Identifying the Foci of Interest to Nurses in Irish Intellectual Disability Services*

Fintan Sheerin BNS PgDipEd RNMH RNT,
Lecturer-Practitioner.
School of Nursing and Midwifery,
University College Dublin,
Earlsfort Terrace,
Dublin 2.
Ireland

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ABSTRACT

Many of the attempts to classify nursing phenomena (or diagnoses) have been developed within the context of acute/chronic general nursing, and may, as such, be seen to represent only a subsection of the profession as a whole, for scant consideration has been made of the phenomena of interest to intellectual disability nurses. This may be 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 intellectual disability nursing in Ireland, 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 was to identify the foci of interest that are specific to nursing intervention within residential, intellectual disability nursing. This was achieved through the use of a Delphi study which was followed up by three focus groups held among Irish intellectual disability nurses working in three service settings, and personal interviews with residential service/nurse managers.

Keywords: Intellectual disability; nursing diagnosis; nursing focus; Delphi; focus groups

INTRODUCTION

Intellectual Disability Nursing in Ireland

In Ireland, the discipline of intellectual disability nursing has only been a reality since the early 1960s, when An Bord Altranais (The Irish Nursing Board) 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. 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 compounded by changes that have seen services move from being primarily segregational and reductionalist to what are now more integrational and holistic, with the paradigm-shift in such services resulting in a move from a medical to a humanistic model (Mercer 1992). It is clear that whilst the psycho-socio-educational approach is in tune with the latter, the biomedical approach is not. This has presented obvious problems for a discipline such as intellectual disability nursing, which has traditionally grounded so much of its practice in the medical model.

The professional literature in Ireland contains little of relevance regarding the role of the nurse in the field of intellectual disability. In a previous paper (Sheerin 1998), this writer 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 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) appears to have viewed the input of specialised nurses as being particularly relevant to 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" (par. 120). The later 1983 report (Department of Health and Social Welfare 1983), suggests that both qualities of kindness, humanity and dedication, as well as practical expertise in relation to training and skills were necessary in such staff. The 1990 Working Party Report, entitled 'Needs and Abilities' (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 further away from the biomedical model towards the psycho-socio-educational one. This mirrors the manner in which service philosophy in the United Kingdom had changed some ten years earlier (Sines 1995), and in the United States twenty years previous to that (Nehring 1994). In considering the living requirements of people with intellectual disabilities, the 1990 Report, in a manner similar to that of the UK Report of the Committee of Inquiry into Mental Handicap Nursing and Care (Department of Health 1979), proposed community based residences as being the way forward. 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 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 the syllabus of nurse training (An Bord Altranais 1993), for, although revised, this was initially set out in 1985, and appeared to reflect a strong biomedical bias evidenced by the inordinate content of biological subject matter. It is hoped that the recent review of the intellectual disability nursing syllabus will address this issue. 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 may be seen to be supported by the fact that only 25.6% of people with intellectual disabilities are located in residential services (National Intellectual Disability Database Committee 1999), whilst the An Bord Altranais database suggests that approximately 75% 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 positions in more generic terms, and to employ a variety of personnel in these posts (Department of Health and Children 1998).

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 Irish Nursing Board 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 (Department of Health and Children 1998). The recent realisation of the Commission on Nursing recommendation (Department of Health and Children 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. This has been the experience in the Northern Ireland situation when, in 1997, nurse education moved from the colleges of nursing to the universities (Orr et al 1999). 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.

The development of Irish intellectual disability services has been heavily influenced by its strong relationship with the medical profession. This has resulted in people with intellectual disabilities being viewed as having a disease or pathology, and, so, as 'disabled' members of society. Although intellectual disability nursing has tried to

break free from this mould over the past few years, its role has tended to be described in purely biomedical terms, with little attempt to describe the foci at which nursing interventions are directed. In the near absence of professional literature on the identification of nursing diagnoses in the specific field of intellectual disability nursing, it is difficult to obtain points of reference that operate from a non-illness-oriented base.

