) a general management component (Tables 7.10a and 7.10b). This division is observed in both groups with similar items therein. The nursing matrix, however, had two items loading onto it that are not in the non-nurse care staff matrix: advocating for clients and developing personal competencies, whereas liaison with the multidisciplinary team appears uniquely in the non-nursing matrix.

Table 7.10a: comparison of items on the management–communication factor in nursing and non-nursing (listed in order of factor loading)

Nursing (10.04% of variance)	*Non-Nursing (9.95% of variance)*
Liasing with other external agencies	Liasing with external intellectual disability agencies
Attending meetings	Liasing with other external agencies
Liasing with external intellectual disability agencies	Liasing with multidisciplinary team
Advocating for clients	Attending meetings
Developing personal competencies	

Table 7.10b: Comparison of items on the management-general factor in nursing and non-nursing (listed in order of factor loading)

Nursing (3.68% of variance)	*Non-Nursing (4.98% of variance)*
Managing staff – rosters	Managing staff – general
Managing staff – general	Training staff
Managing unit finances	Managing staff – rosters

7.1.2.4 Technical Health Factor

The technical health factor encompasses activities that aimed at the maintenance or improvement of health status and which require particular clinical skills for their effective performance. This factor accounted for the second greatest amount of the variance in the community care matrix, but was the fourth, and final, factor in the institutional matrix, accounting for a very small amount of the variance (Table 7.11).

Table 7.11: Comparison of Items on the Technical Health Factor in Institutional and Community Residential Settings (listed in order of factor loading)

Institution (4.16% of variance)	*Community (11.02% of variance)*
Tube feeding	Tube feeding clients
Managing physical illness	Assisting clients with self-care: feeding
Controlling infection spread	Suctioning clients' airways
Suctioning clients' airways	Managing seizures
Managing seizures	Enhancing sleep
	Controlling infection spread

The factor did not arise in the non-nursing care matrix, some of its items being subsumed in the uniquely identified general health factor. Three items loaded onto the factor in the nursing matrix: tube feeding, assisting clients with self-care: feeding, and controlling infection spread. These explained 5.45% of the variance.

7.1.2.5 Mental Health Maintenance Factor

This factor is defined as the interventions that assist clients to successfully perform mental function, resulting in productive activities, fulfilling relationships with other people, and to be able to change and to cope with adversity (DHHS 1999 cited in DHHS 2001). The items that loaded onto it were largely related to mental illness, challenging behaviour and anger. This was present in the community and nursing care matrices, but not in the others.

7.1.3 Conclusions of the Factor Analysis

The factor analysis demonstrated differences in relation to the frequency with which nurses and non-nursing care staff employ combinations of specific interventions. Whilst many of the same interventions arose in the analyses of both groups, they loaded together differently, leading to the emergence of distinct prioritised factors, which suggested varying, and perhaps unique, approaches to care. It is notable that nursing was linked to health (physical and mental) and its management using technical and clinical approaches. Comparison of the analysis of community and institution based residences did not demonstrate marked differences in relation to factor prioritisation.

7.2 Nurses' and Non-Nurses' Employment of Care Interventions

The factor analysis, by drawing out the relationships between the employment of particular items, and organising the related items into a number of relatively discreet factors, provided a basis for further examination of those interventional items and their usage across staff groupings and care settings. Further investigation was carried out through the use of non-parametric analyses in order to explore any differences between the three staff groups in relation to the frequency with which the items within the interventional factors on the Care Role Matrix (Table 7.4) were employed.

7.2.1 Analytic Approach Adopted

The respondents had been requested to identify the frequency with which they carried out forty-four specified interventions. This was measured using a five-point Likert-type scale, where 1= 'daily', 2= 'weekly', 3= 'monthly', 4= 'occasionally' and 5= 'never'. Factor analysis of all nurses and non-nurse care staff had reduced the number of interventions and restructured them under five factor headings: physical health maintenance (nine interventions), psycho-social health maintenance (seven interventions), management (seven interventions), technical health (six interventions) and mental health maintenance (four interventions). It was therefore possible to count for each respondent the number of interventions within a factor that they undertook on a daily basis. This would give an indication of the extent to which a set of interventions were employed. For example, a score of 9 on physical health maintenance would indicate that all nine interventions were performed on a daily basis whereas a score of 0 indicated that none were. This count was repeated for each of the five factors although the maximum score on each varied due to the different number of items on each factor. These are shown in Table 7.12 along with the median and range scores for each factor, broken down by the three subgroups.

Table 7.12: Daily employment of factorial interventions by each of the three staff groups, with median and range scores for each item, and significance of differences between groups.

		Physical Health *(n=9)*	*Psycho-Social Health* *(n=6)*	*Management* *(n=7)*	*Technical Health* *(n=5)*	*Mental Health* *(n=4)*
Nurse (instutution)	N	221	221	221	221	221
	Median	9.00	6.00	1.00	3.00	3.00
	Range	0.00-9.00	0.00-6.00	0.00-7.00	0.00-5.00	0.00-4.00
Nurse (community)	N	71	71	71	71	71
	Median	9.00	6.00	1.00	2.00	2.00
	Range	0.00-9.00	0.00-6.00	0.00-7.00	0.00-5.00	0.00-4.00
Non-Nurse (community)	N	137	137	137	137	137
	Median	8.00	6.00	0.00	1.00	3.00
	Range	0.00-9.00	0.00-6.00	0.00-7.00	0.00-4.00	0.00-4.00
	Chi-Square Test	χ^2=60.412, df=18, p<.0001	χ^2=20.159, df=12, p<.064	χ^2=60.382 df=14, p<.0001	χ^2=59.997, df=10, p<.0001	χ^2=12.114, df=8, p<.146

As the groups were not normally distributed and showed heterogeneity of variance, it was decided to use the Kruskal-Wallis ANOVA by ranks test to identify whether or not significant differences existed across the three groups (Wagner 1992, Munro 2001). Where significant difference was found, post hoc analyses were carried out, through pairwise comparisons using the Mann-Whitney test, in order to identify which groups were significantly different from another. As the performance of multiple pairwise comparisons is identified as being associated with increased chance of type I error (Pett 1997) the Holms Stepdown Procedure was applied to militate against this.

7.2.2 Anticipated Differences

It was anticipated that there would be differences in medians among nurses and non-nurses, with regard to the frequency of employment of interventions within the five factors, such that nursing would be shown to have a distinct role from non-nurses.

7.2.3 Physical Health Maintenance Factor

An examination of the medians among nurses working in institutional settings, nurses working in community settings and non-nurses working in the community, demonstrated that there were no differences between the two nursing groups in respect of the interventions that loaded onto the physical health maintenance factor. There were however differences in the medians among nurses and non-nurses. This was confirmed by the Mann-Whitney test which indicated that nurses employed these interventions more frequently than did non-nurses (Table 7.13). No significant difference was found between institutional-based nurses and community based nurses, or between the two community-based cohorts.

Table 7.13: Results of the Mann-Whitney test with Holms Stepdown procedure in respect of the physical health maintenance factor

Factor	*i*	*Group*	*Comparison*	*Mean Rank*	*Obtained p value*	*α/(k-i+1)**
Physical Health Maintenance	1	1 vs. 2	Nurse (IRS) vs. Nurse (CRS)	Nurse (IRS) 147.07 Nurse (CRS) 144.74	.817	0.017
	2	1 vs. 3	Nurse (IRS) vs. Non-Nurse (CRS)	Nurse (IRS) 189.93 Non-Nurse 162.67	.008	0.025
	3	2 vs. 3	Nurse (CRS) vs. Non-Nurse (CRS)	Nurse (CRS) 114.25 Non-Nurse 99.45	.073	0.05

* This column provides a reference for level of significance in respect of each comparison as per Holms Stepdown

7.2.4 Psycho-Social Health Maintenance Factor

The median score of all three staff groups showed no difference in respect of the employment of the interventions that loaded onto the psycho-social health maintenance factor (Table 7.12). Furthermore, no significant difference was found between the two nursing groups, suggesting that type of residential setting (community or institutional) was not a determining factor. Non-parametric analysis, however, did identify significant differences indicating that non-nurses in community settings employ these interventions more frequently than nurses in either institutional or community residential services as indicated by the rank scores (Table 7.14).

Table 7.14: Results of the Mann-Whitney test with Holms Stepdown procedure in respect of the psycho-social health maintenance factor

Factor	***i***	***Group***	***Comparison***	***Mean Rank***	***Obtained p value***	***α/(k-i+1)****
Psycho-Social Health Interventions	1	1 vs. 2	Nurse (IRS) vs. Nurse (CRS)	Nurse (IRS)149.18 Nurse (CRS) 138.15	.282	0.017
	2	1 vs. 3	Nurse (IRS) vs. Non-Nurse (CRS)	Nurse (IRS) 170.29 Non-Nurse 194.36	.012	0.025
	3	2 vs. 3	Nurse (CRS) vs. Non-Nurse (CRS)	Nurse (CRS) 90.68 Non-Nurse 111.66	.004	0.05

* This column provides a reference for level of significance in respect of each comparison as per Holms Stepdown

7.2.5 Management Factor

Differences were noted in the median scores among nurses and non-nurses, indicating that nurses, irrespective of residential setting, employed management interventions more frequently than did non-nurses in the community. These differences were significant. Further analysis, using the Mann-Whitney test confirmed this (Table 7.15), but identified the significant difference to be between nurses in institutions and non-nurses in the community, with the former employing the interventions more frequently. No significant difference was noted among the two nursing groups or among the two community-based cohorts.

Table 7.15: Results of the Mann-Whitney test with Holms Stepdown procedure in respect of the management factor

Dimension	***i***	***Group***	***Comparison***	***Mean Rank***	***Obtained p value***	***α/(k-i+1)****
Management Interventions	1	1 vs. 2	Nurse (IRS) vs. Nurse (CRS)	Nurse (IRS)152.02 Nurse (CRS) 129.32	.046	0.017
	2	1 vs. 3	Nurse (IRS) vs. Non-Nurse (CRS)	Nurse (IRS) 194.37 Non-Nurse 155.51	.0001	0.025
	3	2 vs. 3	Nurse (CRS) vs. Non-Nurse (CRS)	Nurse (CRS) 106.70 Non-Nurse 103.36	.695	0.05

* This column provides a reference for level of significance in respect of each comparison as per Holms Stepdown

7.2.6 Technical Health Factor

The median scores suggested that significant differences existed in respect of the frequency of employment of technical health interventions (Table 7.12), with nurses in institutions employing these more frequently than either of the other two groups, and with nurses in the community using them more frequently than non-nurses. Further analysis, using the Mann-Whitney test, confirmed that the differences between nursing and non-nursing employment of the technical health interventions was significant (Table 7.16).

Table 7.16: Results of the Mann-Whitney test with Holms Stepdown procedure in respect of the technical health factor

Dimension	***i***	***Group***	***Comparison***	***Mean Rank***	***Obtained p value***	***$\alpha/(k-i+1)$****
Technical Health Interventions	1	1 vs. 2	Nurse (IRS) vs. Nurse (CRS)	Nurse (IRS)151.86 Nurse (CRS) 129.82	.053	0.017
	2	1 vs. 3	Nurse (IRS) vs. Non-Nurse (CRS)	Nurse (IRS) 212.13 Nurse (CRS) 126.86	.0001	0.025
	3	2 vs. 3	Nurse (CRS) vs. Non-Nurse (CRS)	Nurse (CRS) 127.70 Non-Nurse 92.47	.0001	0.05

* This column provides a reference for level of significance in respect of each comparison as per Holms Stepdown

7.2.7 Mental Health Maintenance Factor

No significant differences were found among the medians of the three groups in relation to the employment of mental health interventions, with these activities being carried out to a similar extent by each of the staff groups on a daily or weekly basis (Table 7.12).

7.2.8 Conclusions of the Non-Parametric Analysis

Following on from the factor analysis, statistical analyses were carried out to investigate any differences in the frequency of employment of the five factors among nurses working in institutions, and the two community-based cohorts. In all factors, except mental health, significant differences were found among institution-based nurses and their non-nursing colleagues in the community. The same pattern of difference was noted between nurses and non-nurses in the community, with the exception of the management factor. Whilst nurses in both settings reported more frequent employment of physical health maintenance and technical health factors than did non-nurses, this was reversed for the psycho-social health maintenance factor, which was more frequently employed by non-nurses (Table 7.17).

Table 7.17: Differences and similarities in reported frequency of employment of interventional factors by three staff groupings

	Physical Health	*Psycho-Social Health*	*Management*	*Technical Health*	*Mental Health*
Differences	NIRS > NNCRS NCRS > NNCRS	NNCRS > NIRS NNCRS > NCRS	NIRS > NNCRS	NIRS > NNCRS NCRS > NNCRS	
Similarities	NIRS = NCRS	NIRS = NCRS	NIRS = NCRS NCRS = NNCRS	NIRS = NCRS	NIRS = NCRS NIRS = NNCRS NCRS = NNCRS

NIRS=Nurses in institutional service; NCRS=Nurses in community services; NNCRS=Non-nurses in community services

No significant difference was noted among the two nursing groups in respect of any of the factors. This suggested that there may be a core nursing role transcending settings, and involving, in particular, physical health and technical health interventions. Any demarcation between nursing and non-nursing staff in the community in relation to management and mental health interventions appeared to have disappeared, with similar employment of such interventions reported by both groups.

As these findings were not placed within any context, it was necessary to explore if any other factors could be responsible for the employment of particular factorial interventions, and could therefore be predictors for their occurrence.

7.3 Predicting the Employment of Care Interventions

In the light of the findings of the factor analysis, further analysis was required to be carried out on the data set to ascertain if the employment of such interventions was related to service, client or staff factors in addition to the nursing/non-nurse care staff factor. Although no previous studies were located that employed logistic regression in relation to specific care interventions, it has been used in many studies as a means of establishing relationships between outcome and a set of predictors (Bennett et al 1991). Addington-Hall and Altman (2000) applied a logistic regression model to their investigation into predicting what terminally ill patients would receive care from community specialist care nurses. Bowers et al (2000) reported that they achieved an overall 77% predictive adequacy in respect of identifying which patients in acute psychiatric wards were most likely to abscond. Anthony et al (2000) explored three covariables as predictors of pressure ulcer development in elderly patients, using logistic regression, whilst Preski and Shelton (2001) reported on its use in relation to prediction of serious criminal outcomes in adolescent offenders.

This study was concerned with identifying the factors that predicted the employment of the highest-loading items within each of the interventional factors. As the mental health maintenance factor included the least number of items – four – it was decided that the four items that achieved the greatest loading in each of the factors would be chosen as dependent variables in the logistic regression. As high-loading items, these would provide the best indication of their underlying factors (Table 7.18).

Table 7.18: Dependent variables employed in logistic regression analyses

Physical Health Maintenance Factor	**Psycho-Social Health Maintenance Factor**	**Management Factor**	**Technical Health Factor**	**Mental Health Maintenance Factor**
1. Assisting clients with self-care – dressing & grooming 2. Assisting clients with self-care – bathing & hygiene 3. Promoting good oral health 4. Surveying clients' skin	1. Enhancing communication 2. Providing humour 3. Being present to clients 4. Enhancing socialisation	1. Liasing with external intellectual disability agencies 2. Liasing with multidisciplinary team 3. Managing staff – rosters 4. Managing staff – general	1. Controlling infection spread 2. Tube feeding clients 3. Preventing infection 4. Managing seizures	1. Assisting clients to control their anger 2. Providing mental health assistance 3. Managing mental illness 4. Managing clients behaviour

The regression analyses sought to identify any predictive relationship between these dependent variables and various service, staff and client variables (Table 7.19), with a view to identifying which specific independent variables were predictors for the employment of the dependent variables. These variables, several of which had multiple outcomes, were recoded into dichotomous variables in order to meet the requirements of binary logistic regression. The recoded variable outcomes are presented as footnotes to the table of findings (Table 7.20).

