The development of clinical nurse specialists (CNSs) in intellectual disability nursing in Ireland

Abstract

Since the commencement of intellectual disability nurse training in 1959, both education and service provision philosophies have changed over time in Ireland. These changes have occurred in response to national and international reports and attitudes. Coinciding with the changes in education and philosophy have been the development and advancement of the intellectual disability nursing profession. Currently undergraduate intellectual disability nurse education is unique to Ireland and the United Kingdom and, similar to the developments across other disciplines of nursing, advance practice has become a focus of development. This article traces the development of intellectual disability clinical nurse specialists (CNSs) in Ireland and identifies possible challenges and implications for future practice.

Introduction

While the United States has recognized the clinical nurse specialist (CNS) role since the 1960s and the United Kingdom (UK) since the early 1980s (Daly and Carnwell, 2003), formal recognition in Ireland is relatively new (NCPDNM, 2001; 2004a; 2007; 2008). The roots of the CNS in Ireland can be tracedback to TheWorking Party onGeneral Nursing Report (DoH, 1980); however, it was not until 1998 after a collaborative report between the nursing board and health service employers that the fundamentals and roles for CNSs were recognized. The Report of the Commission on Nursing (GoI, 1998) recommended the establishment of the National Council for the Professional Development of Nursing and Midwifery (NCPDNM) and recognized the need to promote intellectual disability nursing as a career. The NCPDNM was established in 1999; however, in the absence of a framework for development, it resulted in a diverse group of individuals practising with minimal support (Doody and Bailey, 2011). To address this issue an initial pathway for the national development of CNS roles was introduced in 2001 and the Council issued a definition for CNS. This allowed the development of CNS posts in Ireland to formally begin, and the number of nurses working in intellectual disability who have been recognized as a CNS by the NCPDNM has grown from 100 in 2001 to 132 in 2010. Table 1 identifies a range of titles used within intellectual disability CNS practice.

Table 1. Example of titles in intellectual disability CNS practice

- Challenging behaviour and behaviour management
- Creative, recreational and diversional activation
- Community nursing
- Early intervention
- Autism spectrum disorders
- Health promotion with or without intervention

- Continence promotion
- Epilepsy and health promotion
- Feeding and nutrition
- Infection control
- Mobility
- Palliative care
- Personal development and therapeutic programmes
- Physical disability and special

•	Older people with intellectual	needs	
	disabilities	 Sensory integration 	
•	Alternative and augmentative	 Supported living, and vocational 	
	communication	rehabilitation	
•	Complementary therapies		

The NCPDNM identifies a CNS as a nurse specialist in clinical practice that has undertaken formal recognized post-registration education at level 8 or above on the National Qualification Authority of Ireland (NQAI) framework relevant to their area of specialist practice. Such formal education is underpinned by extensive experience and clinical expertise in the specialist area and the level of practice is higher than that expected of a staff nurse (NCPDNM, 2008). In addition the NCPDNM identifies an area of specialty as an area of nursing practice that requires application of specially focused knowledge and skills, which are both in demand and required to improve the quality of client care (NCPDNM, 2008). Within its framework, the NCPDNM described five core concepts of the CNS role based on an adaptation of Hamric's (1989) role components. In addition to expert practitioner, educator, consultant and researcher, the NCPDNM included advocacy as the fifth core concept (Doody and Bailey, 2011). The NCPDNM advocates that each CNS core concept needs to be enacted in order for the nurse to be considered a CNS, and to support the development of the CNS the NCPDNM identified broad descriptors attributed to each core concept which are outlined in Table 2.