RESEARCH PROBLEM

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.

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 client and nurse to be positive. This has, however, been potentially alienating for nursing disciplines, such as intellectual 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 increasingly grounded in qualitative rather than quantitative knowledge. In addition, its relevance from a health-care perspective is recognised in only a few European countries.

I have already said that only limited work has been done in relation to identifying nursing diagnoses in intellectual disabilities nursing. That literature, which is extant, does, however, go some way towards identifying diagnoses that are relevant to that field.

Chambers (1998) examined the application of nursing diagnoses, as classified by the North American Nursing Diagnosis Association (NANDA), to the care planning process at an intellectual disability adult training unit, over a two-year period. 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 were:

High risk of violence directed at self or others

Impaired verbal communication

Altered protection

Self-care deficit: toileting

High risk of suffocation trauma

Alterations in nutrition: eating less than required.

Functional incontinence

Sensory perception alteration

Chambers concludes that there is a need for further terms to be researched to address such areas as 'non-verbal communication'.

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 - alteration in nutrition: less than body requirements; ineffective breathing pattern; alteration in bowel elimination; constipation; fluid volume deficit and impairment of skin integrity - emerged from this study as being significant diagnoses. Whilst these 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, a process which commenced in 1985.

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 intellectual disability and psychiatric impairment. She identifies 12 NANDA diagnoses that were relevant in the care of this client:

- Ineffective individual coping
- Potential for violence, directed at self and others
- Social isolation
- Impaired adjustment
- Knowledge deficit
- Fear/Anxiety
- Impaired verbal communication
- Altered thought process
- Diversional activity deficit
- Sleep pattern disturbance
- Altered growth and development

- Rape trauma syndrome

It is clear that Gabriel's study focuses on aspects of nursing care that are characteristic, not of the medical approach, but rather of an alternative paradigm.

The study described in this paper is the first such Irish study, and complements the findings that have been just outlined. It achieves this by answering the research question: What do residentially based learning disability nurses understand to be the foci of nursing intervention in such services?

METHODOLOGY

The initial investigation, upon which the focus group questionnaires and personal interviews were based, employed a modified Delphi technique. This involved the sampling of a group of eight individuals who had expertise in intellectual disabilities nursing practice. Expertise was defined on the basis that participants be registered mental handicap nurses, have extensive (>5 years) experience of nursing in residential services, and have a strong knowledge base grounded in relevant theory or practice. The final criterion for selection was that participants be proposed by their nurse manager.

The second part of the study incorporated the use of focus groups and personal interviews to reveal the real and perceived foci for nursing interventions in this field, as well as to develop some conceptualisation of future service plans. The focus group interview schedule that was developed was grounded in the results of the Delphi study as well as on the work of Klastermans and Oud (2000), of which more anon. The schedule was passed on to three experienced nurses within residential intellectual disability services for review, and changes made accordingly. Similarly, the interview schedule which was employed in the personal interviews was developed from the same bases, but took account of the information that was gleaned from the focus groups.

FINDINGS

The Delphi Study

The Delphi study was designed to provide some direction as to where the foci of intervention might lie. An initial questionnaire was sent to the eight participants to elicit a listing of the phenomena that are the foci of intervention for intellectual disability nurses in residential services. This questionnaire simply asked the question, "What do you consider to be the issues upon which nursing interventions in residential mental handicap nursing focus?" 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 nursing interventions, instead identified the interventions themselves. After clarification was achieved, a shortened list of issues identified by the participants was developed (Table 1). Only those issues that had achieved at least 50% consensus amongst participants' responses were included. These formed the basis for a second questionnaire, which sought to further clarify the initial responses of the participants, through the allocation of descriptive labels.

