Intellectual disability nursing in Ireland: Identifying its development and future.

Owen Doody, Eamonn Slevin, Laurence Taggart

Abstract

As a profession, intellectual disability nursing has often come under scrutiny and been called into question. Since its inception as an individual nursing profession in 1959 in Ireland, both education and service provision philosophies have changed over time. These changes have been in response to national and international reports and changing attitudes. The changes have led to the current position where intellectual disability nurse education in Ireland is a four-year undergraduate course. As the discipline of intellectual disability nursing is unique to Ireland and the United Kingdom, there is a responsibility on intellectual disability nurses to identify their unique identity and their responses to the demands of changing services. This article traces the development of intellectual disability nursing in Ireland and identifies implications for the future.

Key words:

Care provision, evidence based practice, intellectual disability nursing, nurse education, research base.

Introduction

Intellectual disability nursing is one of the smallest branches of nursing in Ireland and nurse training in this area can be traced back to 1959. Originally nurses in this branch were referred to as registered nurses mental subnormality (RNMS); this later changed to registered mental handicap nurses (RMHN), and at present the term used is registered nurse intellectual disability (RNID). The history of the care of persons with an intellectual disability in Ireland was originally one of institutional care and segregation from the community, but in the 1980s a social model of care began to be implemented and services began transferring to community settings. Intellectual

disability nursing over the years has been subject to much debate, relating to the nature of intellectual disability nursing and the knowledge, skills and role of nurses working in this area. This article traces the development of intellectual disability nursing in Ireland, identifying its educational development, service changes and future position.

History of Intellectual Disability Nursing in Ireland

While nursing had existed informally since early human development, it was not until the endeavours of Florence Nightingale and her peers over 150 years ago that nursing began as a profession. As a profession nursing has diversified greatly over the years, leading to specialization in many fields which are represented by the principal divisions of the Irish professional nursing register maintained by the nursing regulatory board in Ireland, An Bord Altranais (ABA). One specialization represented on the Irish nursing register is intellectual disability nursing, which has had a varied and interesting history. Historically people with intellectual disability were institutionalized along with the poor, the unemployed, the infirm and the mentally ill (Ashton, 1977) and institutional care predominated from the 1700s (Nehring, 1991). Throughout this time members of religious orders and lower class women who were untrained made up the first workforce in hospitals and asylums. Services for people with intellectual disabilities began to develop at the end of the nineteenth century after Stewart's Hospital, Dublin was opened in 1879 as an institution to provide for the education, training and maintenance of children with intellectual disability. However throughout the first half of the twentieth century, under the leadership of religious congregations and voluntary bodies, services were transformed into an organized and structured approach to meeting the needs of people with intellectual disability. Service providers were moving beyond a custodial approach to care, focused on treatment and cure, to a more holistic view of people with intellectual disability that focused on their needs as well as their education and skills development. The nurses working in the field came largely from general and psychiatric nursing backgrounds and, true to those disciplines' philosophies, they attempted to employ illness-oriented approaches to the care of people who were not ill (Reynolds, 1992). Scanlan (1991), in a study of the history of Irish nursing, suggested that the first consideration given to introducing intellectual disability nursing in Ireland was in the late 1940s. This was compounded by the increased public, professional and social awareness that was developing

regarding the needs of people with intellectual disability, in part stemming from the experience of staff working with people with intellectual disability.

Following World War II and the United Nations Declaration on Human Rights (UN, 1948) there was an increased consciousness of human rights and needs, particularly where disadvantaged and minority groups were concerned. This resulted in the Department of Health approaching ABA regarding the possibility of providing specialized training for nurses working in the field of intellectual disability (Robins, 1992). ABA commenced its registered mental subnormality nurse education in 1959 at two newly opened schools, Daughters of Charity at St Joseph's Clonsilla, Dublin and Brothers of Charity at St John of God Drumcar, County Louth. The initial nursing approach was largely related to the custodial policy of the times, namely congregated traditional institutional settings. As the number of registered mental subnormality nurses (as they were called at the time) increased, they started to become influential in relation to the actual manner in which care was provided, having a positive effect on physical care and the organization of that care (Sheerin, 2000). The National Association for the Mentally Handicapped of Ireland (NAMHI, 1962) saw the need for the orientation of staff towards teaching and training rather than nursing, supporting the move from a medical model to a more social model of care. Additionally the Commission of Inquiry on Mental Handicap (DoH, 1965) report was published which was a culmination of four years' (1961–4) examination of existing facilities for the ascertainment and treatment of intellectual disability persons and made suggestions as to how these might be improved or augmented. The report guided the developments and maturation of services for many years ahead, making some specific suggestions on the subject of nurse training (see Table 1) and proposing that more emphasis be placed on social and emotional issues, something that was developed in later syllabi.