Table 7.19: Covariables employed in logistic regression analyses

Service Variables	**Staff Variables**	**Client Variables**
1. Service type	1. Gender	1. Clients' intellectual disabilities
2. Service location	2. Age	2. Clients' age groups
3. Type of residence	3. Length of service	3. Number of concomitant problems
	4. Highest qualification attained	
	5. Nursing qualifications	
	6. Employment role	
	7. Employment location	

One variable, however, 'employment role: nurse/non-nurse care staff' was central to this study, for it provided and insight into whether or not being a nurse was a predictor for the daily employment of specific care interventions, irrespective of service, staff or client variables. If being a nurse was found to be positively predictive, the associated intervention(s) could be suggested to be part of the unique interventional role of intellectual disability nursing.

Logistic regression, with all covariants being entered together in each step (ENTER method) was used, with a variable entry P-value of 0.05 and a removal P-value of 0.10. Goodness-of-fit was measured using the Hosmer and Lemeshow test, which assesses the observed and predicted numbers of cases for each of the two possible outcomes of the variables. This was done separately for the twenty items identified in Table 7.18.

7.3.1 Results

Table 7.20 shows the predictor variables associated with the daily employment of the four interventional items that loaded most highly onto the five factors in the care matrix.

Table 7.20: Variables† showing statistically significant independent contributions towards predicting the daily employment of care interventions

	Estimated Odds Ratio	95% Confidence Interval	*P*-value
Physical Health Maintenance: Assisting clients with self-care: dressing/grooming			
Service Factors			
Service Type: State	6.027	1.031-35.214	*P*=0.046
Staff Factors			
Type of Nursing Qualification: RMHN	0.201	0.063-0.641	*P*=0.007
Physical Health Maintenance: Assisting clients with self-care: bathing/hygiene			
Staff Factors			
Gender: Male	3.407	1.015-11.432	*P*=0.047
Staff Age: 20-39 years	4.704	1.620-13.655	*P*=0.004
Type of Nursing Qualification: RMHN	0.200	0.072-0.560	*P*=0.002
Physical Health Maintenance: Promoting good oral health			
Service Factors			
Service Type: State	12.363	1.277-119.698	*P*=0.030
Staff Factors			
Type of Nursing Qualification: RMHN	0.168	0.047-0.606	*P*=0.006
Client Factors			
Clients' Age Group: 17-30 years	0.301	0.096-0.939	*P*=0.039
Physical Health Maintenance: Surveying Clients' Skin			
Staff Factors			
Staff Age: 20-39 years	2.971	1.170-7.545	*P*=0.022
Type of Nursing Qualification: RMHN	0.370	0.156-0.879	*P*=0.024
Client Factors			
Clients' Age Group:31-50 years	0.100	0.021-0.471	*P*=0.004
Psycho-Social Health Maintenance: Enhancing Communication			
Service Factors			
Type of Residence: Institutional	6.147	1.060-35.639	*P*=0.043
Psycho-Social Health Maintenance: Enhancing Socialisation			
Service Factors			
Service Type: State	6.449	1.835-22.662	*P*=0.004
Management: Liaising with External Intellectual Disability Agencies			
Staff Factors			
Gender: Male	5.821	1.603-21.134	*P*=0.007
Client Factors			
Number of Concomitant Problems: 6-10 problems	8.846	1.684-46.464	*P*=0.010
Management: Liaising with Multidisciplinary Team Members			
Staff Factors			
Gender: Male	4.158	1.713-10.092	*P*=0.002
Client Factors			
Presence of Concomitant Problems: 6-10 problems	3.060	1.434-6.533	*P*=0.004
Management: Managing Staff - Rosters			
Staff Factors			
Type of Nursing Qualification: RMHN	3.879	1.647-9.135	*P*=0.002
Technical Health: Controlling Infection Spread			
Service Factors			
Type of Residence: Institution	2.138	1.020-4.484	*P*=0.044
Staff Factors			
Gender: Female	2.769	1.121-6.839	*P*=0.027
Type of Nursing Qualification: RMHN	0.485	0.242-0.969	*P*=0.040

	Estimated Odds Ratio	95% Confidence Interval	*P*-value
Technical Health: Tube Feeding			
Service Factors			
Type of Residence: Institution	4.594	1.403-15.043	*P*=0.012
Staff Factors			
Type of Nursing Qualification: RMHN	0.260	0.105-0.646	*P*=0.004
Client Factors			
Clients' Age Group: 0-16 years	3.726	1.320-10.518	*P*=0.013
Clients' Age Group: 31-50 years	0.247	0.085-0.718	*P*=0.010
Number of Concomitant Problems: 6-10 problems	6.616	2.040-21.462	*P*=0.002
Technical Health: Preventing Infection			
Staff Factors			
Type of Nursing Qualification: RMHN	0.325	0.139-0.758	*P*=0.009
Client Factors			
Clients' Age Groups: 17-30 years	0.350	0.141-0.866	*P*=0.023
Technical Health: Managing Seizures			
Service Factors			
Service Types: State	3.032	1.272-7.225	*P*=0.012
Client Factors			
Number of Concomitant Problems: 6-10 problems	6.797	3.393-13.616	*P*=0.000
Mental Health Maintenance: Assisting Clients to Control their Anger			
Staff Factors			
Length of Service: 0-19 years	3.138	1.105-8.911	*P*=0.032
Client Factors			
Clients' Age Groups: 0-16 years	0.130	0.049-0.341	*P*=0.000
Clients' Age Groups: 17-30 years	3.224	1.370-7.590	*P*=0.007
Mental Health Maintenance: Providing Mental Health Assistance			
Service Factors			
Service Type: State	3.126	1.272-7.679	*P*=0.013
Staff Factors			
Staff Age: 20-39 years	2.770	1.228-6.247	*P*=0.014
Type of Nursing Qualification: RMHN	0.412	0.207-0.820	*P*=0.012
Employment Role: Non-nurse	3.540	1.062-11.804	*P*=0.040
Mental Health: Managing Mental Illness			
Service Factors			
Type of Service: State	5.516	1.994-15.260	*P*=0.001
Staff Factors			
Employment Role: Non-nurse	6.154	1.599-23.676	*P*=0.008
Client Factors			
Clients' Age Group: 0-16 years	0.328	0.140-0.768	*P*=0.010
Clients' Age Group: >65 years	2.541	1.010-6.393	*P*=0.048
Mental Health: Managing Clients' Behaviour			
Client Factors			
Clients' Age Group: 0-16 years	0.243	0.092-0.642	*P*=0.004

n=455; 79.5% of cases correctly classified.

†Variables included are:

Service Variables: service type (state/voluntary); type of residential unit (institution/community).

Staff Variables: gender (male/female); staff age (20-39 years/>40 years); type of nursing qualification (RMHN/other nursing registration); length of service (0-19 years/>19 years); employment role (nurse/non-nurse).

Client Variables: clients' age group 0-16 years (yes/no); clients' age group 17-30 years (yes/no); clients' age group 31-50 years (yes/no); number of concomitant problems (1-5/6-10).

This table describes those variables that were significantly predictive of daily employment of the interventions (in bold). Estimated odds ratios indicate the increase (or decrease if odds ratio is less than 1) in the odds of an outcome if the predictor value increases by one unit (Tabachnick and Fidell 2001). Thus, the odds ratio becomes a multiplying factor. For example, the odds for the physical health maintenance intervention, ‘assisting clients with self-care: dressing/grooming’ being employed is more than six times greater when the service setting is ‘state run’.

Although a range of predictor variables were identified across all items, ‘employment role’ emerged only in relation to two mental health maintenance interventions, indicating that the odds for mental health assistance to be provided and for mental illness management to be provided was three and a half and six times greater respectively, if the carer was a non-nurse. Furthermore, in all interventions, except managing staff – rosters, there was a significantly reduced likelihood of the interventions being employed on a daily basis, where the nurse was a RNID.

Other relationships of note were as follows. The staff variable ‘gender’ increased the odds of clients being assisted with bathing and hygiene by more then three times when the staff member was male. Similarly, male staff were significantly more likely to liaise with other multidisciplinary team members than female staff. Staff age (20-39 years) increased the likelihood of bathing and hygiene needs being met, of clients’ skin being surveyed and of mental health assistance being provided on a daily basis. Two service-related variables, state-run services and institutional residences were found to be positive predictors for the employment of interventions, whilst the client variable, ‘number of concomitant problems’ increased the odds of particular management and technical health interventions being employed regularly. Client age groups alternately increased or decreased odds. However, the relatively small sample size and the biased sample limits the confidence with which these results can be generalised but it does serve as the basis for further studies.

7.4 Conclusion

The results of the factor analysis and logistic regression provide a rich body of data for discussion, and challenge concepts regarding the professionalisation of caring in Irish intellectual disability services. Differences are, however, evident from both tests with, for example, non-parametric analysis suggesting that physical health maintenance interventions were performed more frequently by nurses than by non-nurses. However, the results of the logistic regression suggest that other pertinent findings may account for these differences in specific interventions; for example, the daily employment of certain interventions was related to staff gender and age, type of nursing qualification, client age and service type. Similar findings emerged in respect of management interventions and technical health interventions. Only service variables were implicated as being predictive of psycho-social health maintenance interventions. Median scores showed no significant differences between nurses and non-nurses employment of a range of mental health interventions. Logistic regression, however, revealed that if the carer was a non-nurse, there was an increased likelihood of specific interventions being employed.

The implications of these findings for the definition and description of nursing’s unique interventional contribution to care will be discussed in chapter 9.

CHAPTER 8

Pan-Organisational Survey: Perceptions on Care Interventions

8.0 Introduction

The conceptualisation of interventions of care, which emerged from the factor analysis, identified what may be termed ‘a role matrix’ for caring in intellectual disability services. Whilst both nursing and non-nursing care staff role matrices were described as a subset of this, further analysis indicated that many of the differences between both groups were not grounded in the employment role of the professional carer, but were, rather, related to other service, staff and client variables.

The previous chapter has described the interventional role of two staff groups based on their reported employment of specific interventions. One other aspect in describing roles was raised by service and clinical managers during the key informant interviews: namely other people’s perception of what nursing’s role is. In this study, respondents were, therefore, also asked to provide information on which staff they considered was responsible for the employment of specific care interventions, and whether these activities were carried out exclusively by one of the staff groups or as shared activities. Thus, respondents provided information on interventions related to each of the factors identifying what staff group(s) they considered to be responsible for their performance. Crosstabulation of the four staff groups with four outcome categories – uniquely nursing intervention, uniquely non-nurse care staff intervention, uniquely other staff group's intervention and shared intervention – allowed staff groups' responses to be presented in percentages.

8.1 Physical Health Maintenance Interventions

Respondents provided information on four interventions related to the physical health maintenance factor identifying what staff group(s) they considered to be responsible for their performance. As Table 8.1 shows, self-care assistance activities, such as 'bathing, hygiene and toileting' and 'dressing and grooming', were considered by all four groups to be predominantly shared activities. This was statistically significant. Two interventions, however, were suggested by the majority of nurses and multidisciplinary team members to be primarily performed by nurses alone.

Table 8.1: Nurses' and non-nurse care staffs' perceptions on who performs selected physical health maintenance factor interventions.

		Nurse	*Non-nurse care staff*	*Other staff*	*Shared Activity*	χ^2
Bathing, Hygiene and Toileting	Nurse	28 (21.5%)	1 (0.8%)	8 (6.2%)	93 (71.5%)	χ^2=48.711, df=9, p>.0001
	Non-nurse	3 (3.2%)	7 (7.4%)	28 (29.5%)	57 (60.0%)	
	Multidisciplinary	3 (11.1%)	1 (3.7%)	2 (7.4%)	21 (77.8%)	
	Service Managers	0 (0%)	0 (0%)	0 (0%)	9 (100%)	
Dressing and Grooming	Nurse	38 (29.0%)	1 (0.8%%)	7 (5.3%)	85 (64.9%)	χ^2=48.986, df93, p>.0001
	Non-nurse	6 (6.1%)	7 (7.1%)	28 (28.6%)	57 (58.2%)	
	Multidisciplinary	5 (18.5%)	0 (0%)	3 (11.1%)	19 (70.4%)	
	Service Managers	1 (11.1%)	0 (0%)	0 (0%)	8 (88.9%)	
Administering Medications	Nurse	120 (88.9%)	0 (0%)	0 (0%)	15 (11.1%)	χ^2=111.895, df=9, p>.0001
	Non-nurse	30 (30.0%)	7 (7.0%)	21 (21.0%)	42 (42.0%)	
	Multidisciplinary	17 (63.0%)	0 (0%)	0 (0%)	10 (37.0%)	
	Service Managers	1 (11.1%)	0 (0%)	1 (11.1%)	7 (77.8%)	
Keeping Medications Safe	Nurse	116 (86.6%)	0 (0%)	1 (0.7%)	17 (12.7%)	χ^2=104.380, df=9, p>.0001
	Non-nurse	28 (28.3%)	7 (7.1%)	23 (23.2%)	41 (41.4%)	
	Multidisciplinary	16 (61.5%)	0 (0%)	0 (0%)	10 (38.5%)	
	Service Manager	3 (33.3%)	0 (0%)	0 (0%)	6 (66.7%)	

These interventions, 'administering medications' and 'keeping medications safe' were on the other hand, considered by non-nurse care staff and service managers to be shared activities, carried out by nurses and others (Figures 8.1 and 8.2). These differences were statistically significant.

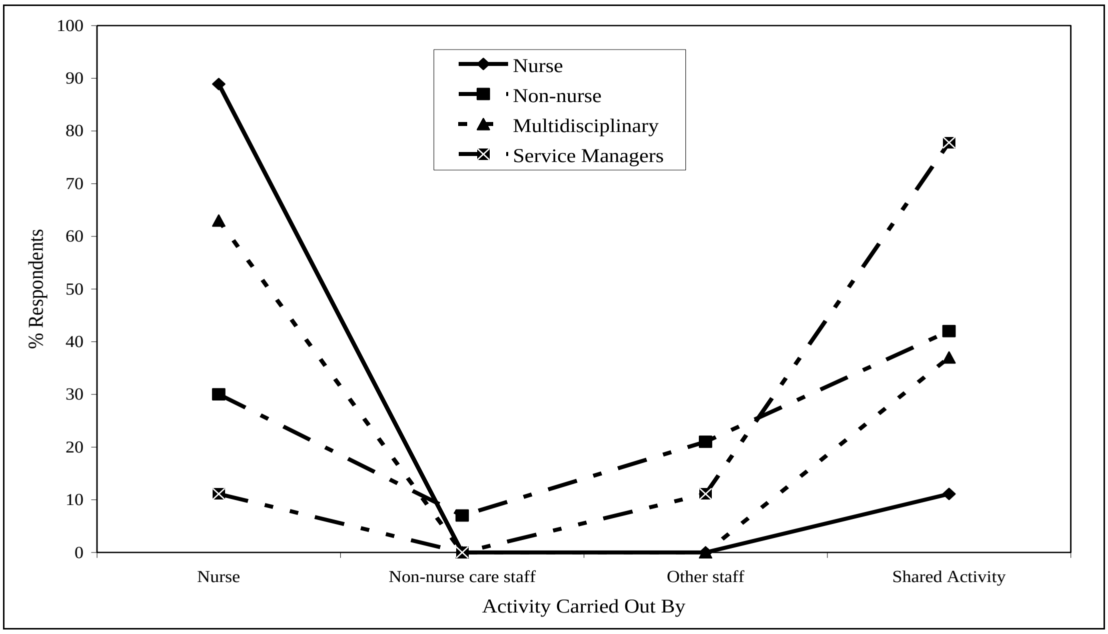

Figure 8.1: The percentage of staff in the four categories who perceived administering of medications to be a nursing task; non-nurse care staff task; a task for other staff or a shared activity across different staff.