- (Risk for/Actual) Inability or reduced ability to perform activities of daily living (specify level of ability & reason)
- (Risk for/Actual) Isolation and/or rejection (related to social isolation/ institutionalisation)
- (Risk for/Actual) Isolation and/or rejection (related to challenging behaviour)
- (Risk for/Actual) Abnormal living patterns (related to social isolation/ institutionalisation)Lack of/requirement for recreation
- Lack of/requirement for knowledge (society)

Table 1: Shortened list of diagnoses identified in the Delphi study

In a third and final questionnaire, the participants were provided with NANDA terms and associated descriptors and were asked to identify whether or not these correlated with the labels which had been allocated to their clarified responses. Alongside this final questionnaire, was included a rating scale, in which the participants were asked to rate the level of importance of each issue identified in the study.

Results

The responses of the participants to the initial questionnaire contained interesting similarities, which provided a basis for immediate progress along a consensual pathway. Most of these responses were presented in the form of nursing activities. As these were not client-focussed descriptors, the writer attempted to clarify the inherent concepts, allowing for these to be validated by the participants.

As previously mentioned, participants were also asked to rate the importance of all issues identified in the study. Those diagnoses that were identified as being important by $\geq$ 50% of participants are presented in table 2. The results of this exercise have provided some guidance as to potential nursing diagnoses in intellectual disability nursing.

Risk for/Actual) Inability or reduced ability to perform activities of daily living (specify level of ability & reason)
(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) 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)
(Risk for/Actual) Isolation related to impaired communication
(Risk for/Actual) Impaired communication (intrinsic or extrinsic)
Lack of/requirement for exercise.
Lack of/requirement for recreation.
(Risk for/Actual) Inability to self-advocate (client/family)

Table 2: Foci for nursing intervention (nursing diagnoses) suggested as significant by Delphi study.

Focus Groups

Whilst the study had been focussing on the responses of nurses in residential settings, it was decided that the scope of participation should be expanded to a group of nurse educators. The reason for this was that it was the writer's plan to explore whether or not the education/training programmes for intellectual disability nurses are in harmony with the reality as experienced by nurses on the ground.

The participants in the study were selected following from responses to invitations that were sent to the specific services. It has been explained above that three focus groups were held which elicited the responses of 17 nurses with a mean of 32.2 years experience in intellectual disability nursing. Whilst all had extensive experience of residential intellectual disability service, the mean for continuous years currently in such services was 4.8 years.

The questionnaire that was administered during the focus groups was developed from a combination of the potential diagnoses identified in the Delphi study and the work of Klastermans and Oud (2000), which was presented at the NANDA Conference in

Orlando, Florida. The questionnaire took the form of an initial investigation into nursing interventions in the field, with a subsequent refocusing on the issues that elicited such interventions (table 3).

1. Anger control assistance	17. Recreation therapy
2. Communication enhancement	18. Safety enhancement
3. Communication enhancement: active listening	19. Security enhancement
4. Documentation	20. Seizure management
5. Emotional support	21. Self-care assistance
6. Exercise promotion7. Home maintenance assistance	22. Self-care assistance: bathing/hygiene
8. Humour	23. Self-care assistance:dressing/ grooming
9. Infection control	24. Self-care assistance: toileting
10. Infection protection	25. Shift report
11. Medication management	26. Skin surveillance
12. Medication management: oral	27. Sleep enhancement
13. Nutrition management	28. Socialisation enhancement
14. Oral health promotion	29. Spiritual support30. Teaching: prescribed medication
15. Perineal care16. Presence	

Table 3: Questionnaire administered during focus groups

The questionnaire was administered during the interview by a moderator and the writer took field notes, which were to prove most valuable in analysis. Participants were asked to rank and rationalise their ‘top-10’ interventions. They were also asked to identify the diagnoses that might lead to the identified interventions being employed. Each focus group lasted a minimum of 90 minutes and elicited a rich quality of discussion.

Findings

The focus groups identified many potential interventions and diagnoses for the field of residential intellectual disability nursing. Of those, special attention was paid to interventions that elicited a greater than 50% occurrence amongst participants’ ‘top-10’, across focus groups. These were examined for contextual meaning, based on the taped and noted responses, and the potentially related interventions were then applied.