Table 2. Core concepts for the CNS specialist role (NCPDNM, 2004a; 2007; 2008)

Core concept	Description	
Client focus	Work must have a strong patient focus whereby the specialty defines	
	itself as nursing and subscribes to the overall purpose, functions and	
	ethical standards of nursing. The clinical practice role may be divided	
	into direct and indirect care.	
Patient/client	Role involves communication, negotiation and representation of the	
advocate	patient/client values and decisions in collaboration with other	
	healthcare workers and community resource providers.	
Education and	Remit for education and training consists of structured and impromptu	
training	educational opportunities to facilitate staff development and	
	patient/client education. Each CNS is responsible for his/her continuing	
	professional development, thereby ensuring sustained clinical	
	credibility among nursing, medical and paramedical colleagues.	
Audit and	Audit of current nursing practice and evaluation of improvements in the	
research	quality of patient/client care. Knowledge of relevant current research to	
	ensure evidence-based practice and research utilization. Contribute to	
	nursing research relevant to his/her particular area of practice. Any	
	outcomes of audit and/or research should contribute	
	to the next service plan.	
Consultancy	Inter- and intra-disciplinary consultations, across sites and services.	
	This consultative role also contributes to improved patient/client	
	management.	

This framework facilitated the national development of CNS roles across intellectual disability nursing in Ireland, and services and organizations were actively involved in developing these roles based on local client population and identified needs. A key function of the NCPDNM supported by national policy (DoHC, 2001) was to establish a clinical career pathway for nurses working in a specialist area of practice in order to progress from staff nurse to CNS (NCPDNM, 2002). In line with these recommendations, the NCPDNM has published three independent pathways for CNS through which nurses working in a specialty could achieve recognition of their experience and learning (NCPDNM, 2001; 2004a; 2007; 2008) (see Table 3).

Table 3. Career pathways for CNS (NCPDNM, 2001; 2004a; 2007; 2008)

Career pathway	Rationale	Qualification/function	Timescale
Immediate pathway: for registered nurses already performing in the role of CNS	To recognize nurses already functioning as CNS at the time of implementation of the framework	Holds an appropriate post-registration qualification and/or a minimum of 5 years' experience in the area of specialty	Closing date for applications was 30 April 2001. After this date applications were via the intermediate pathway
Intermediate pathway:	CNSs newly appointed between 1 May 2001 and 31 August 2010	To identify the academic qualifications and professional experience which a newly appointed CNS must achieve within a specified timeframe of appointment (agreed locally)	The NCPDNM (2002) published guidelines for higher level education programmes for the CNS in order to meet the learning needs of these nurses. This pathway took effect from 1 May 2001
Future pathway	To identify the academic qualifications and professional experience which a newly appointed CNS must hold prior to appointment	All appointments of CNSs will require a minimum of 5 years' post-registration experience, 2 years' practice in a specialist area, and a post-registration diploma (minimum level 8 of National Qualifications Authority of Ireland) related to the area of specialist practice	This pathway took effect from 1 September 2010

Development in the CNS role in intellectual disability in Ireland

The Commission on Nursing (GoI, 1998) suggested seven broad bands to be used to group relevant subspecialist areas and following the establishment of the NCPDNM and the issuing of a definition for CNS. The DoHC commissioned a report to explore the CNS in intellectual disability nursing. The report, Proposed Framework for the Development of Clinical Specialism and Advanced Practice in Mental Handicap Nursing, was published in 2002. It identified clear pathways for the CNS in intellectual disability and further aided the development of CNSs in intellectual disability nursing. The report recommended specific suggestions relating to education, and broadened on the Commission report (GoI, 1998) by listing themes or areas of practice where specialism could occur. Furthermore the Eastern Regional Health Authority, in their report Looking into the Future: Maximising the Nursing Contribution to a Comprehensive Intellectual Disability Service (EHRA, 2003), identified areas of practice for intellectual disability nurses to specialize. Table 4 identifies the areas for development as considered by Commission on Nursing (GoI, 1998) and areas of practice for specialization (DoHC, 2002; ERHA, 2003). The reports highlighted that the role of the CNS in intellectual disability is varied and incorporates such roles as educator, clinical leader, consultant and researcher (DoHC, 2002).

The DoHC (2002) report identified that the value and contribution of specialist roles to client care should not be underestimated, and that the CNS is ideally positioned to provide specialist direct care services to clients and their families and in a position to proactively respond to client needs and identify current and future service requirements. This recognition of potential benefits for clients, the clinical focus of the role, the integration of nursing research and audit in intellectual disability nursing services, and the provision of a clinical career pathway will assist in services significantly increasing treatment options and quality of care (ERHA, 2003). The NCPDNMhas worked to develop CNSs in intellectual disability nursing and explored their effectiveness, noting that the establishment of further CNS posts within intellectual disability services is highly desirable (NCPDNM, 2004b).