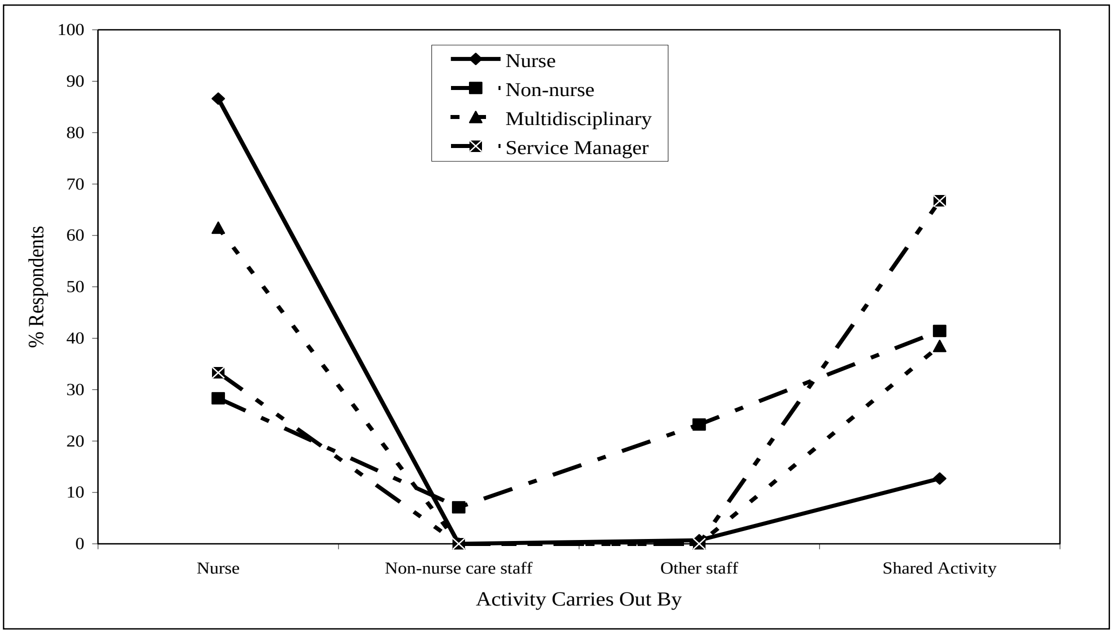

Figure 8.2: The percentage of staff in the four categories who perceived keeping medications safe to be a nursing task; non-nurse care staff task; a task for other staff or a shared activity across different staff.

8.2 Psycho-Social Health Maintenance Interventions

Four interventions, that were part of the psycho-social health maintenance factor, were perceived by all four groups of staff to be carried out on a shared basis (Table 8.2). It is interesting to note, though, that nurses were the only group where a sizeable number of respondents (>20%) considered their own group to be uniquely responsible for the performance of these interventions. For each of the interventions, 100% of service managers suggested that they were shared activities. These findings were statistically significant at the $p<0.0001$ level.

Table 8.2: Nurses' and non-nurse care staffs' perceptions on who performs selected psycho-social health maintenance factor interventions.

		Nurse	*Non-nurse*	*Other staff*	*Shared Activity*	χ^2
Enhancing Communication	Nurse	35 (27.6%)	0 (0%)	4 (3.1%)	88 (69.3%)	χ^2=70.430, df=9, p>.0001
	Non-nurse	6 (6.2%)	8 (8.2%)	32 (33.0%)	51 (52.6%)	
	Multidisciplinary	1 (3.8%)	0 (0%)	6 (23.1%)	19 (73.1%)	
	Service Manager	0 (0%)	0 (0%)	0 (0%)	9 (100%)	
Enhancing Socialisation	Nurse	36 (27.9%)	0 (0%)	5 (3.9%)	88 (68.2%)	χ^2=82.643, df=9, p>.0001
	Non-nurse	3 (3.3%)	9 (9.8%)	34 (37.0%)	46 (50.0%)	
	Multidisciplinary	0 (0%)	1 (3.8%)	5 (19.2%)	20 (76.9%)	
	Service Manager	0 (0%)	0 (0%)	0 (0%)	9 (100%)	
Promoting Activation	Nurse	33 (26.0%)	1 (0.8%)	7 (5.5%)	86 (67.7%)	χ^2=65.960, df=9, p>.0001
	Non-nurse	3 (3.2%)	7 (7.4%)	34 (36.2%)	50 (53.2%)	
	Multidisciplinary	1 (3.8%)	0 (0%)	6 (23.1%)	19 (73.1%)	
	Service Manager	0 (0%)	0 (0%)	0 (0%)	9 (100%)	
Promoting Exercise	Nurse	28 (21.7%)	0 (0%)	8 (6.2%)	93 (72.1%)	χ^2=56.833, df=9, p>.0001
	Non-nurse	2 (2.1%)	8 (8.2%)	28 (28.9%)	59 (60.8%)	
	Multidisciplinary	0 (0%)	1 (3.8%)	6 (23.1%)	19 (73.1%)	
	Service Manager	0 (0%)	0 (0%)	0 (0%)	9 (100%)	

8.3 Management Interventions

Responses were elicited in respect of six management factor interventions (Table 8.3). Significant differences were found between nurses' perceptions and those of the other groups, such that interventions involving liaisons with other groups, general staff management and staff training were all considered by a majority of nurse respondents to be uniquely nursing activities (Figures 8.3, 8.4 and 8.5). It may be seen, from these figures, that the three other groups generally saw these activities as being primarily shared. This pattern of response was seen across all of the liaison activities. It also emerged that nurses had a perception of their management role that was not shared by others. These differences are statistically significant.

Table 8.3: Nurses' and non-nurse care staffs' perceptions on who performs selected management factor interventions.

		Nurse	*Non-nurse*	*Other staff*	*Shared Activity*	*χ^2*
Liasing with External ID Agencies	Nurse	67 (62.6%)	0 (0%)	6 (5.6%)	34 (31.8%)	χ^2=66.476, df=9, p>.0001
	Non-nurse	18 (22.0%)	5 (6.1%)	31 (37.8%)	28 (34.1%)	
	Multidisciplinary	4 (17.4%)	0 (0%)	4 (17.4%)	15 (65.2%)	
	Service Manager	3 (33.3%)	0 (0%)	0 (0%)	6 (66.7%)	
Liasing with Multidisciplinary Team	Nurse	77 (61.1%)	0 (0%)	8 (6.3%)	41 (32.5%)	χ^2=86.999, df=9, p>.0001
	Non-nurse	14 (15.6%)	5 (5.6%)	29 (32.2%)	42 (46.7%)	
	Multidisciplinary	4 (14.8%)	0 (0%)	0 (0%)	23 (85.2%)	
	Service Manager	3 (33.3%)	0 (0%)	0 (0%)	6 (66.7%)	
Liasing with Other External Agencies	Nurse	68 (63.6%)	0 (0%)	6 (5.6%)	33 (30.8%)	χ^2=72.400, df=9, p>.0001
	Non-nurse	13 (16.5%)	5 (6.3%)	30 (38.0%)	31 (39.2%)	
	Multidisciplinary	5 (21.7%)	0 (0%)	3 (13%)	15 (65.2%)	
	Service Manager	3 (33.3%)	0 (0%)	0 (0%)	6 (66.7%)	
Managing Staff - General	Nurse	90 (71.4%)	0 (0%)	8 (6.3%)	28 (22.2%)	χ^2=87.361, df=9, p>.0001
	Non-nurse	18 (19.8%)	4 (4.4%)	38 (41.8 %)	31 (34.1%)	
	Multidisciplinary	5 (20%)	0 (0%)	5 (20%)	15 (60%)	
	Service Manager	2 (25%)	0 (0%)	1 (12.5%)	5 (62.5%)	
Training Staff	Nurse	76 (66.1%)	0 (0%)	5 (4.3%)	34 (29.6%)	χ^2=59.089, df=9, p>.0001
	Non-nurse	24 (28.6%)	2 (2.4%)	28 (33.3%)	30 (35.7%)	
	Multidisciplinary	6 (25%)	0 (0%)	2 (8.3%)	16 (66.7%)	
	Service Manager	3 (37.5%)	0 (0%)	0 (0%)	5 (62.5%)	
Attending Meetings	Nurse	52 (39.4%)	0 (0%)	8 (6.1%)	72 (54.5%)	χ^2=51.662, df=9, p>.0001
	Non-nurse	14 (14.6%)	5 (5.2%)	28 (29.2%)	49 (51%)	
	Multidisciplinary	4 (14.8%)	0 (0%)	2 (7.4%)	21 (77.8%)	
	Service Manager	1 (11.1%)	0 (0%)	0 (0%)	8 (88.9%)	

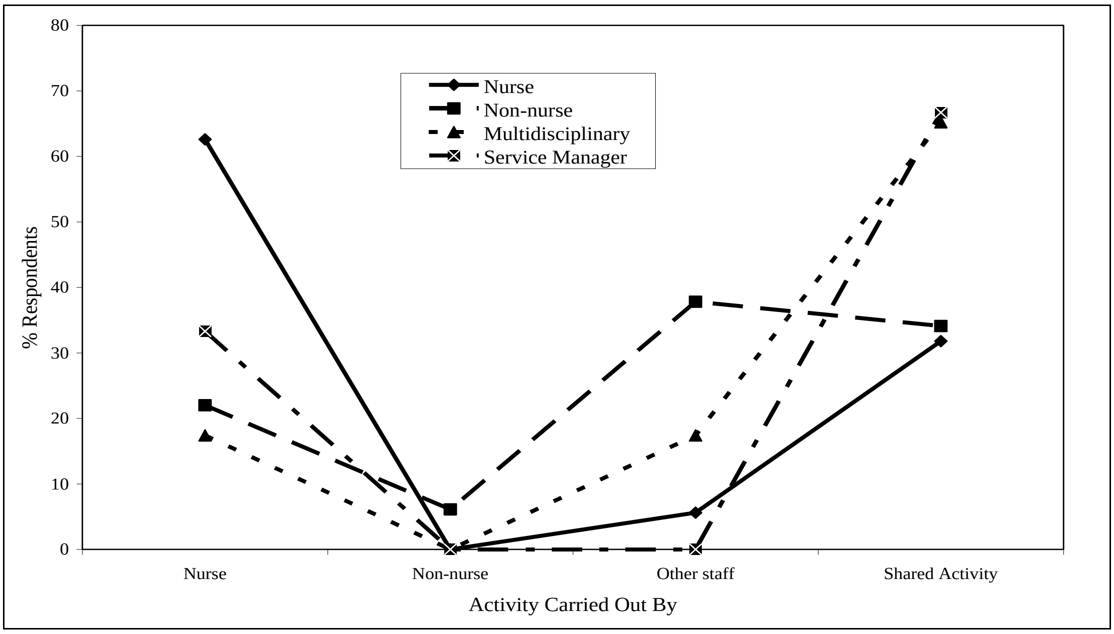

Figure 8.3: The percentage of staff in the four categories who perceived liaising with external intellectual disability agencies to be a nursing task; non-nurse care staff task; a task for other staff or a shared activity across different staff.

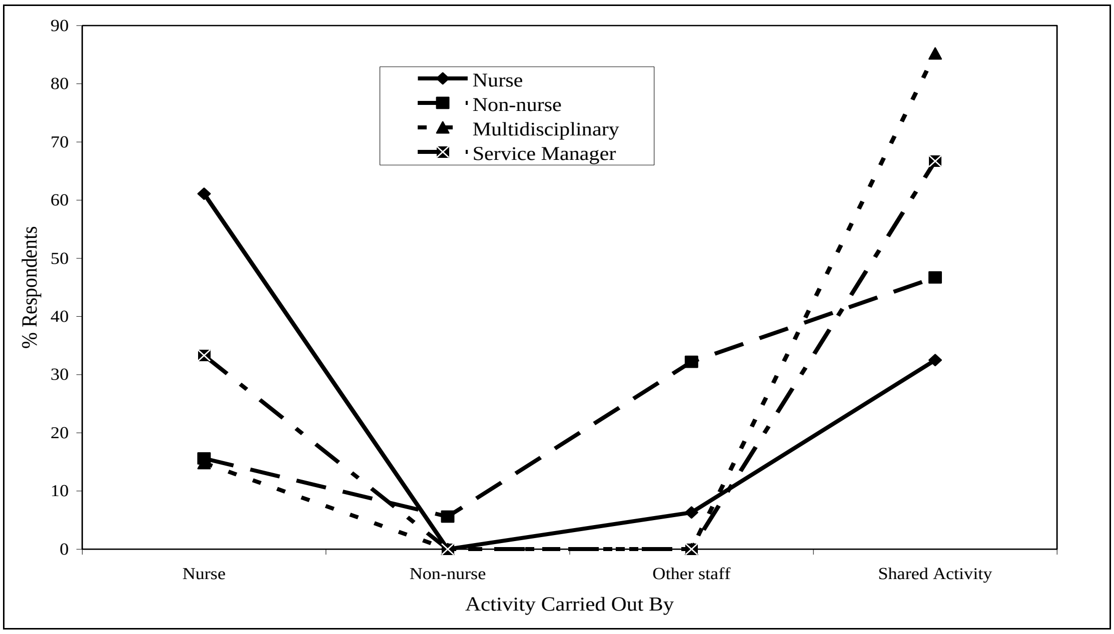

Figure 8.4: The percentage of staff in the four categories who perceived liaising with the multidisciplinary team to be a nursing task; non-nurse care staff task; a task for other staff or a shared activity across different staff.

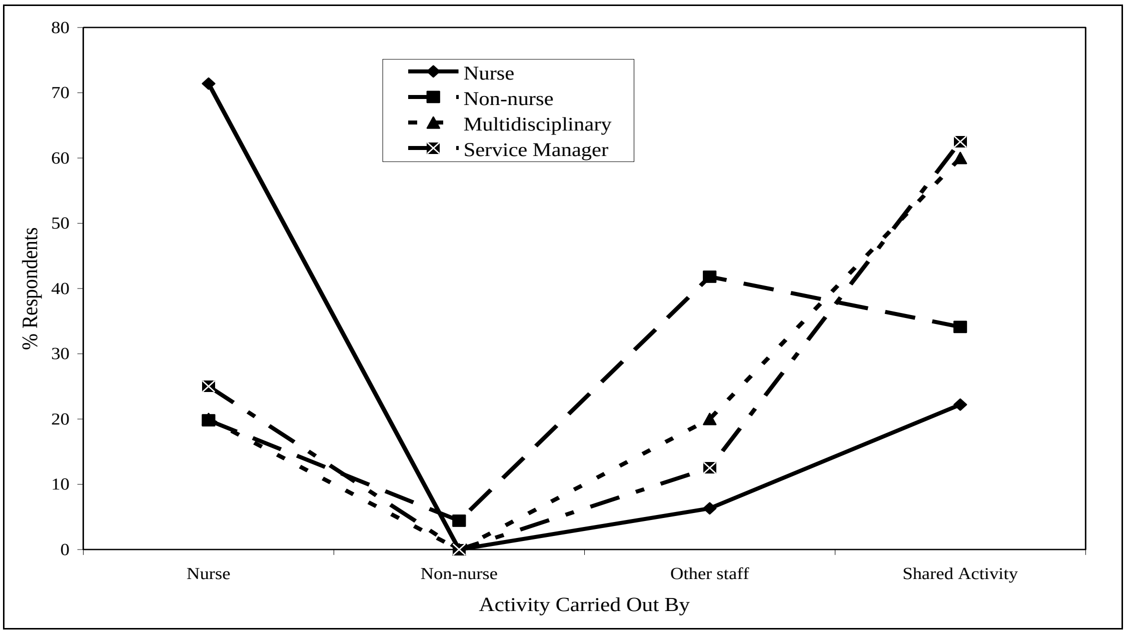

Figure 8.5: The percentage of staff in the four categories who perceived managing staff -general to be a nursing task; non-nurse care staff task; a task for other staff or a shared activity across different staff.

8.4 Technical Health Interventions

The three interventions from the technical health factor included the 'tube feeding' intervention, which had been noted to be a primarily nurse-mediated activity, during the key informant interviews (Table 8.4). When respondents were requested to indicate who carried out this intervention, it was overwhelmingly perceived that nurses uniquely performed it. A majority of nurses considered that the management of physical illness was uniquely carried out by nurses, whilst equal numbers of non-nurses suggested that this was carried out by nurses or as a shared activity. Similar findings were noted in respect of service managers and multidisciplinary team members (Figure. 8.6). All four staff groups supported the perception that tube feeding is a nursing task (Figure 8.7), whilst all four groups also considered assisting with self-care: feeding to be a shared activity. These findings, with the exception of tube feeding, were statistically significant.