Table 1. Focus of Nurse Training;

(a) Treatment and care of the severely handicapped of all ages.
(b) Treatment, care and training of the lower ranges of moderately handicapped children.
(c) Treatment, care and training of moderately and mildly handicapped adults with further

involvement in the care of other mentally handicapped persons where illness or emotional crisis present.

Department of Health (1965)

In the 1970s two further schools of nursing opened that contributed greatly to the number of nurses in this field. These developments came at a time when the contributions of Bank-Mikkelsen, Nirje and Wolfensberger on the philosophy of normalization were becoming a major force in service planning and delivery in the late 1970s and throughout the 1980s, leading to profound changes for people with intellectual disability (Stella, 1996). A core principle of normalization was that similar standards of health, safety and comfort should apply to systems and programmes for people with intellectual disability as are applied to comparable settings for other citizens (Wolfensberger, 1972: 39). This resulted in a shift away from the medical model in the 1970s (Carman-Brown and Fox, 1996), which was eventually replaced with the social model in the early 1980s (Bottroff et al., 2000). The ideas expressed by NAMHI (1962) and DoH (1965) and the philosophy of normalization created a sense of awareness that intellectual disability nursing was developing its own identity and was different from the mainstream of the profession. Signs of change were instigated by the publication of the government report Training and Employing the Handicapped (DoH, 1974), where it seemed certain that the character of intellectual disability services were to change. ABA responded to this challenge and issued a revised syllabus of training for registration as a mental handicap nurse (ABA, 1979), which looked critically at the skills and knowledge requirement of the nurse in what was beginning to be seen as a field of nursing unlike the other nursing disciplines in Ireland. The headings used in the syllabus were different from those in other disciplines whose syllabi focused on treatment and care (see Table 2).

Table 2. Sections of the Nursing Syllabus of Training;

- Nursing
- Mental handicap
- Social sciences

- The needs and special requirements or mentally handicapped persons
- Special therapeutic methods
- Medicine and allied sciences

An Bord Altranais (1979)

However, while the syllabus had changed in focus, there was still a strong biomedical orientation among nurse educators and within the discipline, thereby limiting the potential for developing nursing concepts along the normalization pathway. The 1980s were characterized by continued change within intellectual disability services in Ireland, with ever more heightened social awareness of marginalized people, as evidenced by the publication of several government reports, namely the Report of the Working Party on Services for the Mentally Handicapped (DoH, 1980), Towards a Full Life (DoH, 1983a) and The Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland (DoH, 1983b). These reports focused on the idea that people with intellectual disability had the potential to develop within many areas of their lives, with education, training and employment becoming not only a possibility but a right for even the most disabled person. While this education and training aspect was gaining acceptance within intellectual disability nursing, the DoH (1983b) report severely challenge that concept, noting that 'even allowing for modifications in the new syllabus, nurses of people with intellectual disability are primarily nurses, not teachers'. The report consigned the role of the nurse to providing care within residential living units, while residential services were being increasingly relocated away from traditional institutions under the community-based residences model (DoH, 1980).

