Nursing in Intellectual Disabilities: Irish and International Perspectives

Edited by
Paul Michael Keenan and Dr Owen Doody

Foreword by
Professor Bob Gates

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ABBREVIATIONS

ABA – An Bord Altranais (Since 2012 renamed Bord Altranais agus Cnáimhseachais na hÉireann: Nursing and Midwifery Board of Ireland (NMBI))
ANP – Advanced Nurse Practitioner
CCT – Chernobyl Children’s Trust
CIPOLD – Confidential Inquiry into Premature Deaths of People with Learning Disabilities
CLDN – Community Learning Disability Nurse
CPA – Collaborative Practice Agreement
CNS – Clinical Nurse Specialist
CT – Computed Tomography
DCYA – Department of Children and Youth Affairs
DECLG – Department of Environment and Local Government
DoH – Department of Health
DoHC – Department of Health and Children
DSFA – Department of Social and Family Affairs
EEG – Electroencephalogram
EFN – European Federation of Nurses Associations
ERHA – Eastern Regional Health Authority
FEDOMA – Federation for Disability Organisations in Malawi
GoI – Government of Ireland
GORD – Gastric Oesophageal Reflux Disorder
HEI – Higher Education Institute
HIQA – Health Information and Quality Authority
HSE – Health Service Executive
HSP – Health Service Provider
IASSID – International Association for the Scientific Study of Intellectual and Developmental Disability
ICD – International Classification of Disease
ID – Intellectual Disability
LD – Learning Disability
MHC – Mental Health Commission
MRI – Magnetic Resonance Imaging
NARI – National Ageing Research Institute
NCNM – National Council Nursing and Midwifery
NDA – National Disability Authority
NDS – National Disability Survey
NFVB - National federation of Voluntary Bodies
NIDD – National Intellectual Disability Database
NMBI – Nursing and Midwifery Board of Ireland (Prior to 2012 formerly known as An Bord Altranais: Irish Nursing Board)
RCN – Royal College of Nursing
RNID – Registered Nurse Intellectual Disability
RNP - Registered Nurse Prescriber
UK – United Kingdom
UNICEF - United Nations International Children’s Fund
USSR - Union of Soviet Socialist Republics
WHO – World Health Organisation
FOREWORD

BOB GATES

It is always a privilege, and an honour to be asked to write a foreword for any new text book. To be asked to write one for, as far as I am aware, the first ever text book by the Nursing Network in Intellectual Disability Ireland for students and nurses; this makes it a particularly prestigious task. Paul Keenan and Owen Doody, both respected academics in the field of intellectual disability nursing have made a splendid job in the mammoth task of preparing a new text book.

The book comprises ten chapters the first of which conceptualises the nature of Intellectual Disability, which is followed by an overview of Irish social policy relevant to people with Intellectual Disability, as well as Intellectual Disability nursing. The book then shifts its emphasis to explore the domains of competence for Intellectual Disability nursing required by the Nursing and Midwifery Board of Ireland to support this group of people and their families. Intellectual disability nursing has a long association of providing innovative practice that has supported people with Intellectual Disabilities which is accounted for in a chapter on developments in the field of Intellectual Disability nursing in Ireland. Recognising the importance and centrality of the person with intellectual disabilities in any caring, and, or supportive role is addressed in an insightful chapter person centeredness. A chapter on nurse prescribing follows that articulates the role of intellectual disability nurses, and this is followed by another new and contemporaneous role that is emerging internationally in Intellectual Disability nursing; that of liaison nursing. Both these chapters have potential to empower nursing practice to address some aspects of the health inequity experienced by people with Intellectual Disabilities. Next a chapter is provided on the importance of networking in the field of Intellectual Disability nursing. The book concludes with two fascinating chapters on Malawi and then Belarus, both these chapters have been written by past Intellectual Disability students of nursing, and remind us of the many parts of the world where people with intellectual disabilities do not have the same rights, social policy frameworks and, or, access to specialist services. Collectively these chapters form a coherent whole which student and nurses of Intellectual Disability nursing will find essential reading for their education and practice.
This is indeed an important new text book for the specialism of intellectual disability nursing. More widely it is a valuable resource for Intellectual [Learning - in the UK] Disability nursing students. It provides the reader with both national and international perspectives that will enable students of Intellectual Nursing to appreciate both the complexity of intellectual disability, and contextualise this with disability issues more generally. I wish the Editors well with this venture, and congratulate the Nursing Network in Intellectual Disability Ireland and contributors in their role in bringing into fruition a much needed text book for Intellectual Disability Nursing.