Table 8.4: Nurses’ and non-nurse care staffs’ perceptions on who performs selected technical health factor interventions.

		Nurse	*Non-nurse*	*Other staff*	*Shared Activity*	χ^2
Tube Feeding	Nurse	109 (89.3%)	0 (0%)	3 (2.5%)	10 (8.2%)	χ^2=8.535, df=9, p>.481
	Non-nurse	65 (79.3%)	1 (1.2%)	5 (6.1%)	11 (13.4%)	
	Multidisciplinary	20 (76.9%)	0 (0%)	1 (3.8%)	5 (19.2%)	
	Service Manager	7 (100%)	0 (0%)	0 (0%)	0 (0%)	
Managing Physical Illness	Nurse	92 (69.7%)	0 (0%)	4 (3%)	36 (27.3%)	χ^2=46.881, df=9, p>.0001
	Non-nurse	35 (37.6%)	5 (5.4%)	19 (20.4%)	34 (36.6%)	
	Multidisciplinary	10 (38.5%)	0 (0%)	1 (3.8%)	15 (57.7%)	
	Service Manager	5 (55.6%)	0 (0%)	0 (0%)	4 (44.4%)	
Assisting with Self-Care: Feeding	Nurse	23 (17.8%)	1 (0.8%)	7 (5.4%)	98 (76%)	χ^2=52.968, df=9, p>.0001
	Non-nurse	3 (3.3%)	7 (7.6%)	30 (32.6%)	52 (56.5%)	
	Multidisciplinary	2 (7.4%)	2 (7.4%)	2 (7.4%)	21 (77.8%)	
	Service Manager	0 (0%)	0 (0%)	0 (0%)	9 (100%)	

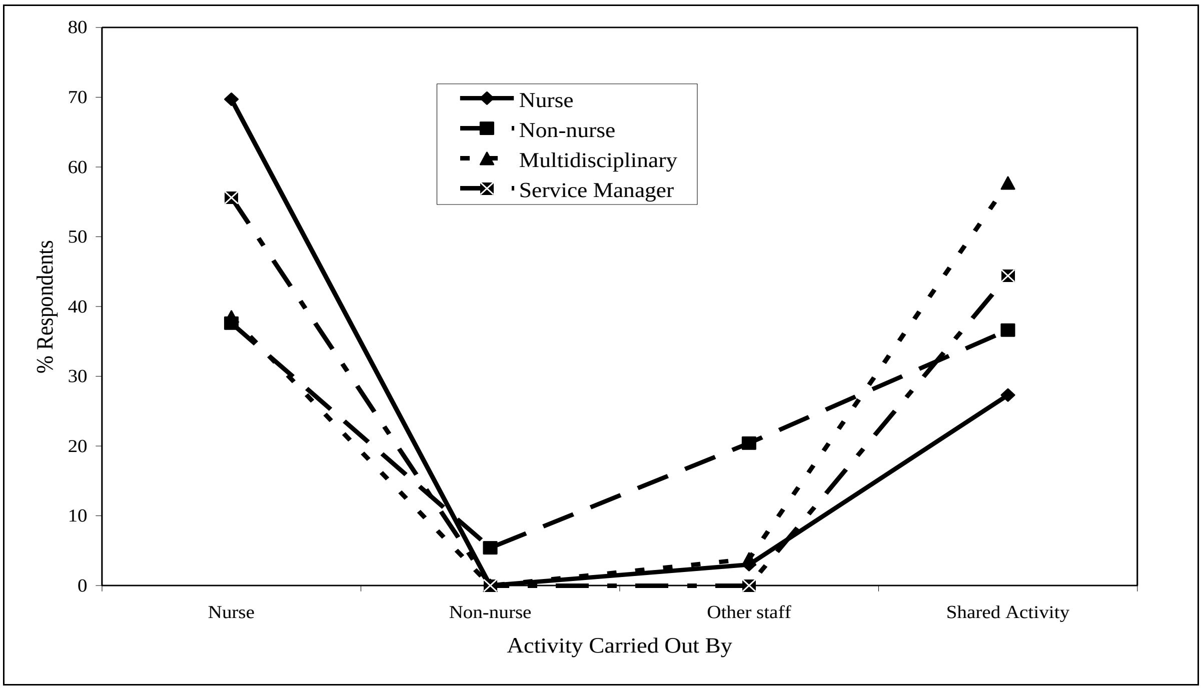

Figure 8.6: The percentage of staff in the four categories who perceived managing physical illness to be a nursing task; non-nurse care staff task; a task for other staff or a shared activity across different staff.

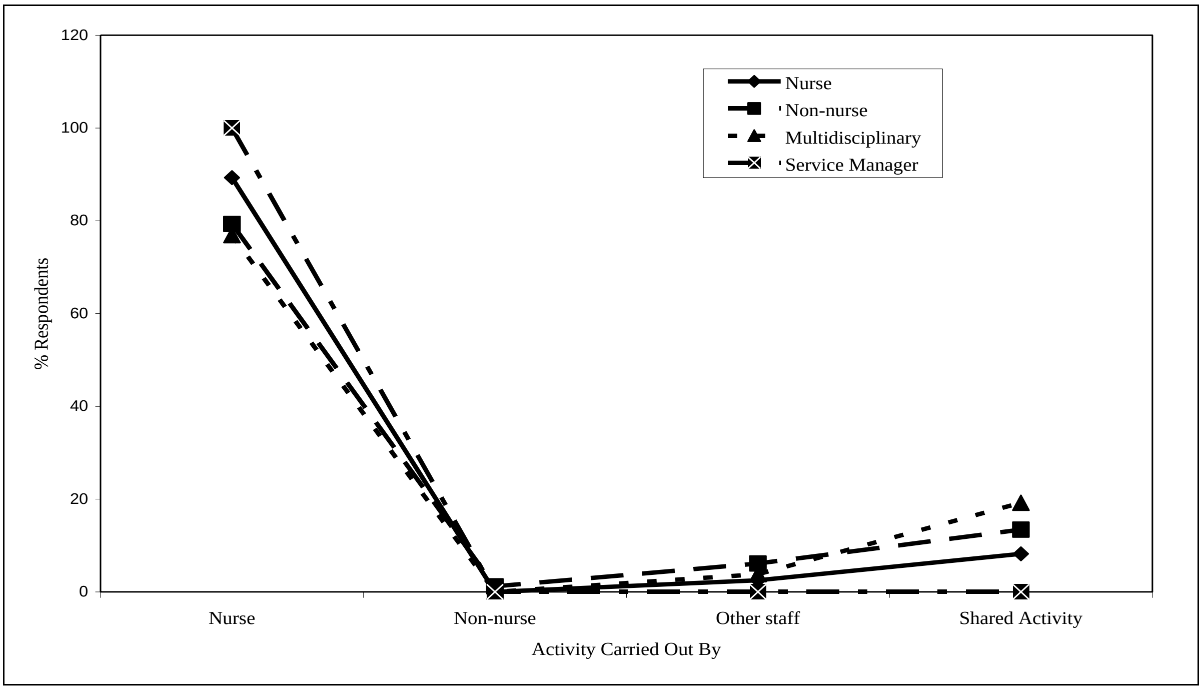

Figure 8.7: The percentage of staff in the four categories who perceived tube feeding clients to be a nursing task; non-nurse care staff task; a task for other staff or a shared activity across different staff.

8.5 Mental Health Maintenance Interventions

Significant differences were demonstrated in respondents' perceptions of who performed the mental health maintenance factor intervention, 'managing clients' behaviour', with a large minority of nurses suggesting that it was performed uniquely by nurses (Table 8.5). However, the majority of nurses, service managers and multidisciplinary team members considered it to be a shared activity. Nearly half of the non-nurse care staff concurred with this (Figure 8.8).

Table 8.5: Nurses' and non-nurse care staffs' perceptions on who performs selected mental health factor interventions.

		Nurse	*Non-nurse*	*Other staff*	*Shared Activity*	χ^2
Managing Clients' Behaviour	Nurse	54 (41.2%)	0 (0%)	3 (2.3%)	74 (56.5%)	χ^2=80.520, df=9, p>.0001
	Non-nurse	10 (10.5%)	7 (7.4%)	32 (33.7%)	46 (48.4%)	
	Multidisciplinary	1 (3.7%)	0 (0%)	6 (22.2%)	20 (74.1%)	
	Service Manager	1 (11.1%)	0 (0%)	0 (0%)	8 (88.9%)	

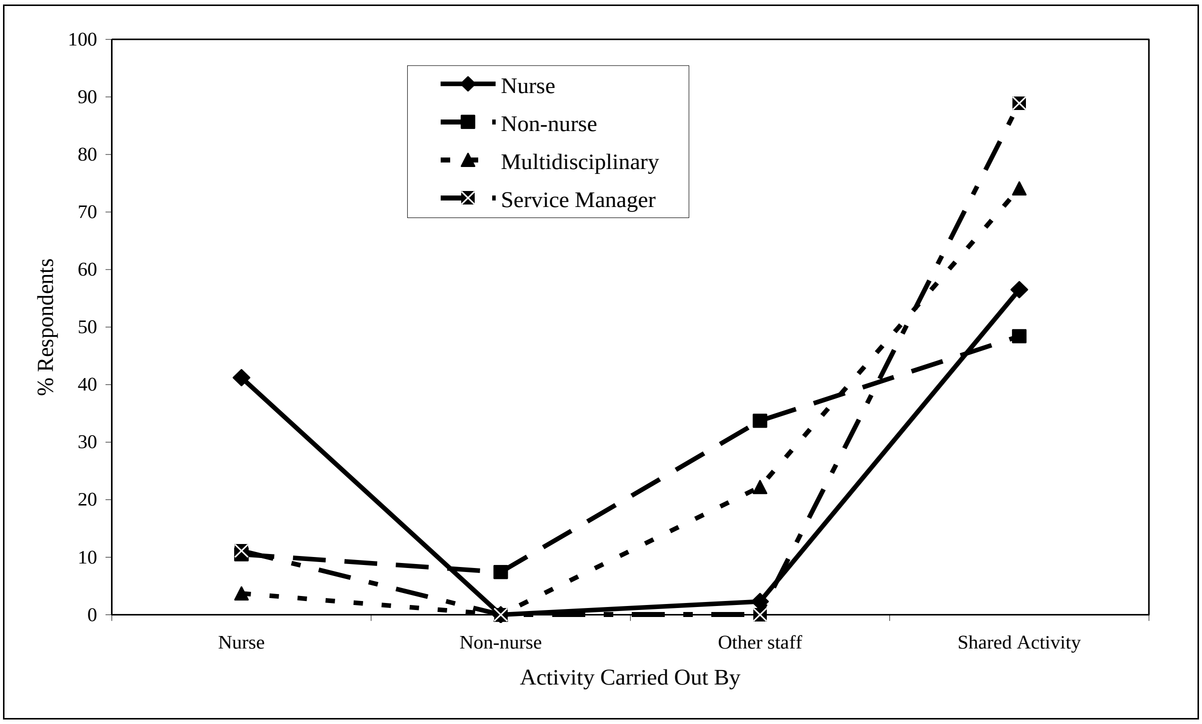

Figure 8.8: The percentage of staff in the four categories who perceived managing clients' behaviour to be a nursing task; non-nurse care staff task; a task for other staff or a shared activity across different staff.

8.6 Conclusion

It has been shown that significant differences were found between the four staff groups' perceptions of who is responsible for the performance of interventions of care. More specifically, it appears that nurses considered that their role involves the employment of interventions that are unique to nursing practice. This perception was, however, not shared by the other staff groups, for, although a proportion of all three groups did suggest that some interventions were unique to nursing, the majority of respondents identified many interventions to be carried out by both nurses and other staff as shared activities. It is interesting to note that the staff group that works most frequently alongside nursing was not perceived to have any unique interventions.

Service managers and multidisciplinary team members appear to view care interventions as generic tasks that are not the ambit of any one professional group, but which, rather, may be performed by a variety of staff. This reflects the comments of the key informant service managers.

CHAPTER 9

Discussion and Recommendations

9.0 Introduction

It has been repeatedly stated that the nurse for people with intellectual disabilities (RNID) occupies a central, and indeed essential, position in the provision of services in Ireland (Department of Health 1997, Bruton 2003, ERHA 2003). Furthermore, it is suggested that there is a distinct identity and unique skill complement associated with this nursing specialty such that it must be preserved and promoted (Government of Ireland 1998). The first significant attempt to explore the role of the Irish RNID (Department of Health 1997) produced a series of generalised statements which said little about either the interventional component or interventional foci of such nurses. Yet this has formed the basis for some of the above suggestions indicating the uniqueness of intellectual disability nursing (Government of Ireland 1998, ERHA 2003), even though it has been noted that the evidence regarding utilisation of nursing skills in Irish intellectual disability services is inadequate (ERHA 2003). Hence the present study aimed to fill an important gap in knowledge regarding nursing practice.

9.1 Summary of Findings

This study attempted to provide evidence regarding the uniqueness, or otherwise, of nursing skills in Irish residential intellectual disability services. Whilst a nursing skill complement has been identified – irrespective of whether the nurses were general trained or held an intellectual disability nursing qualification - it was found that many of the component skills were not unique to nursing and were more often shared by nurses with other staff groups. The findings are summarised below in relation to the questions posed in section 1.3.2 of the thesis.

9.1.1 Questions Addressed

1. *What are the interventional foci of nursing in residential intellectual disability services?*

This question was addressed specifically during the exploratory Delphi study and focus group interviews. Forty-six foci for intervention were identified which were suggested to be of relevance to residential intellectual disability nursing practice in residential care settings, including interventions related to, self-care, physical care, behaviour management, preventive care, social/emotional care, normalisation/ inclusion and recreation (see sections 3.4; 4.1.4; 4.1.4.11). The breadth of these interventions is reminiscent of the broad scope associated with the definition of the intellectual disability nursing role in the *Report of the Working Party on the Role of the Mental Handicap Nurse* which proposes that nurses:

> "have a diversity of roles, on a continuum from intensive physical nursing or persons with a severe degree of handicap to supportive guidance in the management and habilitation of children, adolescents, adults and elderly."
>
> Department of Health (1997) p.10.

The variety of tasks suggests that the RNID is a generalist nurse-cum-support worker for people with intellectual disabilities. It is noteworthy that this scope and variety was reported at all stages of the study, and by all levels of staffing, from top-level management to direct-care providers. This pan-organisational perspective on interventional caring suggests that the needs of the people with intellectual disability are the primary determinant of the caring task, rather than discipline-specific skills of any one profession such as nursing. These data represent an important contribution to the debate how such caring should be structured in services.

Moreover, there is no suggestion, in this study, that many of these interventional foci were unique to nursing. Nonetheless, it is the interpretation and contextualisation of the foci that forms a basis for the practice decisions which determine outcomes and interventions, and this might distinguish nurses from other staff, a point which will be discussed later.

2. *What is the current contribution of nursing in residential intellectual disability services?*

A role matrix of caring was developed based on the responses of nursing and non-nurse care staff. This matrix incorporated five prioritised interventional factors: 1) physical health maintenance; 2) psycho-social health maintenance; 3) management; 4) technical health; and 5) mental health maintenance. It was found that nurses were more significantly involved with two of the five domains, the employment of physical health maintenance and technical health interventions, than were non-nurse care staff but that the opposite was true in respect of psycho-social care interventions. It was similarly found that the majority of nurses perceived themselves as uniquely employing interventions that were representative of these two domains, as well as the management domain. These findings are detailed in sections 8.1 to 8.5 of this thesis.