While the move to community-based residences was to change the lives of many people with intellectual disability and provide opportunities for new possibilities, it also led to a questioning of the role of the nurse in such environments. During this time new approaches to care became evident, such as client allocation and key worker approaches. The latter became the favoured norm in the 1990s as it took on the key characteristics of primary nursing approaches, with the nurse having total responsibility for the care of a small group of clients over a long period. This formed

the basis for developing the advocacy, inclusion and empowerment role of the registered nurse intellectual disability (RNID) which was set against the background of further changes in the focus and structure of intellectual disability services recommended by the report Needs and Abilities (DoH, 1990). The report identified training of residential personnel 'in home-making, home sharing, housekeeping and home-management, counselling and personal support' (1990: 50) as being prerequisite in moving services more towards the socio-educative paradigm. In recognition ABA (1992) developed a revised syllabus of nurse education and training (Table 3), aimed at reflecting modern services and the growth and development of services from a narrowly focused custodial model to one that captured the diversity of individually determined approaches to meeting the needs and developing the potential of persons with intellectual disability.

Table 3. Sections of the Nursing Syllabus of Training;

• Education and development of the Child
• Education and Development of the Adult
• Disorders of Human Behaviour
• The Body in Health and Disease
• Management
• Allied Topics
An Bord Altranais (1992)

The changes in education and training led to developments within computer-assisted learning, multisensorial and alternative therapies and recreational endeavours within services. In 1997 the Working Group on the Role of the Mental Handicap Nurse issued its report, which described the nurse as being 'an essential and integral element of the multidisciplinary team required to deliver the services which persons with intellectual disability require' (DoH, 1997: 11); however this report was never officially published. While there has often been some uncertainty about the future of the intellectual disability nurse, this was to some degree reduced by the 1998 Report of the Commission on Nursing which affirmed the 'need to promote the distinct

identity and unique working environment of intellectual disability nursing' (GoI, 1998: 172). Accompanying this, however, was a recognition that intellectual disability nursing needed to change in order to respond to the complexities of services and clientele. Again changes were ahead within the realm of nurse education syllabi, guided by ABA in their requirements and standards for nurse registration education programmes (ABA, 1999; 2000; 2005) (Table 4). Following the developments that had been occurring within the fields of general and psychiatric nursing in the mid 1990s (delivery of a three-year diploma programme), intellectual disability nurse education moved to a shared approach of intellectual disability nurse training between nursing schools and third-level institutions. These courses saw nurses in intellectual disability graduating with university diplomas, and with the possibility of completing a bachelor degree in nursing studies afterwards. Further development occurred with the introduction of a four-year degree programme for pre-registration to third level institutes in 2002, thereby gaining increasing academic recognition for the profession. With increased education and professionalism the intellectual disability nurse is tasked with making their contribution to healthcare visible (Treacy and Hyde, 2003).

Table 4. Requirements and Standards for Nurse Registration Education Programmes;

• Nursing and Professional Development
• Person-Centred Care
• Health Sciences and Applied Nursing Principles
• Nursing, Sociology, Law and Environment
An Bord Altranais (1999; 2000; 2005)

The road ahead

A Strategy for Equality (National Federation of Voluntary Bodies, 1996), National Disability Strategy (GoI, 2004), Time to Move On from Congregated Settings (HSE, 2011). Intellectual disability nurses need to identify and articulate their multifaceted role in caring for persons with intellectual disability, which includes direct care, management, administration, liaison work and educational activity (Alaszewski et al.,

2001; Sheerin, 2004) in whatever setting they work. Fundamental to these roles is the promotion of autonomy of the person with intellectual disability, a greater need for health promotion (Bollard, 2002; Moulster and Turnbull, 2004) and evidence-based care (Haynes et al., 1996; Barnsteiner and Prevost, 2002), and these need to be incorporated into future RNID practice. In short the role of the RNID should be guided by evidence, promotion of health and therapies leading to empowerment that are person centred.

Ireland is moving towards the final stages of a paradigm shift of service ideologies away from long-term residential services for people with intellectual disability to a complex landscape of service provision (Malin and Race, 2010). Models of service delivery are changing and are shifting to more personalized services that will require access to an appropriately trained and skilled workforce (Mansell, 2010). In this evolving landscape of services and personalization agenda there will be a new range of roles to be embraced by intellectual disability nurses, for example in supporting secondary healthcare in acute hospitals and in mental health services as well as in primary care. The changing landscape of service provision will comprise supported living, independent living, in-home support, community-based support, primary care and specialist support (HSE, 2011) with a contemporary focus on employment, education and personalization. Nonetheless there remain larger service configurations and specialist settings, such as treatment and assessment services and challenging behaviour units, as well as specialist health or social care settings such as homes for older people and hospices providing care for children with life limiting conditions, or respite services for children with complex and continuing health needs or social care needs (Gates, 2011). This complex landscape of service arrangements typically involves a range of agencies working collaboratively to support people with intellectual disability in their preferred lifestyles and involves immediate families and the networks of support offered by friends and the social care and healthcare workforce; the latter comprises a range of professional disciplines.