The activities of the CNS in intellectual disability and within individual roles have rarely been explored. Evidence that exists regarding the CNS in intellectual disability in Ireland comes from the NCPDNM's own evaluations of the role across all disciplines in nursing. The NCPDNM (2004b) evaluation report highlights some interesting factors, such as the active role of the CNS in client care, education and advocacy, and the limited evidence of a research role. In the evaluation the clinical component was rated the most important (63%) followed by advocacy (26%), education and training (20%), consultancy (8%) and audit and research (4%). The evaluation utilized focus groups with CNSs, directors of nursing, clinical nursing managers, staff nurses and service users, along with a questionnaire sent to all CNSs to examine issues that arose from the literature review and the focus groups. However, as the evaluation only achieved an 8 percent response rate from the specialist area of intellectual disability, these results have to be considered in relation to the limited sample size and representation of the findings to intellectual disability CNSs and practice. Furthermore the multifaceted role in caring for persons with

intellectual disability including direct care, management, administration, liaison work and educational activity may have resulted in potential participants not feeling they could identify with the specific questions used in the survey. Intellectual disability nursing has often been marginalized within nursing due to its reluctance to be part of the medical model of care which has been at the core of nursing values (Mitchell, 2004). However, as intellectual disability nurses moved beyond the medical model they incorporated models of practice based on education and social care. These developments have created a system of care which fosters a person-centred approach that supports the person's rights, inclusion, equality and participation. In light of this fact the medical orientation of the survey may have failed to capture the activities of the intellectual disability CNS and thus resulted in the poor response.

Table 4. Clinical career pathway for CNS proposed role

Report of the Commission on Nursing: A Blueprint for the Future (GoI, 1998): seven broad bands High dependency nursing Rehabilitation and habilitation nursing Medical surgical nursing Maternal and child health nursing Community health nursing Mental health nursing Disability nursing Proposed Framework for the Development of Clinical Specialism and Advanced Practice in Mental Handicap Nursing (DoHC, 2002) Sensory development Management of behaviour Multiple and complex disabilities Assistive technology Health promotion/screening Respite care, crisis intervention and assessment Training and employment Community nursing Palliative care Mental health and intellectual disability Advocacy and activation Communication, speech and language development Developmental education and play therapy Care of the older person Interpersonal relationships and counselling Early intervention Primary care Multiculturalism Looking into the Future: Maximising the Nursing Contribution to a Comprehensive Intellectual Disability Service (EHRA, 2003) High dependency nursing Rehabilitation and habilitation nursing Medical surgical nursing Medical surgica	Table 4. Clinical career pathway for CNS proposed role				
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Community nursing		Community nursing			

Challenging behaviour; management of behaviours that challenge
Dementia-related care
Dual diagnosis: mental health and intellectual disability
Intellectual disabilities with physical/neurological deficits
Psychotherapy
Palliative care
Rehabilitation
Health promotion
Advocacy
Communication and assistive technology
Social role valorization
Alternative therapies