This is the first time that such a study has been performed in respect of intellectual disability nursing. The focus on physical and technical issues that has emerged, along with the suggestions that nursing may, in the future, take on more of a coordination role (see section 4.2.4.4) suggests a potential deviation from the holistic perspective that is grounded in the nurse-client relationship and which has been identified as being central to nursing care in other areas of nursing, such as care of the older person (Yonge and Molzahn 2002, Berg et al 2005), palliative care (Taylor et al 1999, Luker et al 2000, Richardson 2002) and parish nursing (Bergquist and King 1994, Tuck 2001).

One curious finding was that non-nurse care staff were six times more likely than nurses to employ the mental health intervention, managing mental illness. This is an unexpected outcome, although it has been suggested that the mental health needs of people with intellectual disability are not being adequately met due to the absence of proper mental health teams (Irish College of Psychiatrists 2004). Furthermore, Gilbert et al (1998) suggest that "learning disability nursing operates without a clear model of mental health" (p.1151). The findings of this study, that nurses were gravitating towards physical and technical health interventions, and non-nurse care staff were employing more psycho-social health interventions may indicate a movement of the nurse away from the nurse-client relationship thus reducing the interpersonal context within which mental health issues may be addressed.

The interplay between the perceptions of nurses and non-nurse care staff is an important feature of this study, which gives a perspective on caring that has not been presented in the nursing literature before, thus allowing for responses of both groups to be compared and contrasted. In the absence of this contrast, it would be easy to assume that frequently performed interventions were the prerogative of the nurses, whereas this data showed that many of these tasks are, in fact, shared with other workers.

Moreover, nurses considered that many of the interventions were performed uniquely by nurses whereas service managers and multidisciplinary team members perceived that they were carried out by nurses and others on a shared basis. Similarly, non-nurse care staff were less likely to identify nurses as the principal employers of interventions, suggesting that they or others carried them out. *Managing physical illness* was, however, tentatively perceived to be carried out uniquely by nurses as was, to a lesser extent, *administering medications*.

3. *Is the nursing terminological approach useful for describing the unique contribution of nursing?*

This study has examined the usefulness of standardised terminology as a basis for describing the contribution of nursing to interventional caring. In this it has revealed some of the practical and cognitive complexity underpinning nursing practice (Clark and Lang 1992). It has shown this approach to be useful in this regard. It has facilitated the explication of the unique and shared interventions of, not only intellectual disability nursing, but also of non-nurse care staff. It has, therefore, been demonstrated to have relevance outside of nursing and may provide a structure for the exploration of the role of any or all of the professional groups involved in the care, training and education of people with intellectual disability.

In the literature there is limited evidence of standardised nursing language being used in relation to intellectual disability nursing practice. There is, however, evidence of the interventional foci and interventions employed by nurses, albeit scattered throughout studies and reports of varying subject. The use of standardised terms has been found to be a useful approach for collating and describing these aspects of nursing practice, and, consequently for describing the unique interventional contribution of nursing. As the first attempt to provide such a description of intellectual disability nursing in residential settings, this approach has provided a significant basis for further study. It is evident, however, that, in the absence of further methodological approaches, the use of standardised language *per se* may not cast a light on the more qualitative aspects of nursing. Thus, whilst it may be possible to empirically describe the foci, interventions and, indeed, outcomes of nursing, the manner in which these are addressed in interactions with clients may be missed.

9.1.2 Central Finding

Overall then, it can be concluded on the basis of this study, that interventional caring in intellectual disability services is a generic entity which transcends professional boundaries and overlaps greatly with the tasks undertaken by non-nurse care staff. Thus, it could be argued that specialised nursing has, with very few exceptions, no *unique* interventional complement to add to such caring in residential settings for this population. However, this may need to be tempered by a number of considerations.

9.1.2.1 Considerations

1. The relatively small numbers involved in the exploratory stages of the study may have limited the interventional items on the questionnaires, thus, omitting other interventions that are unique to nursing.
2. The restraints on sampling that were experienced in the survey resulted in services and individuals being sampled on a self-selection basis. This may have led to biases in the results of this part of the study.
3. The interventional items incorporated on the survey tool may have been or such an empiric nature that they did not capture the qualitative nature of those items.

4. The changing natures of the client group as evidenced by consecutive reports of the *National Intellectual Disability Database* (Barron and Mulvaney 2004), of staff structure (Department of Health and Children 2001a) and of service

provision (Department of Health 1990) may be resulting in a dynamism that is redefining client needs towards higher dependency and so altering the foci of intervention of the various direct-care groups.

5. A particularly important consideration, however, may be the change in the context of care that has taken place contemporaneously with the course of this study, namely an increase in the numbers of non-nursing staff within intellectual disability services. This study, therefore, presents a unique window on a period of important change in the provision of residential care to persons with intellectual disability.

These considerations will be discussed further in this chapter.

9.2 Interventional Caring as a Generic Concept

9.2.1 The Context of Caring in Residential Intellectual Disability Services

The development of intellectual disability services, over the past century, has been marked by a movement away from the medical model of Eugenics, with its policy of confinement, segregation and exclusion, towards a social model of disability, marked by desegregation and inclusion (Eyre cited in Robins 1986 p.135, Mercer 1992, Rafter 1992, Sheerin 2000, Boxall 2002). Prior to the evolution of the social model in the 1980s (Oliver 1996), various manifestations of its medical counterpart had seen a gradual development of staffing along acute hospital structures. Thus, nurses, in the 1960s, became the main providers of direct care, taking over from the untrained attendants who worked under general nurses, and through whom the custodial model was mediated (Dingwall et al 1988, Robins 2000b). For the following few decades, the majority of Irish residential services maintained a context of medically-led and nurse-mediated caring (Department of Health 1965).

This context started to change following the development of newer models of voluntary service provision and the increasing influence of the social model of disability. This has challenged the continuation of the biomedical approach to care. The *Needs and Abilities* report (Department of Health 1990) was a milestone in this process advocating a fulfilling and normal life for every person with intellectual disability through appropriate education, training and normative living environments. This paradigm shift, associated with a refocus of service away from commonality and onto individuality has also had an effect on staffing, with genericisation of roles (Government of Ireland 1998) and the formalisation of the health care assistant (HCA) post throughout health services (Department of Health and Children 2001a, 2003e, 2004a). This has been associated with a rapid increase of HCAs in the Irish intellectual disability services, as compared with a much more gradual rise in new nursing posts over the same period (Department of Health and Children 2004b) (Figure 9.1).

Whilst the emergence of HCAs “as members of health care teams to assist and support nurses and midwives” (Department of Health 2001 p.118) has seen the introduction of trained HCAs throughout all types of residential service, it is in the community group homes that they have been able to access such posts that are also open to nurses (Daughters of Charity Service 2005, St. John of God Kerry Services 2005).

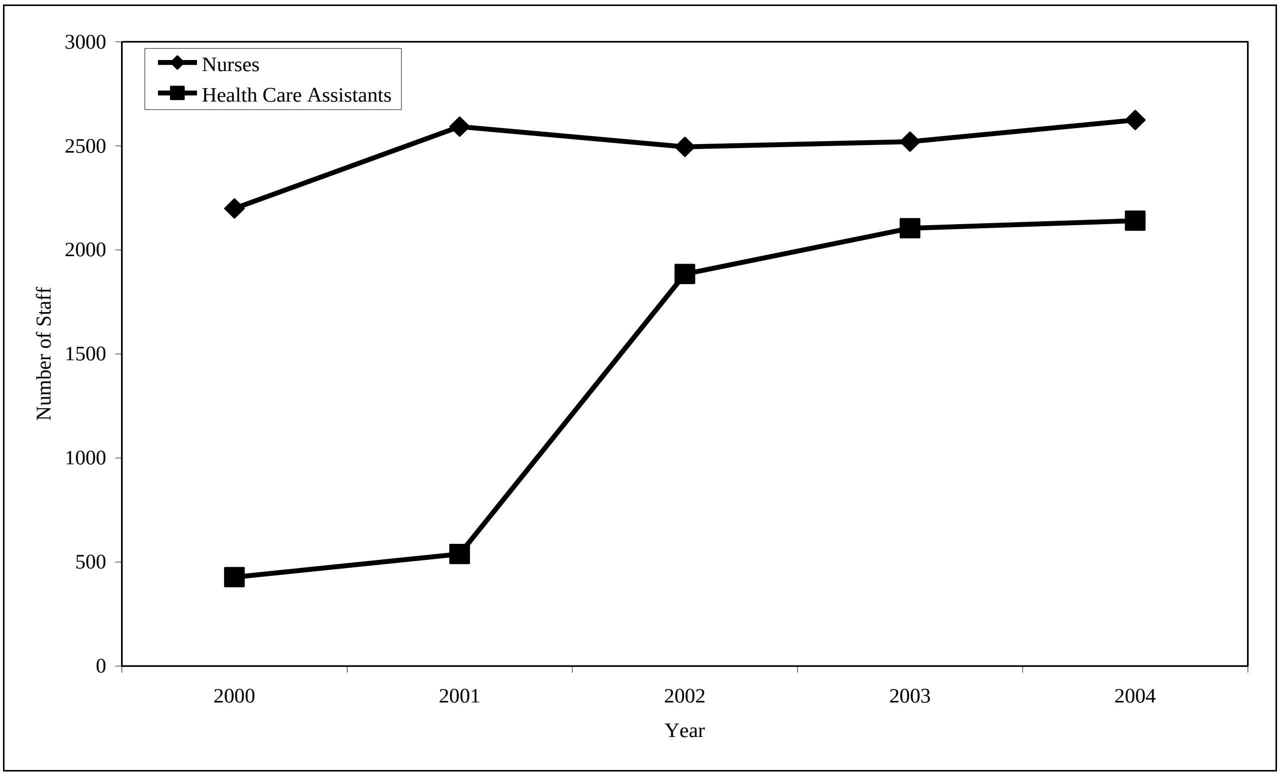

Figure 9.1: Nursing and health care assistant posts in intellectual disability homes 2000-2004 (Department of Health and Children 2004b).

This has been more marked with the redesignation of HCAs as *social care workers* (Department of Health and Children 2004c). This has allowed the role of the social care worker in such residences to become more akin to that previously undertaken by nurses (Pointu and Cole 2005).

9.2.2 Description of Caring in Residential Intellectual Disability Service Provision

The aforementioned developments in the provision of intellectual disability services have been associated with, not only a change in the locus of direct-care provision, but also a change in the character of that care provision. This has probably presented the greatest challenge to intellectual disability nursing, the practice of which developed within institutional residential services. Nursing can either remain focused on caring for those remaining in such services – those people with more severe disability and concomitant problems – or reinvent itself for the changing service structures and thereby remain relevant to the majority of intellectually disabled people now living in the community.

The findings in this study would suggest that Irish intellectual disability nursing has not responded creatively to this challenge and has approached community care with the same priorities that relate to care in institutions – physical and technical health. Social care workers (non-nurse care staff) appear to have taken on board a more person-centred focus through their relatively greater employment of psycho-social health interventions. What is the reason for this?

The *Report of the Working Group on the Role of the Mental Handicap Nurse* (Department of Health 1997) identifies that "the majority of persons with a mental handicap who need professional help, require a mixture of both health and social care" (p.12). It further identifies the RNID as the professional who is competent to meet "the day to day needs…health needs…and social well-being of each individual person" (p.12-13). This is also recognised by the current syllabus for intellectual disability nurse registration education programmes which centres on: 1) nursing and professional development; 2) person-centred care; 3) health sciences and applied nursing principles; and 4) nursing, sociology, law and environment (An Bord Altranais 2005b). It is interesting to note that a significant component of the RNID's competencies are also met by the social care workers whose role is:

> "the professional provision of care, protection, support, welfare and advocacy for vulnerable or dependent clients, individually or in groups. This is achieved through the planning and evaluation of individualised and group programmes of care, which are based on needs, identified in consultation with the client and delivered through day-to-day shared life experiences. All interventions are based on established best practice and in-depth knowledge of life-span development."
>
> Department of Health 2001 (cited in Bruton 2003 p.29)

The amalgamation of changes in staff demographics and the redesignation of a significant component of the intellectual disability nurse’s defined role to a newly registered professional group acts to reaffirm the reality that nurses have gravitated towards provision of care to those in institutional residential services. Nursing may, therefore, be seen to be focused, in practice, on the performance of those interventions that are associated with physical health maintenance and technical health skills. Moreover, these are skills that generically trained nurses can provide rather than specialist nurses, a fact that is reflected in the high proportion of RGNs employed in residential care settings (see section 6.1.2.5.1).The difficulties associated with crossing over of nurses’ and social care workers’ roles were identified previously by Kennerly (1989), Workman (1996) and Alaszewski et al (2001). Blumenthal et al (1998) and Keeney et al (2005) suggest that the reason for such cross-over is a lack of clarity regarding roles, for, whereas the World Health Organisation (1948) defines health in terms of physical, social and psychological well-being, intellectual disability nursing has been developed as a flexible profession (Department of Health 1997) that can be employed in any setting and with any intellectual disabled people across the life-span (ERHA 2003). Such a situation may make it difficult for the unique contribution to be understood. The data from this study suggests that the lack of clarity persists within Irish services and further debate is required within and between professional groups.

The development of the health care assistant/social care worker, in the Republic of Ireland, was strongly related to the examination of skill mix and the nursing workload (Department of Health and Children 2003e). Although Thibault et al (1991) (cited in Department of Health and Children 2003e) suggest there to be four aspects to nursing workload: 1) direct nursing clinical activities – direct care; 2) indirect nursing clinical activities – care planning; 3) non-nursing tasks; and 4) invisible work – cognitive and emotional work, it is proposed that the key differentiators of professional nursing are: 1) knowledge; 2) clinical judgement; 3) personal accountability; and 4) the structured nurse-patient relationship (Department of Health and Children 2003e). This essentially points to a difference between professional (registered nurse) and non-professional (untrained/trained health care assistant) nursing, something that has been alluded to in Department of Health and Children (2001b). It was originally planned that the latter would assist the nurse in the performance of non-nursing tasks (Government of Ireland 1998). The key difference between both groups of staff has, however, been removed by the *Health and Social Care Professionals Bill 2004* (Department of Health and Children 2004c).

This study has, for the first time, set out an interventional core for caring in intellectual disability services, the origin of which is based in the knowledge, clinical judgement and professional accountability referred to above. Findings from the key informant interviews suggest, however, that nurse managers predict the nursing role to move away from direct clinical activities, non-nursing tasks and, arguably, from some of the invisible cognitive and emotional work, with the emphasis becoming firmly focused on management and direction/planning of care. There is some evidence of this emerging from the study, with nurses reporting more frequent performance of management interventions than non-nurse care staff. The potential removal of nurses from the care setting is problematic, for, although they may plan and manage care using knowledge, clinical judgement and personal accountability, the structured nurse-patient relationship – the fundamental context for such planning - could be lost, leading to a movement away from the holistic nature of care (Daykin and Clarke 2000), an aspect of care considered to be vital to modern nursing (Richardson 2002).

It is recognised that Irish intellectual disability nursing has provided care of a high quality to its clientele for over four decades, and has been an integral element of the health care team (Department of Health 1997, Bruton 2003). It appears from this study that, as services become more focused on “integration at school, work and the community” (Government of Ireland 1998 p.171), the aspiration that the RNID “should be present and a key provider of educational and related services” (Bruton 2003 p.15), will not be realised unless the discipline undergoes a significant process of restructuring and redefinition.

9.3 Nursing and Its Interventional Contribution to Caring in Residential Services

9.3.1 Uniqueness of interventions

Training programmes for the *mental handicap nurse* in the 1980s were geared towards preparing a professional that could be employed within a variety of settings – institution, community house, training centre, school and day-care centre (Department of Health 1997). It is arguable that, if this study had been carried out during that decade, nursing would have been shown to have a broad body of unique interventions.