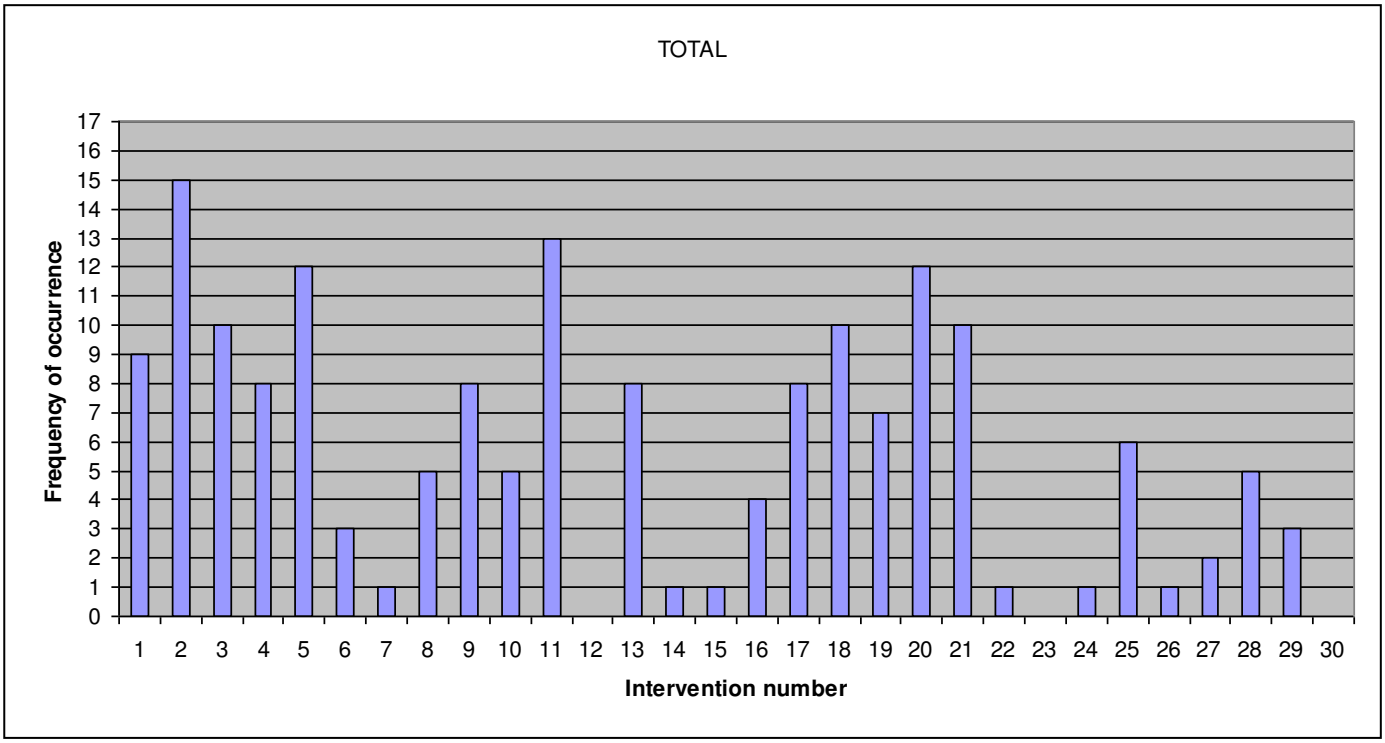

Diagram 1: Frequency of occurrence of interventions in participant's 'top-10' (intervention numbers refer to those in table 3)

This led to the identification of eight potentially related nursing interventions (as per McCloskey & Bulechek 1996) (table 4).

1 - Anger control assistance 2 - Communication enhancement 3 - Communication enhancement: active listening 5 - Emotional support	11 - Medication management 18 - Safety enhancement 20 - Seizure management 21 - Self-care assistance

Table 4: Nursing interventions suggested as significant by focus group study

The key questions in the focus group schedule asked participants to identify the foci for the listed interventions, and thus, elicited a contextual aspect for these interventions. This further directed the analysis process to identify nursing diagnoses that were suggested to lead to the interventions being used. The resultant list can be seen in table 5, which includes both interventions and diagnoses.