Intellectual disability nursing may have been marginalized within nursing due to the failure to fully subscribe to the medical model of care that has been at the core of nursing values and following models of practice based on education and social care (Mitchell, 2004). However, intellectual disability nurses have the potential to become

agents of inclusion because of their contribution to current health and social care reforms and the fact that they are working at the very heart of initiatives to develop services for people with intellectual disability (Gates, 2007). The discipline of intellectual disability nursing is unique to Ireland and the UK as they are the only professionals who gain a specialist qualification exclusively concerned with addressing the needs of people with intellectual disability (Gates, 2006; Jenkins et al., 2006; Griffiths et al., 2007). Thereby the future of intellectual disability nursing is in the hands of intellectual disability nurses, and it is within the grasp of the discipline to identify its unique identity and place within the overall profession of nursing. Intrinsic factors will influence the future of intellectual disability nursing which relate to the ability of the discipline to respond appropriately to the demands of changing services, and intellectual disability nursing will have to expand its core roles to the limit of and beyond what is conventionally defined as nursing (Sheerin, 2000). For this to occur there needs to be a sound accessible research base that is useable by nurses, both in highlighting needs and in identifying effective strategies for caring for persons with intellectual disability (Griffiths et al., 2007).

It has been suggested that there is a distinct and unique skill complement associated with the intellectual disability nursing specialty, and that it must be preserved and promoted (GoI, 1998; Mitchell, 2004; Atkinson et al., 2010). However, these unique skills need to be visible and utilized across healthcare environments, thereby ensuring the health needs of people with intellectual disability are met. This would be a new venture for intellectual disability nursing in Ireland, as in the past it has been largely intellectual disability service based and has not been good at multiagency working within and across general healthcare provision. Additionally Gates (2006) identifies that people with intellectual disability themselves view the RNID role as a helper and an enabler, and as possessing specialist knowledge. Therefore appropriate knowledge, skills and attitudes are vital to providing a holistic and person-centred approach to care delivery. However, in the past intellectual disability nursing in Ireland has not published evidence on which nurses can base their practice, and in today's society care provision and policy must be articulated and disseminated not only to other professions but to service users who have individual rights to such information.

While referral, coordination and liaison are crucial and important roles for the intellectual disability nurse, these are not reflected in the research literature, and intellectual disability nurses need to focus their research endeavours in this area. Furthermore the virtual absence of robust nursing evaluations and interventions for widely identified problems for persons with intellectual disability may reflect a heavy reliance for the provision of evidence for practice from other disciplines or professionals, further compounded by the absence of intellectual disability nurses in most other countries (Griffiths et al., 2007). Therefore, the essence of intellectual disability nursing should be to endeavour to capture and illuminate the very heart and kernel of care, thus leading to evidence-based quality services worthy of underpinning caring for service users with an intellectual disability. Through conducting research the intellectual disability nurse can create a knowledge base specific to their own practice rather than operating mainly on their own practice wisdom (Doody and Doody, 2011).

Conclusion

Since the inception of intellectual disability nurse education in 1959, the RNID has been on the front line of care provision for people with an intellectual disability in Ireland (Sheerin and McConkey, 2008). Though registered intellectual disability nurses have only been a reality since the 1960s, the discipline has grown to its current status as one of the main divisions of Irish nursing. Intellectual disability nursing has been constantly challenged to change at a pace and degree not required of other disciplines, and as a discipline it has tried to respond to these challenges in a positive way. This is witnessed in the changes in intellectual disability nurse education, philosophy and service provision over the years. However, the profession has been stifled by its uncertain relationship to and identity within the wider nursing profession, which has created debate on the existence of intellectual disability nursing in the past and which continues to re-emerge over time. As relocation occurs to community-based residences and a social model of care, role evaluation needs to be ongoing to take account of changing contexts of care. This is essential in order to develop evidence for practice and to frame care in a client-focused manner. The future of the profession is in the hands of the nurses themselves and in their willingness to make visible their contribution. This can be achieved through dissemination of research and

practice-based publications and the ongoing modernization of services along with sustaining the intellectual disability nursing workforce (Barr and Gates, 2008).