This broad complement of knowledge and skills are still characteristic of modern day intellectual disability nursing and have been acknowledged by Government Reports cited above, as well as by the service managers who partook in the key informant interviews. Indeed, it was implied that the ‘package’ offered by such staff was greatly admired by employers, such that RNIDs would often be preferred at interview over other applicants (section 4.2.4.5). It appears, however, that this ‘package’ is not perceived by employers to be nursing in character, and is, perhaps, better located within the post of the social care worker (section 4.2.4.4). The rationale behind this perception is that:

> *At then end of the day people aren't sick; they have a learning problem...and that's not about nursing.*
>
> (SM2 section 4.2.4.4)

9.3.2 Parallels with the United Kingdom

The position at which Irish intellectual disability nursing finds itself is not unique. A similar juncture was approached by their colleagues in the United Kingdom during the period 1979-1995, following the publication of the *Jay Report* (Department of Health and Social Security 1979), and its recommendation that “mental handicap nursing be phased out in favour of social care” (Mitchell 2003 p.355). It is clear that the challenge to intellectual disability nursing in the UK was met with a resolve and an acceptance within nursing of the philosophy underpinning the *Jay Report* (Mitchell 2003, Atherton 2003). Indeed Atherton (2003) notes that this report set in play a dynamic process that led the discipline to redefine itself and readapt to changing service structures and client demographics (Department of Health 1994). A significant milestone along this journey was the publication of the report *Continuing the Commitment* (Department of Health 1995a) with its key recommendations for nurses that they “should ensure that their contribution is more explicitly linked to the maintenance and improvement of the health of people with learning disability…[and]…place stronger emphasis on the support of initiatives that enable people with learning disabilities to advocate for themselves” (p.40).

Whilst not all of the recommendations of the report were welcomed (Birchenall 1996) this refocusing of nursing appears to have found resonance with UK practitioners of intellectual disability nursing particularly in relation to health (Gilbert et al 1998, Barr et al 1999, Thornton 1999, Hunt et al 2001, Donovan 2002, Mobbs et al 2002, Marshall et al 2003, Powrie 2003), suggesting that a unique body of knowledge and skills has been recognised. This has led to the development of community intellectual disability nurses, employed as part of a multi-disciplinary team of co-professions who offer assessment and interventions to persons referred for specific difficulties and problems (Mobbs et al 2002, McCray 2003, Slevin and Sines 2005).

9.3.3 The Future of Intellectual Disability Nursing in the Republic of Ireland

Whereas intellectual disability nurses in the UK were faced with the stark reality that their discipline could be discontinued, this has not been the case in Ireland. Nurses there have been subject to a quiet redistribution of their skill-base with the growing perception that their unique role and contribution to service provision is being ever more poorly regarded. This has been compounded by recent events whereby RNIDs working in community houses are being paid less than their non-nurse assistant houseparent or houseparent counterparts, who they may be supervising (Irish Nurses Organisation 2005).

The recent *Report of the Special Working Group on the RMHN* (Bruton 2003), which was instigated by the nursing unions and the Health Service Employers Agency has reaffirmed the value of the intellectual disability nurse to service provision. Curiously, it allies the skills and competencies of the RNID to “educational and related services…with the cooperation of the Department of Education and Science” (p.5), whilst positing a role for the nurse in relation to a variety of services. The role of the RNID in relation to health care is defined in terms of him/her being a link or resource person to the primary health care team. It further suggests that the RNID will be appointed as coordinator of multidisciplinary teams *where appropriate*. Thus, the role of the *generalist* intellectual disability nurse (the RNID) is not viewed as having an explicit health-related role. This is worrying, considering the findings of this study, allied with the changing needs of this client group and the changes in service provision.

One further report of note, *Looking into the Future* (ERHA 2003) has also explored the development and future role of the RNID. It bases its recommendations and suggestions in the acknowledgement that intellectual disability nursing must constantly redefine and redesign itself (Department of Health and Children 2002b). The proposed role framework for the RNID is again very broad, covering primary, secondary and tertiary care throughout the lifespan, and within various service locations. Whilst health surveillance, promotion and maintenance are explicit in this, the diversity of foci is reminiscent of previous attempts to describe the role of the RNID, and again overlaps heavily with the foci of concern to social care professionals. This diversity and lack of specificity continues into the recommendations for clinical specialisms and advanced practice in intellectual disability nursing, the latter of which are proposed along the life-span of the clientele (as per Department of Health and Children 2002b).

This study suggests alternately that, in consideration of the finding that intellectual disability nurses in Irish residential services are particularly focused on physical health maintenance and technical health interventions, this may be an appropriate context within which to redevelop their role at least within residential service provision, if not more broadly throughout all intellectual disability services.

9.4 Recommendations for Further Research

The findings of this study provide a base for further study in relation to refining the interventional foci, interventions and outcomes of caring in intellectual disability service provision. In particular, they have contributed to describing the unique contribution of intellectual disability nursing to such caring. Further study will, however, need to be pursued in order to build on these findings and provide a more complete picture of this contribution. It is, therefore, recommended that research should be carried out in relation to the following areas of concern.

1. **Testing and refinement of the above interventions and interventional foci.**
   Future studies will need to validate the diagnostic and interventional concepts that have emerged from this study, with consideration taken of the context within which they occur. The study has, however, only sought to identify and label those phenomena and to explore their association with nursing and other groups that are responsible for the provision of care to persons with intellectual disability. Further research will facilitate the explication of defining characteristics and risk factors associated with the diagnostic concepts and refinement of the interventional concepts, thus allowing for the development of a terminology of caring for intellectual disability service provision. This will provide a basis for cross-mapping between professional groupings, improving understanding of each group’s contribution to such care provision.

2. Evaluation of the qualitative component of the RNID’s role.

It has been suggested that the approach employed in this study, whilst providing an important perspective on intellectual disability nursing, may not have captured the totality and, indeed, the uniqueness of that role. Alaszewski et al (2001), in their study of the changing roles of *learning disability nurses* in the UK explored users’ and families’ perceptions of the nurse. The results are reported to be “generally favourable” (p.86) with emphasis placed on the caring approach of nurses in the performance of their role. It has been postulated that, it is not the skill complement of the RNID alone, that sets them out as being unique, but rather, that it is the unique combination of skills and knowledge that was unique (Clifton et al 1992) creating a qualitative aspect (Raynes et al 1994). It is recommended that research be carried out to explore the qualitative aspect of the interventions identified in this study being applied in intellectual disability practice, by intellectual disability nurses, other-registered nurses and social care workers, using observational techniques and interviews with staff and clients.

3. Examination of the outcomes of care interventions.

Care diagnoses and interventions provide only a limited perspective on the decision-making and care process, for they give no indication of what the end products of such interventions are. This is an area of particular interest to health care providers as outcome measures provide measures of the effectiveness of health care delivery (Johnson and Maas 1997). They are also, however, indicators of the adequacy of diagnostic judgement (Nielsen and Mortensen 1998). The relationship of outcome to diagnosis and intervention is clear: client outcome is defined as “a client’s status at a defined point(s) following health affecting intervention(s)” (Alberta Association of Registered Nurses 1994). It is recommended that research be undertaken to explore and identify the outcomes of care interventions within intellectual disability services. This would further facilitate the comparison and contrasting of varying staff groups’ decision-making.

4. Development of an intellectual disability nursing minimum data set.

Nursing minimum data set development has been proceeding throughout a number of countries, leading to the “a minimum data set of items of information with uniform definitions and categories concerning the specific dimension of nursing, which meets the information needs of multiple data set users in the health care system” (Werley et al 1991 p.422).

It is suggested that the identification of such *minimum data* has the capacity to demonstrate cross-population comparisons, forecast client dependencies and plan workforce requirements (Boer and Delesie 1998). Interestingly, it may also stimulate nursing research, an activity found to be lacking among *learning disability nurses* in Northern Ireland (Parahoo et al 2000) as well as describing nursing care across settings and populations (Goossen et al 1998). The Irish Nursing Minimum Data Set (NMDS) project is currently being carried out on a collaborative basis by a nursing research team based in Dublin City University and University College Dublin. This team is developing and validating the NMDS in general and mental health nursing. The findings of this thesis form a base upon which an intellectual disability NMDS could be developed.

9.5 Recommendations for Training and Services

This study, coming at a time of great change in Irish intellectual disability service provision, has provided a unique insight into the complex staffing dynamics that are being developed. The perspective on the interplay of intellectual disability nursing and social care work provides a basis for recommendations in relation to the domains of practice, service and education.

9.5.1 Recommendations for Practice

- Service providers should initiate dialogue with local representatives of the various groups of direct-care staff and service users, or their proxies, to explore the contribution of each group. This would allow for the identification and prevention of interventional cross-over, thus promoting efficient use of staffing resources.
- Registered Nurses (Intellectual Disability) should develop a non-union professional network at local, regional and national level to provide a platform for discussion and sharing of experiences. This could be facilitated through the National Council for the Professional Development of Nurses and Midwives.
- The role of the Registered Nurse (Intellectual Disabilities) should be re-examined locally in a collaborative manner, within the context of identifying and valuing the contribution of this profession to caring in intellectual disability services.
- Skill mix should continue to be introduced in services, with the aim of meeting individual client needs. General direct care interventions should, therefore, be client-needs-driven and not be specifically allied to one profession or discipline.
- The specialist health-related skills and knowledge of the Registered Nurse (Intellectual Disabilities) should be employed more effectively within residential service provision, with the nurse providing health-related direct care

interventions, as required, and working as a key health professional in the multi-disciplinary team.

- Registered Nurses (Intellectual Disabilities) who wish to provide general direct care interventions should be offered the same conditions as qualified social care leaders.

9.5.2 Recommendations for Education

- An intellectual disability nurse education forum, with layered participation, and involving all intellectual disability nurse educators, practice coordinators, tutors, clinical educators and placement coordinators should be set up, with the remit of researching and making recommendations regarding the development of nurse education programmes that are responsive to service and client needs.
- Structures should be explored and developed to facilitate the involvement of clients and families in the development of direct-care programmes, whether nursing or social care.
- Academic establishments offering both nurse education and social care programmes should explore the possibility of joint learning between the two professional groups.
- An Bord Altranais should instate a Community Intellectual Disability Nurse division on the Nursing Register.
- Ongoing professional development should be provided conjointly through Centres for Nurse Education and Staff Development Units to provide for the ongoing professional development, education and training of direct-care staff.
- Third level colleges should develop and enact Community Intellectual Disability Nursing programmes at higher diploma level.

- Clinical Nurse Specialisms should be developed within the context of issues that are a focus to nursing and should not be attempt to cover all aspects of intellectual disability service provision.
- Advanced Nurse Practitioners should be encouraged to practice as primary health care professionals within community teams.
- Suitably qualified direct care staff (nurses and social care workers) who are interested in pursuing post-graduate research studies relevant to intellectual disability should be encouraged and supported by both academic establishments and Service Providers.

9.5.3 Recommendations for Service Provision

- The Health Service Employers Agency (HSEA) and the Federation of Voluntary Bodies (FVB) should move quickly to resolving the pay anomaly in residential intellectual disability services, thus allaying the tension that currently exists between nurses and social care workers.
- The HSEA and the FVB should initiate discussion on a regional and national level to explore the actual contribution of the Registered Nurse (Intellectual Disability) and of the social care worker to interventional care provision.
- Implementation of the recommendations of the Special Working Group (Bruton 2003) should be completed as soon as possible, especially with regard to the development of Community Intellectual Disability Nurse posts and appointment of Registered Nurses (Intellectual Disability) to posts of coordinator of multi-disciplinary teams.
- A national alliance of direct-care staff forums, the HSEA, the FVB and national organisations, such as the National Association for People with an Intellectual

Disability and the National Disability Authority should be initiated to facilitate ongoing discussion and recommendation in order to meet the changing needs of people with intellectual disabilities.

9.6 Strengths and Limitations of the Study

This study has, as the first attempt to describe the interventional component of intellectual disability nursing, represents a significant contribution to the debate on whether or not such specialist nursing should be retained. It has been noted that it comes at a time of great change in intellectual disability service provision. It also comes at a time of potential change in the structure of Irish nursing itself, for the An Bord Altranais sponsored research study into the *Five Points of Entry to Nursing*, is expected to reach conclusion in late 2005. This study may recommend that the five points of entry to the Register of Nurses be retained, or that a single point of entry be instigated – a generalist nursing registration – with specialist registration being obtained after completion of post-graduate studies. The findings of this study may be of importance in providing a basis for understanding the contribution of specialist branches of nursing, such as intellectual disability nursing.

This study has incorporated a two stage, qualitative-quantitative, approach to examine the topic in question. This approach has subsequently been employed in the two main national studies that are currently underway in Irish nursing: the *Five Points of Entry Study* and the *Irish Nursing Minimum Data Set Study*. Unlike those studies, however, which employed either a Delphi technique or focus groups along with key informant interviews, the research presented in this thesis has incorporated all three approaches to maximise the qualitative contribution of the informants and participants.

It is acknowledged, though, that, whilst every attempt has been made to maintain the rigor of the study, there have been a number of limitations.

1. Sample size – The numbers of respondents in each of the Delphi study, focus group interviews and key informant interviews were small and, therefore, limited the generalisability of findings. The rationale for such numbers are explained in the text of this thesis (see sections 3.2, 4.1.1, 4.2.1 and 4.3). This limitation should be tempered by the fact that these exploratory studies were intended to inform the pan-organisational survey and were not expected to produce generalisable findings.
2. Possible sampling bias – The pan-organisational survey employed a non-probability, convenience sampling approach (see section 5.3). Such an approach may be associated with inherent selection biases, as the accessible population was defined by those services that allowed questionnaires to be distributed amongst their staff. Furthermore, these staff had the choice to respond or not, implying a self-selection sampling technique. It is possible that those who did respond were particularly motivated to do so and may have been biased in this regard. Thus, for example, intellectual disability nurses may have been biased towards reaffirming a perceived unique contribution of such specialised nursing, and against affirming the contribution of non-nurse care staff. Such biases could be present in any of the staff groups that responded. Responses obtained in relation to staff groupings’ perceptions of who carried out each intervention suggest selection bias towards of one’s own professional group in respect of nurses and non-nurse care staff (see chapter 8).

3. Response-rate – For reasons explained in the text of this thesis (see section 5.3), the response rate in the pan-organisational study was not optimal, thus limiting the ability of the findings to be generalised. The findings do, however, provide the basis for further studies to be carried out for the purpose of describing the unique contribution of the intellectual disability nurse in residential services.
4. Professional scope – The study explored only the interventional contribution of nurses and non-nurse care staff. This suggests that these two groups are the only direct-care professions in residential services. Non-inclusion of the interventional role of other staff groups, such as other members of the multidisciplinary team and service managers may have biased the results.

9.7 Ethical Considerations

Signed consent was obtained from respondents in respect of the Delphi study, focus group and key informant interviews. It was not obtained in respect of the survey for two reasons: 1) the study was anonymous and so did not set out to identify respondents; 2) all potential respondents received a cover letter which explained the study, its purpose, and its context. In relation to the survey, this letter also explained that respondents were free to complete or disregard the questionnaire, and that completion and return of the questionnaire implied consent.

9.7.1 Informed Consent

None of the services referred the research proposal to an ethics committee. In all cases, however, the decision to allow the study to take place was made at the level of service director. All of the participating services agreed that their staff were free to participate or not, and that such participation implied consent. In keeping with this, the cover letters that were sent to those in the target population clearly identified that consent was implied and explained that the respondent could withdraw from the study at any time. Voluntary participation and informed consent was therefore adhered to.

9.7.2 Non-Maleficence

While the study posed no explicit harm to participants, it was recognised that the method of collecting questionnaires via a third party was potentially harmful to respondents, if the security of their completed questionnaires was compromised (De Vaus 2002). The lack of any identifying data on the questionnaires as well as the fact that they were sealed in envelopes militated against the above risks. It was acknowledged, though, that participation in focus groups and key informant interviews were potentially harmful, if confidentiality was compromised. Full assurances and explanations regarding the security and planned destruction of data were given.

9.7.3 Beneficence

It may be suggested that, by initiating research into identifying the key components of care in intellectual disability services, this study has the potential to bring about beneficent outcomes for both staff and clients within residential intellectual disability services.

9.7.4 Anonymity and Confidentiality

Throughout the studies, the requirement for anonymity and confidentiality was maintained (Judd et al 1991). Focus group and key informant information is maintained in a locked cabinet, within a locked office. Any information that could identify either participating services, or interviewees, was removed and stored under similar security in a separate location.