However, in 2010 the NCPDNM produced a further evaluation of the CNS role in Ireland in its report Evaluation of Clinical Nurse and Midwife Specialist and Advanced Nurse and Midwife Practitioner Roles in Ireland (Begley et al., 2010). This report involved all key stakeholders, CNSs, directors of nursing, healthcare team members, policy makers and service users. Again the response rate achieved was only 8 percent from the specialist area of intellectual disability and difficulties arose in attaining comparable sites with and without CNSs in the areas of practice identified. However, the report does highlight that developments in the clinical career pathway of intellectual disability nurses have not taken place at the same pace as those of the other disciplines of nursing. Additionally the report addresses the difficulties of the CNS concept in intellectual disability services, unlike in acute care services, where care is largely similar in each acute care hospital; this is not the case in intellectual disability services (Begley et al. 2010). The report noted during the recruitment and data collection stages of this study that there are significant differences in specialist services and also in the scope and role of CNSs working in such specialist areas. Associated with this is the ongoing movement of services away from a nursing model towards one rooted in a more social approach, and within this move there is a risk that the concept of CNS may become increasingly alien as that model takes root unless there is a focus on the holistic and biopsychosocialeducational elements of care. With this change in service focus, and given the current economic climate, there is a risk hat improved outcomes may not be valued against financial savings (Doody, 2012). In addition the Health Service Executive (HSE, 2011) issued its report calling for the closure of congregated settings and calling for a move to community settings. However it is clear that a one-size approach to health and personal services will not fit all or produce the desired outcomes (Doody, 2012). Thereby it is necessary to develop an approach that will take into account the differences between groups such as age, type or degree of disability and incorporate health, social and personal service, and intellectual disability nurses and CNSs have a significant and leading role to play in the future of services. Nonetheless the Begley et al. (2010) evaluation did highlight the education and health promotion role of CNS post-holders as contributing to the maintenance of quality standards of care and serving as a role model for nursing and staff. In addition within intellectual disability services, in particular, it was noted that the CNS impacted on broader outcomes related to quality of life for clients and families (Begley et al., 2010).

The road ahead

The role of the CNS in intellectual disability nursing is very diverse and challenging; however, CNSs occupy a central and indeed essential position in the provision of services to people with intellectual disability (Begley et al., 2010). Just as promotion of autonomy along with evidence based care is fundamental to the roles of intellectual disability nurses (Barnsteiner and Prevost, 2002), they too are essential for persons occupying one of the highest clinical position within the profession. Furthermore, the distinct identity and unique skill complement associated with this nursing specialty must be preserved and promoted (GoI, 1998; Mitchell, 2004; Atkinson et al., 2010). These unique skills are essential and need to be utilized across healthcare environments, thereby ensuring the health needs of people with intellectual disability are met. Intellectual disability nursing may be marginalized within nursing due to the failure to be part of the medical model (Mitchell, 2004). Nevertheless, 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, 2006). As the discipline of intellectual disability nursing is unique to Ireland and the UK, the future of intellectual disability nursing is in the hands of intellectual disability CNSs and nurses, as it is within the discipline's grasp to identify its unique identity and place within the profession. The future of intellectual disability CNSs will relate to their ability to respond appropriately to the demands of the changing intellectual disability services, and for this to occur there needs to be sound accessible evidence of effective intellectual disability nursing interventions that highlights the needs and effective strategies for caring for persons with intellectual disability (Griffiths et al., 2007).

While the core concepts of CNS practice are important roles, these are not reflected in the research literature, and there is a lack of literature and research from an intellectual disability CNS perspective. Thereby CNSs need to focus on research endeavours in their nursing evaluations and interventions for widely identified problems for persons with intellectual disability to provide evidence for practice. Therefore the CNS should endeavour to capture and illuminate the very heart and kernel of their care, thus leading to an evidence-based quality service worthy of underpinning caring for service users with an intellectual disability. Hence intellectual disability CNSs will lead the way in achieving positive health outcomes for people with intellectual disabilities. They will use an inclusive and collaborative approach to address barriers to social inclusion and will function as integral members of the wider family of nursing, developing and using specialist knowledge and skills to improve the health and wellbeing of children, adults and older people with intellectual disabilities across all settings (Northway et al., 2006).

In recent years, intellectual disability nursing has been diverted from health-focused roles to embrace more social care management activities, while in some instances the health needs have not been fully met (DoH, 2007). Given that people with intellectual disability

often have complex needs and poorer health, it is clear that intellectual disability CNSs and nursing skills are too valuable to be diluted by being used in non-health-focused roles. Thereby intellectual disability CNSs and nurses need to refocus their activities on health-related areas, and they can support social care through delivering education, support, advice and consultancy to primary, acute and secondary healthcare providers, thereby enhancing their ability to work with people with intellectual disability and promote a more inclusive service (Atkinson et al., 2010). In this matter the intellectual disability CNS can take responsibility for the advancement of their profession by:

- using advanced evidence-based skills in nursing assessment, planning and delivery of specialist therapies and care
- focusing on the health needs of people with intellectual disability
- communicating their professional viewpoints and negotiating with other disciplines
- being able to work as an autonomous practitioner
- actively contributing to research programmes and/or initiatives
- accessing programmes of further education
- disseminating evidence of their practice through publication and conferences.