References

ABA (1979) Syllabus of Training and Record of Instruction and Experience for Nurses in the Field of Mental Handicap. Dublin: An Bord Altranais.

ABA (1992) Syllabus for the Education and Training of Student Nurses: Mental Handicap. Dublin: An Bord Altranais.

ABA (1999) Requirements and Standards for Registration Education Programmes. Dublin: An Bord Altranais.

ABA (2000) Requirements and Standards for Nurse Registration Education Programmes (2nd edn). Dublin: An Bord Altranais.

ABA (2005) Requirements and Standards for Nurse Registration Education Programmes (3rd edn). Dublin: An Bord Altranais.

Alaszewski A, Motherby E, Gates B, Ayer S and Manthorpe J (2001) Diversity and Change: The Changing Roles and Education of Learning Disability Nurses. London: English National Board for Nursing, Midwifery and Health Visiting.

Ashton GA (1977) Essentials of Intellectual Retardation. Sydney: McGraw-Hill. Atkinson D, Boutler P, Pointu A, Thomas B and Moulster G (2010) Learning disability nursing: how to refocus the profession. Learning Disability Practice 13 (1): 18–21.

Barnsteiner J and Prevost S (2002) How to implement evidence based practice. Reflections on Nursing Leadership 28 (2): 18–21.

Barr O and Gates B (2008) Education for the future: the changing face of education for staff. Tizard Learning Disability Review 13 (1): 18–27.

Bollard M (2002) Health promotion and learning disability. Nursing Standard 16: 47–53.

Bottroff V, Grantley J and Brown R (2000) Tertiary education for professionals in the field of disability services: roads of progress and cross roads. International Journal of Practical Approaches to Disability 24 (1/2/3): 18–24.

Bruton M (2003) Final Report of the Special Working Group on the RMHN. Dublin: Health Service Employers Agency.

Carman-Brown K and Fox C (1996) Making a new profession: social trainers and intellectual disability. In: Cocks E, Fox C, Brogan M and Lee M (eds) Under Blue Skies: The Social Construction of Intellectual Disability in Western Australia. Australia: Optima.

Clark LL and Diack G (2007) A vision for learning disability nursing: where to now? Learning Disability Practice 10 (2): 16–19.

DoH (1965) Report of the Commission of Inquiry on Mental Handicap. No. IRL 362.2 BRIS 632234. Department of Health. Dublin: Stationery Office.

DoH (1974) Training and Employing the Handicapped: Report of a Working Group. Department of Health. Dublin: Stationery Office.

DoH (1980) Report of the Working Party on Services for the Mentally Handicapped. Department of Health. Dublin: Stationery Office.

DoH (1983a) Towards a Full Life. Department of Health. Dublin: Stationery Office.

DoH (1983b) The Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland. Department of Health. Dublin: Stationery Office.

DoH (1990) Needs and Abilities: A Policy for the Intellectually Disabled. Report of the Review Group on Mental Handicap Services. Department of Health. Dublin: Stationery Office.

DoH (1996) Towards an Independent Future: The Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities. Department of Health. Dublin: Stationery Office.

DoH (1997) Report of the Working Group on the Role of the Mental Handicap Nurse. Department of Health (unpublished).

Doody CM and Doody O (2011) Introducing evidence into nursing practice: using the IOWA model. British Journal of Nursing 20 (11): 661–664.

ERHA (2003) Looking into the Future: Maximising the Nursing Contribution to a Comprehensive Intellectual Disability Service. Dublin: Eastern Regional Health Authority.

Gates B (2006) Care Planning and Delivery in Intellectual Disability Nursing. Oxford: Blackwell.

Gates B (2007) Learning Disabilities: Towards Inclusion (5th edn). London: Churchill Livingstone.