For the Delphi and survey studies, services were assigned date-based codes by which they could be identified. These codes were incorporated in date form on each of the questionnaires. The key to this code is maintained in a password-protected file on a password-protected computer. Upon opening of sealed envelopes, a specific sequentially-derived number was written on each questionnaire. This was for purposes of questionnaire identification, and, as respondents' names were not provided to the researcher, at no stage was it possible to ascertain the identity of individual respondents.

All written data are maintained under lock and key in a locked office. Electronic data are stored on a password-protected computer in this locked office. Access to the office, cabinet and computer is restricted to the researcher alone.

9.8 Conclusions

Armiger stated in 1974 that "there exists today an unprecedented need for the identification of the uniqueness of nursing science and practice, lest overriding forces in contemporary society lead to a disintegration of nursing as a distinct profession" (p.160). These prophetic views appear to have pre-empted the findings of this study by suggesting that the non-description of *what nursing is and what it is not* is linked to the potential loss of that unique contribution to other new or extant groups (Smith 1992).

In the context of the paradigmatic changes that have been described, it may be asked 'is nursing relevant to intellectual disability care any more?' People with such disabilities, like other members of society, have health care needs. Within a socially inclusive approach to intellectual disability, such health care needs should, ideally, be met within the mainstream services that are employed by all other members of society. Many people with intellectual disability, however, are unable to easily access those services. Also, the meeting of those health care needs may need be addressed within the context of the person's intellectual disability. As it stands, the RNID remains the only specialist whose qualification is wholly focused on caring for the person with intellectual disability, with all others commencing from a generic base. The absence of this specialist knowledge within general health care services suggests that intellectual disability nursing remains relevant, at least within the provision of health care to clients. The need to define *this* unique contribution remains as vital today as it did thirty years ago, when Armiger wrote the above lines, and as it did one hundred and forty years ago, when Florence Nightingale's premised that "the elements of nursing are all but unknown" (Nightingale 1860 p.8). This study has gone some way towards making those elements known. It remains to be seen whether future research, building on this, will reveal the remaining elements of intellectual disability nursing.

APPENDIX A – Delphi Study

- **Letter and Study Information for Participants**
- **Consent Forms**
- **Initial Delphi Questionnaire**

FINTAN SHEERIN BNS, RNMH, RGN

Date

«Title» «FirstName» «LastName»
«Address1»
«Address2»
«City»

Dear «FirstName»

I am writing to you to in regard to a research study, which I am undertaking and which focuses on identifying what the 'nursing diagnoses' in this field of nursing are. It is to be conducted using a four-stage correspondence with individual nurses who are adjudged to be experts, by virtue of their qualification, and knowledge and/or experience.

I would be most grateful if you would peruse the enclosed data sheet, and, if you are willing to participate, sign the attached consent form.

If you wish to take part in the study, you should open the sealed envelope marked ‘QUESTIONNAIRE’ and respond to the question asked therein. Please return the completed form by return, using the enclosed S.A.E.

I do hope that it will be possible for you to participate in this study, which has being supported by NAMHI, and which will contribute to a definition of what it is we do in the field of Mental Handicap Nursing. If it is not possible to participate, I would be grateful if you would return the contents in the enclosed S.A.E

Sincerely,

Fintan Sheerin BNS PgDipEd RNMH RGN RNT
(UKCC)

Identifying the Foci of Interest to Nurses in Irish Residential Learning Disability Services

There has, over the past decade, been a worldwide movement towards the classification of the phenomena of interest to nurses. This is evidenced by the production of the International Classification for Nursing Practice (ICN 1996) and through the work of the North American Nursing Diagnosis Association (NANDA), the Nursing Interventions Classification (NIC), and the Nursing Outcomes Classification (NOC). In Europe, this work is being actively supported by the Association for Common European Nursing Diagnoses, Interventions and Outcomes (ACENDIO), of whose Board the researcher is a member. It is envisaged that the classification systems that will be produced by these groups will form the basis for a common understanding amongst nurses, worldwide. They will also facilitate the introduction of information technology within health-care services, with obvious potential for the estimation of nursing activity and consequent manpower and financial planning, at governmental level. These language systems will also interact with those of other professions, including medicine, such that cross-referencing will be possible. The development of similar classification systems outside of learning disability nursing is also evident through the publication of the International Classification of Impairments, Activities and Participation (ICIDH-2 β-1) (WHO 1997).

Within nursing, most of the attempts to classify nursing phenomena (or diagnoses) have come from the context of acute/chronic general nursing. As such, they may be seen to represent only a subsection of the profession, as a whole. No consideration has been made of the phenomena of interest to learning disability nurses, perhaps because such nurses have traditionally been located in only a handful of countries, and have not been motivated to examine this area themselves.

Considering that learning disability nursing is at a crucial juncture, with various forces, within and outside of nursing seeking to relegate it to a post-graduate, specialist level, there is a risk that the specific input of this nursing will be lost, and will be subsumed within an illness/problem-oriented approach, that is not representative of the reality of care in this field.

The purpose of this study is to identify the foci of interest that are specific to nursing intervention within residential, learning disability nursing. It will achieve this through the use of questionnaires sent to ten expert nurses working in residential–associated services throughout the country. A Delphi Technique approach will then be employed, whereby analysed and summarised responses will be returned to the participants for further refinement and clarification.

Research Problem

There is an immediate need for the explication of the essence of learning disabilities nursing, through the identification of the specific phenomena that are the focus of nursing intervention in that area. These interventional foci will represent a base upon which to conceptualise that discipline.

Background

Much taxonomic work has been carried out in order to classify the phenomena (diagnoses) that are of interest to nursing (Gordon 1997; ICN 1997). It must be noted however, that these have been based on the premise that there is a problem that requires intervention, such that the outcome will represent a development, perceived by the patient and nurse to be positive. This has, however, been potentially alienating for nursing disciplines, such as learning disabilities, that do not have their grounding in problem-focused care. Apart from the fact that it is decidedly different from the more traditional clinical nursing disciplines in that it is neither illness-oriented nor hospital-based, it is firmly grounded in qualitative rather than quantitative knowledge. In addition, its relevance from a health-care perspective is recognised in only a handful of European countries.

The paradigmatic difference that is represented in learning disabilities nursing is of sufficient importance that it should be considered to represent a basic conceptual variance in relation to that of those disciplines of nursing in which current nursing diagnoses arose.

Little work has been done in relation to identifying nursing diagnoses in learning disabilities nursing. One recent paper by Chambers (1998) looked at the application of validated NANDA diagnoses to nursing in the context of a community-based day activity/occupational service. He concluded that there was a need for further development of the diagnoses, and indeed, proposed a new diagnosis in relation to non-verbal communication.

Methods

In keeping with the Delphi Technique approach (Polit and Hungler 1987), it will be necessary to identify a group of individuals who may be considered to be experts in learning disabilities nursing practice. Expertise has been defined on the basis that participants must be registered mental handicap nurses, have extensive experience of nursing in residential services, and be knowledgeable in relation to their profession.

An initial questionnaire will be sent to these individuals to elicit a listing of the phenomena that are the foci of intervention for learning disability nurses in residential services. Upon receipt of the completed questionnaires, a shortened list will be compiled of phenomena identified, in common, by all participants. These will form the basis for a second questionnaire. The responses of the second questionnaire will be submitted to summary statistics and a third questionnaire will be devised with requests for explanation of the participants' rationales for their decisions. The responses will be summarised and returned to the participants in a fourth questionnaire, for confirmation. These will be accompanied by similar, validated terms from the North American Nursing Diagnosis Association’s classification. The participant will be asked if the definitions accompanying the NANDA terms have the same meanings as those based on the participants’ responses. The results of this final correspondinal consultation will comprise a set of proposed interventional foci, and would be then subjected to validation studies.

Researcher Details

The researcher possesses certification in both mental handicap and general nursing, and has obtained a Bachelor of Nursing Studies (Hons) degree at University College Dublin., and a Post-Graduate Diploma in Education of Nurses, from the University of Ulster. He currently pursuing an MPhil/DPhil (Nursing) at University of Ulster.

The researcher has extensive experience in learning disability nursing, having worked in residential and day services. He has authored many publications within the nursing literature, and is a Board member of the Association for Common European Nursing Diagnoses, Interventions and Outcomes. He is also on the Scientific Committee of that group. He was the first Irish person to present a paper at ACENDIO's European Conferences, and was also the first to explore nursing diagnoses from the context of learning disabilities nursing. He is on the reviewing panels for the Journal of Advanced Nursing and the International Journal of Nursing Studies.

Reference List

Chambers, S. (1998) Nursing diagnosis in learning disabilities nursing. British Journal of Nursing. 7(19), 1177-1181.

Gordon, M. (1997) Manual of Nursing Diagnosis 1997-1998. St. Louis: Mosby Year Book.

International Council of Nurses (1996) The International Classification for Nursing Practice. Geneva: International Council of Nurses.

Polit, D. & Hungler, B. (1987) Nursing Research: Principles and Methods. Philadelphia: J.B. Lippincott Company.

World Health Organization (1997) International Classification of Impairments, Activities and Participation. Geneva: World Health Organization.

Respondent's Consent Form

In signing this document, I am giving consent to receive four questionnaires from Fintan Sheerin, in relation to a study into the identification and labelling of the issues that are the foci of interest in residential learning disabilities nursing.

I understand that I will be asked questions about what I consider to be the foci of interest to nursing that area based on my knowledge and experience as a professional nurse. I understand also that participation in this study is entirely voluntary, and that I can terminate my involvement in the study at any point. I am aware that my answers will, in association with answers of other participants, form the basis for identifying and labelling the issues that learning disabilities nursing aims to address in residential services. I also understand that no reports of this study will ever identify me in any way, and that my identity will be known only to the research assistant.

I agree that the questionnaires can be addressed to my home address at:

____

____

____

I understand that the results of this research will be given to me if I ask for them, and that any questions I have can be directed to Fintan Sheerin (phone 041 9844548).

____

____

Date Respondent's Signature

QUESTIONNAIRE 1

Please answer the following question as completely as you can. Do not discuss it with anyone else, as what is being sought here are *your* views as a professional nurse. When you are finished, please place the completed form in the attached S.A.E. and post by return.

What do you consider to be the issues upon which nursing interventions in <u>residential</u> mental handicap nursing focus?

(For example: wound care nurses may focus on the prevention of infection as one of their issues)

Please continue over as necessary.

APPENDIX B – Focus Groups

- **Service Introduction Letter**
- **Participant Letter**
- **Consent Form**
- **Topic Guide**
- **Interventional Schedule**
- **Interventional Rating Scale**
- **Interventional Definitions**
- **Locations of Identified Diagnoses on NANDA Taxonomy II**

FINTAN SHEERIN

Date

<name>,
<post>,
<centre name>,
<address 2>,
<city>,
<county>.

Dear <name>:

I am undertaking a study examining nurses' and service managers' perceptions of what the foci of nursing interventions are within Irish residential (institutional or community-based) learning disability services. This is being done as part of an MPhil/DPhil research degree, and is being supervised by Roy McConkey.

The study, which is largely qualitative in methodology, will, at this stage, require the holding of focus groups at various centres throughout the country, at which 6-10 registered learning disability nurses will be facilitated in discussing what they perceive to be the foci of their nursing care/interventions. It is intended that this will be followed later in the year by focussed individual interviews with service managers (nursing and non-nursing), and finally, by a pan-organisation study of one service's staff perceptions. In a further study that I hope to commence next year, I will be looking at clients' and advocates' perceptions of what nursing should be about. The two of these studies, in combination, should provide important information that can be used to help guide the development of future learning disability nursing courses, which have, sadly, fallen far behind in terms of client and service need, as well as regarding their philosophical contexts.

I wonder if it would be possible for me to conduct a focus group with 6-10 of the <centre name> nursing staff that are working within residential services, including those in respite units. If this is possible, would I be able to do this at a central <centre> venue, during the <date period>. The interview itself would take no longer than 90 minutes, and would be moderated by a colleague, <assistant name>.

I would be grateful if this could be facilitated, and look forward to your reply.

Sincerely,

Fintan Sheerin BNS PgDipEd, RNMH, RGN
RNT
Research Associate

105 FIVE OAKS, DUBLIN RD • DROGHEDA • CO. LOUTH
PHONE: 0419844548 • EMAIL: shamelle@eircom.net

FINTAN SHEERIN

Date

Dear Colleague:

You are receiving these documents because you have been selected to participate, along with seven others, in a 90-minute discussion session, aimed at exploring what the focus of nursing in residential learning disability services is. This session, which has been kindly facilitated by your service manager, will be held on <date>, from <time> hrs.

If you are willing to participate, I would be grateful if you would complete the enclosed consent form and bring it to the meeting on the above date. I would also be grateful if, prior to attending the meeting, you would complete the attached biographical form and questionnaire. These should be completed by you alone, and should only represent your views. The questionnaire will form a basis for discussion at the group meeting.

I look forward to seeing you on <date>.

Regards,

Fintan Sheerin BNS, PgDipEd, RMHN, RGN,
RNT
Research Associate, University of Ulster.

105 FIVE OAKS, DUBLIN RD • DROGHEDA • CO. LOUTH
PHONE: 0419844548 • EMAIL: shamelle@eircom.net

Questions for Focus Group on Foci for Nursing Interventions

Participants

A group of 6-8 registered intellectual disability nurses from one residential service for people with intellectual disabilities.

Venue & Time

Purpose

To explore residential-based registered intellectual disability nurses' ideas of what they consider to be the foci (diagnoses/ problems) for nursing interventions in residential services for people with intellectual disabilities.

Objectives

To find out participants':

1. Understanding of the concept of 'nursing diagnosis' and 'interventional focus'.
2. Perceptions on what the interventions appropriate to each category are.
3. Estimation of the relative importance of these interventions.
4. Judgements of what stimulates these interventions to be employed in residential intellectual disability nursing.
5. Experience of using diagnosis-intervention-outcome approaches in clinical practice.

Welcome

Good afternoon, and welcome to our meeting. First of all I would like to thank you all for coming today and I look forward very much to hearing your contributions. My name is <moderator's name>. This is my colleague, Fintan Sheerin, who is a research associate at the University of Ulster, and is currently studying how nursing language might be developed in intellectual disability nursing.

This meeting is being held as part of a study that is aiming to explore your perceptions of what are the most important and relevant client problems or issues which require nursing intervention.

You were asked to attend because, as Registered Mental Handicap Nurses, you are the experts in the field, and possess much knowledge which is pertinent to the research topic. You have all indicated your consent to participate in this focus group by signing and returning the consent forms. You may, however, at any stage, withdraw from the meeting.

Please feel free to share your point of view even if it differs from what others have said. There are no right or wrong answers but rather differing points of view.

Before we begin, .let me share some ground rules. Please speak up, only one person should talk at a time. I'm tape recording the session because I don't want to miss any of your comments. If several are talking at the same time, the tape will get garbled and we'll miss your comments.

The session, this afternoon, will last, at most, 90 minutes. Let's begin! I have placed name cards on the table in front of you to allow us to remember each other's names.

Opening Question:

1. Let's find out some more about each person, by going around the room one at a time. So, tell us your name and something about your nursing career to date.

Introductory Question:

Prior to taking part in this focus group, you were given a list of nursing interventions that have been suggested, by other studies, to be of relevance to residential intellectual disability nursing care. Take a moment to reacquaint yourselves with this list.

1. Now I would like you to consider which of these interventions would constitute your ten most important nursing interventions, and what determined your choice. (moderator now explores participants' ranking of the interventions, and elicits discussion from them on rationales for their choices).
2. The list of interventions is, by no means, exhaustive. After looking at this list, do you want to include any other interventions that you use in your practice? (moderator adds these to list on flipchart)

Key Questions:

1. Looking at the list of nursing interventions on the flipchart, and focussing on them one-at-a-time, what would cause these interventions to be employed in residential intellectual disability nursing? (Moderator hangs up new flipchart, and writes responses beside each intervention)
   Prompts: *nursing diagnoses; nursing problems; foci for nursing intervention*.