Additionally as intellectual disability nurses and CNSs work exclusively with people who have intellectual disability, their future may involve working with other populations and healthcare professionals who could benefit from intellectual disability nurses and CNSs. Atkinson et al. (2010) in the UK identifies people with autistic spectrum conditions who do not have an intellectual disability, and people who have global impairments of intellectual functioning and difficulties with adaptive functioning that have manifested during adulthood, such as those with head injury, dementia or chronic psychotic illnesses, as groups who could benefit from the input of intellectual disability nurses and CNSs. Utilizing intellectual disability nurses and CNSs in this manner would acknowledge the relevance and transferability of intellectual disability specialist nursing skills to such groups. However, various UK reports, including Treat Me Right! (Mencap, 2005), Death by Indifference (Mencap, 2007) and Six Lives (PHSO, 2009), have publicized that acute and primary healthcare services need to improve their care and treatment of people with intellectual disability. Thus it may be best for Ireland to focus on supporting education and training of other healthcare professionals in these areas as a priority. This support should include the intellectual disability CNS within a liaison role to offer leadership and the provision of educational opportunities for generic staff and GP services (Michael, 2008). In addition, as Ireland moves to a personalization agenda with individualized payment schemes, this will enable individuals to purchase resources, services or support workers and/or assistants to support them. The challenge for intellectual disability nurses and CNSs will be the way they present their specialist services. They will have to clearly identify and market their specialist skills, interventions and supports that are based on the best available evidence. Furthermore they will need to engage in research, as failure to do so may be seen to threaten the development of the profession and nursing practice. Thereby the CNSs are challenged to raise the status of research in intellectual disability nursing and be more transparent as a professional group, working more collaboratively with service users, families and other professionals across all health sectors.

Conclusion

Since its inception in the 1960s, the role of the intellectual disability nurse has been at the front line of care provision for people with an intellectual disability in Ireland. While intellectual disability nursing in Ireland has had a relatively short history, the discipline has grown and been challenged to change at a pace and degree not required of other branches of nursing, and as a discipline it has responded to these challenges in a positive way (Doody et al., 2012). Given the current restructuring of services, models of service provision and national policy, intellectual disability nursing will continue to be challenged to change and respond to meet the needs of services, clients and families. As part of the wider advancement of nursing in Ireland, CNS posts have developed within all branches of nursing services in Ireland. However, intellectual disability CNSs have developed at a slower rate than other branches of nursing and, in order to build on the achievements of the NCPDNM and to realize its vision for advancing nursing practice, it is imperative that CNSs adopt and fulfil the components of their role to their full potential. In doing so they also need to articulate and highlight their work and engage in research that will highlight their contribution and lead the profession.

Within practice, the CNS is well placed to assume a leadership role for the profession and CNSs need to be supported in this objective. As little evidence is available regarding the practice outcomes of intellectual disability CNSs in Ireland, increased support is required to encourage and facilitate these specialists to publish the outcomes of their care. It may be seen that the future of the profession is in the hands of the nurses and CNSs themselves and in their willingness to make visible their contribution through research and practice-based publications. While the future of intellectual disability nursing has often been debated, and while this is not a focus of this article, the authors suggest that the leaders within intellectual disability nursing of which the CNS is one should transcend beyond traditional services and support other health and social services such as primary, acute and secondary healthcare providers. For this to occur they need to investigate and promote how their skills can be utilized with all healthcare environments to support people with intellectual disability and, once the profession has developed and highlighted its impact, its services can transcend other areas of disability such as dementia and head injury. Since the first mention of nurse specialism in Ireland in 1980 there have been many developments; the NCPDNM has highlighted the developments in intellectual disability from 1998 to 2009 (Hughes, 2009), and additional to this summary has been Begley et al.'s (2010) evaluation report.

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