Gates B (2011) Learning Disability Nursing: Task and Finish Group Report for the Professional and Advisory Board for Nursing and Midwifery, Department of Health England. Hertfordshire: University of Hertfordshire.

GoI (1998) Report of the Commission on Nursing. Government of Ireland. Dublin: Stationery Office.

GoI (2004) National Disability Strategy. Government of Ireland. http://www.justice.ie/en/jelr/nds.pdf/files/nds.pdf

Griffiths P, Bennett J and Smith E (2007) The Research Base for Learning Disability Nursing: A Rapid Scoping Review. London: Kings College.

Haynes RB, Sackett DL, Gray JM, Cook DJ and Guyatt GH (1996) Transferring evidence from research into practice. 1: The role of clinical care research evidence in clinical decisions. ACP Journal Club 125 (3): A14–16.

HSE (2011) Time to Move On from Congregated Settings Report: A Strategy for Community Inclusion. Report of the Working Group on Congregated Settings. Dublin: Health Service Executive.

Jenkins R, Wheeler P and James N (2006) Care planning in residential settings. In: Gates B (ed.) Care Planning and Delivery in Intellectual Disability Nursing. Oxford: Blackwell, 53–67.

Malin N and Race DG (2010) The impact of social policy on changes in professional practice within learning disability services: different standards for children and adults? A two-part examination: Part 1. The policy foundations: from welfare markets to valuing people, personalization and Baby P. Journal of Intellectual Disabilities 14 (4): 315–328.

Mansell J (2010) Raising Our Sights: Services for Adults with Profound Intellectual and Multiple Disabilities. University of Kent: Tizard Centre.

Mitchell D (2004) Learning disability nursing. British Journal of Learning Disabilities 32: 115–118.

Moulster G and Turnbull J (2004) The purpose and practice of learning disability nursing. In: Turnbull J (ed.) Learning Disability Nursing. Oxford: Blackwell, 57–72.

NAMHI (1962) Report on Day Training Centres for Mentally Handicapped Children. Dublin: National Association for the Mentally Handicapped of Ireland.

National Federation of Voluntary Bodies (1996) A Strategy for Equality: Report of the Commission on the Status of People with Disabilities. http://www.fedvol.ie/_fileupload/Next%20Steps/strategy_for_equality.pdf

Nehring WM (1991) Historical look at nursing in the field of mental retardation in the United States. Mental Retardation 29 (5): 259–267.

Reynolds J (1992) Grangegorman: Psychiatric Care in Dublin since 1815. Dublin: Institute of Public Administration.

Robins J (1992) From Rejection to Integration: A Centenary of Service by the Daughters of Charity to Persons with a Mental Handicap. Dublin: Gill and Macmillan.

Scanlan P (1991) The Irish Nurse. A Study of Nursing in Ireland: History and Education 1718–1981. Manorhamilton: Drumlin.

Sheerin F (2000) Mental handicap nursing. In: Robins J (ed.) Nursing and Midwifery in Ireland in the Twentieth Century. Dublin: An Bord Altranais, 163–175.

Sheerin F (2004) Identifying the foci of interest to nurses in Irish intellectual disability services. Journal of Learning Disabilities 8 (2): 159–174.

Sheerin FK and McConkey R (2008) Frontline care in Irish intellectual disability services: the contribution of nurses and non-nurse care staff. Journal of Intellectual Disabilities 12 (2): 127–141.

Stella L (1996) Normalisation and Beyond: Public Sector Residential Care 1965-1990, in Cocks E, Fox C, Brogan Mand Lee M (eds) Under Blue Skies: The Social Construction of Intellectual Disability in Western Australia. Perth: Optima Press, Centre for Disability Research and Development, Faculty of Health and Human Sciences, Edith Cowan University, pp. 92–136.

Treacy MP and Hyde A (2003) Developments in nursing in Ireland: the emergence of a disciplinary discourse. Journal of Professional Nursing 19 (2): 91–98.

UN (1948) Universal Declaration of Human Rights. Geneva: United Nations. www.un.org/en/documents/udhr/

Wolfensberger W (1972) Normalisation: The Principle of Normalisation in Human Services. Toronto: National Institute of Mental Retardation.