   Example: one might employ bowel care interventions where a client presents with an altered pattern of bowel elimination (i.e. constipation or diarrhoea) or where preparation of bowel is required for an upcoming examination.

2. Have you ever heard the term 'nursing diagnosis'? What you understand by that term?
3. The issues that you have identified as causative factors for specific nursing interventions could be considered to be nursing diagnoses. Consider these nursing diagnoses and on a scale of 0-5 (0=no importance and 5=very important) can you tell me what level of importance would you ascribe to each of them in relation to residential intellectual disability nursing? (Moderator writes responses beside each issue)

Ending Questions:

1. Of all the issues identified above, is there one that you consider to be of paramount importance in residential intellectual disability nursing?
2. The aim of this meeting has been to discuss the issues that provide a focus for our nursing interventions in residential intellectual disability nursing, and so, to come to

> some understanding of what it is we do in this field. From the issues discussed, can you think of anything else of importance or anything that we have forgotten?

Summary & Conclusion

INTERVENTIONAL SCHEDULE FOR FOCUS GROUPS

FOCUS GROUP TO EXPLORE RESIDENTIAL-BASED REGISTERED INTELLECTUAL DISABILITY NURSES' IDEAS OF WHAT THEY CONSIDER TO BE THE FOCI FOR NURSING INTERVENTIONS IN RESIDENTIAL SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES.

General Instructions for Completion of Biographical Form

1. All responses to this form will be strictly confidential.
2. No one apart from the researcher will see your responses.
3. Please complete the form by placing a tick (✓) unless instructed otherwise in the box(s) provided for each question.
4. Please complete all questions.

Biographical Details

1. What is your name? ____

2. Please tick the box that most closely approximates to your age:

20-25 ☐	26-30 ☐	31-35 ☐	36-40 ☐	41-45 ☐
46-50 ☐	51-55 ☐	56-60 ☐	61-65 ☐	

3. What is your professional work title? ________________________________.

4. How many years are you qualified as a RMHN? _________________________.

5. If you have a dual registration qualification, please tick the appropriate box(s):

RGN ☐ RPN ☐ RSCN ☐ RNT ☐ Other ☐

6. If you have other qualifications please specify:

____

____

____

____

INTERVENTIONAL RATING SCALE FOR FOCUS GROUPS

FOCUS GROUP TO EXPLORE RESIDENTIAL-BASED REGISTERED INTELLECTUAL DISABILITY NURSES' IDEAS OF WHAT THEY CONSIDER TO BE THE FOCI FOR NURSING INTERVENTIONS IN RESIDENTIAL SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES.

General Instructions for Completion of Interventions Rating Scale

1. All responses to this form will be strictly confidential.
2. No one apart from the researcher will see your responses.
3. This form asks you to rate 30 specific nursing interventions according to how important you consider them to be to residential intellectual disability nursing.
4. A definition of each intervention is provided in the latter part of the form.
5. Please complete the form by placing a tick (✓) in the appropriate box provided for each question.

Please complete all questions.

INTERVENTIONS RATING SCALE

	INTERVENTION	IMPORTANT	NEITHER IMPORTANT NOR UNIMPORTANT	UNIMPORTANT
1.	Anger control assistance			
2.	Communication enhancement			
3.	Communication enhancement: active listening			
4.	Documentation			
5.	Emotional support			
6.	Exercise promotion			
7.	Home maintenance assistance			
8.	Humour			
9.	Infection control			
10.	Infection protection			
11.	Medication management			
12.	Medication management: oral			
13.	Nutrition management			
14.	Oral health promotion			
15.	Perineal care			
16.	Presence			
17.	Recreation therapy			
18.	Safety enhancement			
19.	Security enhancement			
20.	Seizure management			
21.	Self-care assistance			
22.	Self-care assistance: bathing/hygiene			
23.	Self-care assistance: dressing/grooming			
24.	Self-care assistance: toileting			

25.	Shift report			
26.	Skin surveillance			
27.	Sleep enhancement			
28.	Socialisation enhancement			
29.	Spiritual support			
30.	Teaching: prescribed medication			

INTERVENTIONAL DEFINITIONS

	INTERVENTION	DEFINITION
1.	Anger control assistance	Facilitation of the expression of anger in an adaptive non-violent manner.
2.	Communication enhancement	Assistance in accepting and learning alternate methods for living with impaired communication.
3.	Communication enhancement: active listening	Attending closely to and attaching significance to a client's verbal and non-verbal messages.
4.	Documentation	Recording of pertinent data in a clinical record.
5.	Emotional support	Provision of reassurance, acceptance, and encouragement during times of stress.
6.	Exercise promotion	Facilitation of regular physical exercise to maintain or advance to a higher level of fitness and health.
7.	Home maintenance assistance	Helping the client to maintain the home as a clean, safe, and pleasant place to live.
8.	Humour	Facilitating the client to perceive, appreciate, and express what is funny, amusing, or ludicrous in order to establish relationships, relieve tension, release anger, facilitate learning, or cope with painful feelings.
9.	Infection control	Minimising the acquisition and transmission of infectious agents.
10.	Infection protection	Prevention and early detection of infection in a patient at risk.
11.	Medication administration: oral	Preparing and giving medications by mouth and monitoring client responsiveness.
12.	Medication management	Facilitation of safe and effective use of prescription and over-the-counter drugs.
13.	Nutrition management	Assisting with or providing a balanced dietary intake of foods and fluids.
14.	Oral health promotion	Promotion of oral hygiene and dental care for a client with normal oral and dental health.
15.	Perineal care	Maintenance of perineal skin integrity and relief of perineal discomfort.
16.	Presence	Being with another in times of need.
17.	Recreation therapy	Purposeful use of recreation to promote relaxation and enhancement of social skills.
18.	Safety enhancement	Intensifying a client's physical and psychological safety.
19.	Security enhancement	Intensifying a client's sense of physical and psychological safety.
20.	Seizure management	Care of a client during a seizure and the postictal state.
21.	Self-care assistance	Assisting another to perform activities of daily living.
22.	Self-care assistance: bathing/hygiene	Assisting a client to perform personal hygiene.
23.	Self-care assistance:	Assisting a client with clothes and makeup.

	dressing/grooming	
24.	Self-care assistance: toileting	Assisting another with elimination.
25.	Shift report	Exchanging essential client care information with other nursing staff at change of shift.
26.	Skin surveillance	Collection and analysis of client data to maintain skin and mucous membrane integrity.
27.	Sleep enhancement	Facilitation of regular sleep/wake cycles.
28.	Socialisation enhancement	Facilitation of another person’s ability to interact with others.
29.	Spiritual support	Assisting the client to feel balance and connection with a greater power.
30.	Teaching: prescribed medication	Preparing a client to safely take prescribed medications and monitor for their effects.

Placement of Nursing Diagnoses Identified in Focus Group Study under the NANDA Taxonomy II Structure

Domain 1: Health Promotion

Class 2: Health Management

Ineffective Health Maintenance

Domain 2: Nutrition

Class 1: Ingestion

Risk for Imbalanced nutrition: Less than Body Requirements

Risk for Imbalanced Nutrition: More than Body requirements

Domain 3: Elimination

Class 2: Gastrointestinal System

Constipation

Risk for Constipation

Domain 4: Activity/Rest

Class 2: Activity/Exercise

Dressing/Grooming Self-Care Deficit

Bathing/Hygiene Self-Care Deficit

Feeding Self-Care Deficit

Toileting Self-Care Deficit

Domain 5: Perception/Cognition

Class 4: Cognition

Knowledge Deficit (Safety)

Disturbed Thought Processes

Class 5: Communication

Impaired Verbal Communication

Domain 6: Self-Perception

Class 1: Self-Concept

Disturbed Personal Identity

Risk for Loneliness

Class 2: Self-Esteem

Risk for Situational Low Self-Esteem

Risk for Chronic Low Self-Esteem

Domain 7: Role Relationships

Class 2: Family Relationships

Interrupted Family Processes

Class 3: Role Performance

Impaired Social Interaction

Domain 9: Coping/Stress Tolerance

Class 2: Coping Responses

Anxiety

Dysfunctional Grieving

Impaired Adjustment

Ineffective Coping

Domain 11: Safety/Protection

Class 1: Infection

Risk for Infection

Class 2: Physical Injury

Risk for Injury

Risk for Trauma

Risk for Suffocation

Ineffective Protection

Class 3: Violence

Risk for Self-Mutilation

Self-Mutilation

Risk for Other-Directed Violence

Risk for Self-Directed Violence

Class 4: Environmental Hazards

Risk for Poisoning

Domain 12: Comfort

Class 3: Social Comfort

Social Isolation

APPENDIX C –Key Informant Interviews

- **Service Introduction Letter**
- **Key Informant Interview Schedule**

FINTAN SHEERIN

Date

<name>.
<position>.
<service name>,
<address 1>,
<city>,
<county>.

Dear:<name>

I am currently undertaking a study examining nurses' and service managers' perceptions of what the foci of nursing are within Irish residential (institutional or community-based) learning disability services. This is being done as part of an MPhil/DPhil research degree, and is being supervised by Roy McConkey, from the University of Ulster.

The study, which is largely qualitative in methodology, has, to date, involved the holding of focus groups at various centres throughout the country, at which nurses have discussed what they perceived to be the foci of their nursing care/interventions. These groups have yielded a surprisingly high consensus of opinion and foci that are of interest when compared with the ongoing development of learning disability services in Ireland.

The next stage of the process will delve into service and nursing managers' perceptions of what the focus of nursing is in this area. In order to do this I hope to carry out personal interviews with 1 service manager (director, CEO or deputy) and 1 nursing manager (CNM3 up) in each of 5 learning disability services which incorporate a residential component.

I would be grateful if it would be possible for me to meet with you (or your deputy) and also with a nursing manager in your service, for separate 1-hour interviews. I will, of course, be guided by you as to when such interviews might be held, but would request that they be on the same day.

I look forward very much to your response.

Sincerely,

Fintan Sheerin BNS PgDipEd RMHN RGN RNT

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PHONE: 041-9844548 • EMAIL: SHAMELLE@EIRCOM.NET

Questions for Key Informant Interviews with Service/Nurse Managers

Participants

Five Service Managers in Irish learning disability services which have a residential component.

Five Nursing Managers (CNM3 and higher) in Irish learning disability services which have a residential component.

Venue & Time

Individual focused interviews at each participant's service.

Date and time to be decided.

Purpose

To explore service and nursing managers' ideas of what they consider to be the most important interventions for nurses in residential learning disability services, and what they perceive to be the foci (diagnoses/ problems) for such nursing interventions in those services.

To explore if service and nursing managers' consider if the *actual* foci of learning disability nurses in residential services are in tune with the philosophy underpinning such services.

Objectives

To find out managers':

1. Understanding of what philosophy underpins the current direction in service provision.
2. Perspectives on what the principal interventions of nurses in residential learning disability services are.
3. Perspectives on what the actual principal foci of nursing in learning disability residential services
4. Consideration of the current relevance of nursing to residential learning disability service provision
5. Consideration of how residential services will develop in the next 10-20 years
6. Perspectives on the future relevance of nursing to residential learning disability service provision
7. Understanding of how future residential services will be staffed

Welcome

First of all I would like to thank you for meeting with me today and I look forward very much to hearing your contributions. My name is Fintan Sheerin. I am a research associate at the University of Ulster, and I am studying the perceptions of nurses, nurse managers and service managers on the focus and scope of learning disability nursing in residential services.

This meeting follows on from a Delphi study and a number of focus groups which were held among nurses in winter 2000.

You were asked to attend because of your experience in managing (nursing in learning disability services) (learning disability services). As such, you are the experts in this field, and possess much knowledge which is pertinent to the research topic.

I would ask you to be as candid as possible. I would like to tape record the session, if that is ok, because I don't want to miss any of your comments.

The interview itself should last, about 60 minutes.

Opening Questions:

1. Services have changed a lot over the past few decades. What type of developments have you seen in the `[name of service]` since you became involved here?
2. What has driven these changes?

Introductory Questions: (5-10 minutes)

3. In what way have your residential services changed over this time period
4. If you had to describe the philosophy that is currently underpinning residential service provision and developments in `[name of service]` what would it be?
5. As it currently stands, how do you see nursing fitting into this approach?

Key Questions: (45 minutes)

1) More specifically, in terms of 'nursing interventions', what do unit/ward-based nurses actually do in your residential learning disability service?
    a) Is this the case throughout your residential services?
    b) Does any other grade of staff do these activities, and if so, who?
2) Taking this a bit further then, what do you consider to be the principal foci for nurses in residential services? *(prompts – on a gross level: physical care, psychological care, training, education etc; on a more detailed level: bowel care; behaviour modification; social skills training etc)*
3) With regards to recruitment of nursing staff, what skills or competences would you expect a nurse to bring to a job in your organisation that an applicant from another discipline would not have?
4) What views do you have on how residential services will develop over the next 10-20 years?

5) As it currently stands, how do you see nursing fitting into those future residential services?
6) I have noticed over the past few years that many jobs in learning disability services, which were previously nursing posts, are now being advertised in different, more generic terms, and being opened to a diversity of persons.
   Do you see learning disability services being staffed in this way in the future, and if so, what would you consider to be the nurse's contribution within such a framework?

7) In the context of future developments, do you think that the retention of a specific learning disability nurse program is desirable or would you see a generic form of nurse education/training as producing nurses to meet your organisation's requirements?
8) One issue that relates quite closely to this area is 'skill mix'. Whilst I do not want to delve into this, as such, what, if any, has your experience been with the employment of non-RMHNs and non-Irish trained nurses?

Summary & Conclusion (5 minutes)

Ending Question:

1. The aim of this meeting has been to find out your ideas on residential service provision, and on the place of the nurse in that structure. From the issues discussed, can you think of anything else of importance or anything that I have forgotten? Or is there anything that you would like to add?

APPENDIX D – Pan-Organisational Survey

- **Collegial Letter to Available Population**
- **Questionnaires**
    - **Pilot Questionnaire**
    - **Nurses & Non-Nurse Care Staff Questionnaire**
    - **Multidisciplinary Team & Service Manager Questionnaire**
- **Tabulated Matter**
    - **D1 - Frequency of Employment of Interventions as Reported by Nurses**
    - **D2 - Frequency of Employment of Interventions as Reported by Non-Nurse Care Staff**
    - **D3 - Factor Matrix for Nursing Role in Intellectual Disability Services**
    - **D4 - Factor Matrix for Non-Nurse Care Staff Role in Intellectual Disability Services**
    - **D5 - Factor Matrix for the Care Role in Institutional Residential Services**
    - **D6 - Factor Matrix for the Care Role in Community Residential Services**

FINTAN SHEERIN

Date

Dear:Colleague

You are invited to participate in a study examining nurses’, service managers’ and multidisciplinary team members' perceptions regarding the current and future focus of nursing within Irish residential (institutional or community-based) intellectual disability services.

The study, which is part of a broader, research doctoral work, has been ongoing for the past two years and has, to date, been largely qualitative in nature. The next stage of the process will quantify the responses of service employees to a questionnaire that has been developed as a result of that qualitative work. The explicit aim of this study is ***to set out the current contribution of intellectual disability nursing in Irish residential services***, and ***to extrapolate the perceptions of nurses, non-nursing service managers, and multidisciplinary team members regarding this contribution***.

Your service management has graciously agreed to allow me distribute this questionnaire to staff within your service, in order to assess its adequacy. I, therefore, invite you to participate in this pilot study, and to complete the enclosed questionnaire and associated feedback form, returning it to me in the SAE within seven days from date of receipt.

You are not required to provide your name and address, and I will not be aware of your identity. You may, however, be interested in participating further in this on-going study. If so, please write your details on the last sheet of the questionnaire. As with all such studies, anonymity and confidentiality will be maintained at all times.

I do hope that you will participate in this study, and I look forward to receiving your views on the focus of intellectual disability nursing.

Sincerely,

Fintan Sheerin BNS PgDipEd RMHN RGN RNT
Research Associate

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