Anger control assistance	**Communication enhancement**	**Communication enhancement: active listening**	**Emotional support**
Risk for violence: directed at others	Impaired social interaction	Impaired social interaction	Ineffective individual coping
Risk for violence: self-directed	Social isolation	Social isolation	Social isolation
Risk for self-mutilation	Altered thought processes	Altered thought processes	Risk for loneliness
Altered thought processes	Impaired verbal communication	Impaired verbal communication	Dysfunctional grieving
			Anxiety
			Impaired adjustment
Medication administration	**Safety enhancement**	**Seizure management**	**Self-care assistance**
	Altered protection	Risk for injury	Self-care deficit
	Knowledge deficit (safety)	Risk for trauma	Altered thought processes
	Risk for self-mutilation	Altered protection	
	Risk for injury	Altered thought processes	
	Risk for violence: self-directed	Self-esteem disturbance	
	Risk for violence: directed at others	Personal identity disturbance	
	Altered thought processes	Impaired social interaction	
	Altered health maintenance	Knowledge deficit (safety)	
	Risk for trauma	Risk for suffocation	

Table 5: Nursing interventions cross-referenced to NANDA nursing diagnoses using contextual data.

When placed under the pattern structure of the NANDA (1999) classification, the nursing diagnoses presented in table 6 are identified.

Pattern 1: Exchanging	Pattern 2: Communicating	Pattern 3: Relating	Pattern 4: Valuing
Risk for injury	Impaired verbal communication	Impaired social interaction	
Risk for suffocation		Social isolation	
Risk for trauma		Risk for loneliness	
Altered protection			
Pattern 5: Choosing	**Pattern 6: Moving**	**Pattern 7: Perceiving**	**Pattern 8: Knowing**
Ineffective individual coping	Altered health maintenance	Self-esteem disturbance	Knowledge deficit (safety)
Impaired adjustment	Self-care deficit	Personal identity disturbance	Altered thought processes
Pattern 9: Feeling			
Dysfunctional grieving			
Risk for violence: directed at others			
Risk for self-mutilation			
Risk for violence: self-directed			
Anxiety			

Table 6: Nursing diagnoses suggested as significant by the focus group study

Personal Interviews

The principal aim of the overall study was to identify the foci for nursing interventions in residential intellectual disability nursing, as perceived by nurses working in that domain. It was considered though that this might produce data, which, in the absence of other perspectives, could be contrived as being rather 'sterile'. This was borne out in the information gleaned in the first two parts of the study, for it took no account of the status of service provision, but was, rather a 'snapshot' of where nursing was at that point in time. It was decided, therefore, that a series of interviews would be held with senior non-nursing and nursing service managers who were working in residential services, so as to address this contextual vacuum. These were identified by random sampling of residential service providers across four defined situations/models of service – rural institutional; urban institutional; rural village/community; urban village/community – and by purposive sampling of

individuals within the chosen services. One service was sampled from each of the four categories but only three of these could be pursued, with one service manager and one senior nurse manager being interviewed in each organisation (n=6).

Findings

Following transcription of the one-hour interviews, the data was subjected to thematic analysis. Four key themes were identified which demonstrated interesting differences between non-nursing service managers' and nursing managers' perceptions. The four themes related to: developments in residential service provision; ideas regarding intellectual disability nursing; issues in recruitment; training/educational programmes. The interviewees considered that focus of intellectual disability nursing needed to be examined from the perspective of current and future service provision. Whilst the three services in question were vastly different in organisation and residential provision, those interviewed proposed that this provision would develop towards a more individualised, community based approach over a 5-10 year period. This would see a movement from institutional to village-type units, from village-type units to community group homes, and from community group homes to supported living respectively. This was seen to be a key factor in determining the appropriate focus of nursing interventions and so introduced the variable of current and future service provision. Nursing was identified as having a role of coordinating care around physical illness and other medical issues. As such, it was perceived that it had become relevant to specific client groups namely people with multiple handicap, illness, profound disability, significant 'nursing' needs (such as altered feeding needs) and challenging behaviour. This concurs with the previously noted observation based on figures from the Irish Nursing Board and National Intellectual Disability Database (2000). It was strongly suggested by nurse interviewees that intellectual disability

nursing is relevant to residential services, and that it would be an integral part of future provision, albeit in a coordinating role, with generic grades providing hands-on care. This was contested by service managers who identified the concept of the 'nurse' carer as being in contradiction to the philosophy of normalisation which was seen to imbue services. They also suggested that the professional aspect of 'being a nurse' went against the concept of genericism which is growing within many services. Whereas there was agreement across all interviewees that nurses brought skill and expertise to residential service provision, it was clear that nurses' skill repertoire was not seen to be exclusive to nursing and that they were to a large degree seen to be expendable.

DISCUSSION

Early in this paper it was suggested that intellectual disability nursing is approaching a crucial juncture in its history. The challenge is emanating from three main fronts – the demands of the changing service landscape, the 'genericisation' of caring roles and the similar genericism of nurse education. The findings of this study suggest though that intellectual disability nursing may not be prepared for or even aware of the challenge.

As residential services develop towards a more person-centred model, so also is the paradigm underpinning such services changing from a biomedical to asocio-educational one. This suggests a move away from the conservationism of the institution to the risk-filled world of society, with an increased emphasis on possibility rather than disability. In this study, however, nurses have that the following nursing diagnoses are currently relevant to Irish residential intellectual:

- Ineffective individual coping
- Risk for violence: directed at others
- Risk for violence: self-directed
- Risk for self-mutilation
- Social isolation

- Impaired social interaction
- Risk for loneliness
- Impaired adjustment
- Knowledge deficit (safety)
- Anxiety
- Impaired verbal communication
- Altered thought processes
- Altered protection
- Self-care deficit
- Risk for suffocation
- Risk for trauma
- Risk for injury

The focus of many of these diagnoses is on negativity, disability and on failure (risk for injury/loneliness/self-mutilation etc.) It would appear that these are not in keeping with the changing landscape.

The development of generic roles within intellectual disability services has seen an increasing tendency to advertise hitherto nursing posts as ‘house parent’, ‘team leader’ and ‘unit head’ positions, thus attracting applicants from a rich variety of backgrounds. This has, however, occurred alongside a growing awareness that, apart perhaps from medication management, registered nurses’ roles could not be defined as being quantifiably unique. The rigidity of professional identity has further complicated this. Within this developing context, nurses in this study have clearly stated that they are central to the development and running of future services, and whilst they do suggest that this will be from a coordinating role, they do not appear to be aware of the potential that exists for the demise of their profession.

While further analysis and study needs to be carried out to verify the relevance of these diagnoses to residential intellectual disability, it is interesting to make a quick comparison of the results with those of other cited studies for it can be seen immediately that certain diagnoses have been identified by one or more authors in their studies.

That nurses see the emphasis of their practice as focusing on preventive strategies and to mental health issues appears to contradict the idea that such nurses work from a biomedical paradigm. It is not possible to make any concluding judgement in this regard, but it does give some food for thought for, if it is the case, then it supports the suggestion that the reality of nursing practice in residential intellectual disability care is significantly awry from that which is contained within the syllabus upon which nurse education is based.

CONCLUSION

In conclusion, this study has sought to derive the foci of nursing intervention in Irish residential learning disability nursing, from the practical and theoretical knowledge of nurses experienced and working in that area. It has identified a number of such foci which have achieved various levels of consensus among the study participants. The 38 that have achieved a significant level of consensus have been correlated by the writer with validated NANDA terms. It is accepted that this study has limitations in relation to its sample size and population as well as in confirming the validity of these diagnoses. Further research is being undertaken by the writer to address these issues.

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