**Bob Gates**

*Professor of Learning Disabilities, University of West London, UK, Visiting Professor of Learning Disabilities, Institute of Education, University of Derby, UK, Editor in Chief, British Journal of Learning Disabilities, Emeritus Professor, the Centre for Learning Disability Studies, University of Hertfordshire, UK.*
AUTHORS CONTRIBUTION

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Nurse Consultant, NHS Lothian and Reader in Health and Social Care, Edinburgh Napier University. Michael holds a clinical academic post as Consultant Nurse with the NHS Lothian specialist learning disability services and as a Reader in Health and Social Care at Edinburgh Napier University. He is a graduate from Queen Margaret University, Edinburgh in Health Sciences, holds a Master’s degree in policy and politics from the University of Edinburgh. He undertook a post graduate teaching certificate and PhD at Edinburgh Napier University and is a Fellow of the Higher Education Academy. He has published in the nursing literature on a range of issues relating to the care and treatment of people with intellectual disabilities.

Dr Owen Doody PhD, MSc, BSc, RNID - Owen interests lie in intellectual disability nursing and supporting people with intellectual disability and their families live their life. Owen’s PhD looks at the contribution of ID CNS to service delivery in Ireland and has published on nurse education, intellectual disability practice and supporting families. Owen lectures and researches in the University of Limerick. In 2015 Owen was nominated for the University of Limerick Excellence in Teaching Award and in 2016 won the Faculty of Education and Health Sciences Excellence in Teaching Award. He has published widely on intellectual disability nursing and issues related to intellectual disability practice, and was a member of the research group looking at the future role of the RNID in Ireland.

Professor Bob Gates – Bob works part-time as a Professor of Learning Disabilities at the University of West London. He is also an Emeritus Professor of Learning Disabilities at the University of Hertfordshire and an Honorary Professor of Learning Disabilities at the Hertfordshire Partnership University NHS Foundation Trust. He has a long career in learning disabilities spanning and is known internationally for his contribution to the field. During his career he has held numerous positions across the UK in learning disability services, management and education settings. Bob is the Founding Editor in Chief of Journal of Intellectual Disabilities published by SAGE and he serves on numerous editorial boards of international journals. In January 2014, he was appointed Editor in Chief of the British Journal of Learning Disabilities.
Paul Michael Keenan MSc, MA, BSc, PGCE, DipRS, DipHE NP, RNID, RNT – Paul is an Assistant Professor - Intellectual Disability Nursing at the School of Nursing and Midwifery, Trinity College Dublin. Since 1988 he has worked with people with an Intellectual Disability in UK, New Zealand and Ireland. He is Co-Chairperson of Nursing Network in Intellectual Disability, Ireland (NNIDI). He was Head of Discipline - Intellectual Disability Nursing TCD (2008-2012); Executive member of the Centre for Practice and Healthcare Innovation, TCD (2012-2016); External Examiner Keele University (2002-2005). He has published in the nursing literature on a range of issues relating to person-centred practice, and the role of the RNID. He is co-editor of Nursing and Networking in Ireland: A guide for nurses working in Intellectual Disability Services (NNIDI 2012) and co-editor of the first three editions of Special Olympics Ireland Tutor Training Manual (SOI 2017 [In Press], 2013 & 2011).

Dr Lynn Marsh - Lynn is a lecturer in the School of Nursing and Midwifery UCC. In 2009, along with her colleagues she was awarded a UCC President's Award for Excellence in Teaching and Learning. Lynne commenced the first Doctor of Nursing (DN) Degree programme in Ireland in 2010 exploring the experiences of becoming a father of a young child with an intellectual disability.

Professor Ruth Northway PhD, MSc, RNLD, ENB 805, Cert Ed(FE), FRCN, PFHEA, OBE - Ruth is a professor of learning disability nursing in the UK. Ruth interests lie in learning disability nursing, participatory research and ethical issues relating to vulnerable persons. Ruth has been editor of the Journal of Intellectual Disabilities since January 2013 and Chair of the Royal College of Nursing Research Society Steering Committee since 2011. Her work and publications in the learning disability field has seen her become an active member of the UK Steering Group for Strengthening the Commitment and the Steering Group of the UK Learning Disability Nursing Advisory Network.

Eloise Sheerin BSc (Hons) – Eloise is a Registered Nurse in Intellectual Disability and a recent graduate from Trinity College Dublin.
Suzanna Weedle BSc (Hons), Sch. - Suzanna is a Registered Nurse in Intellectual Disability. She is a graduate from Trinity College Dublin. Suzanna became a Trinity Scholar in her discipline in the second year of her degree. She also became a Trinity Gold medallist upon graduating. She has published in the nursing literature on various topics related to people with intellectual disabilities. Although a recent graduate, Suzanna gained extra practical experience both prior to and throughout her degree through her voluntary work with people with disabilities both in Belarus and Malawi.
THE NURSING NETWORK IN INTELLECTUAL DISABILITY, IRELAND: A BRIEF HISTORY.

As far back as the 1980s there was a network of people working in intellectual disability health and social care in Ireland who came together to share and promote education and practice. This was originally in the form of the ‘Nurse Teachers Group’ with representatives from the eight schools of Intellectual Disability Nursing. With the move of Nurse Education to third level establishments in 2002 there was a need to reconsider the group’s function and future and in 2007 the group extended its membership to include representation from practice areas and intellectual disability services. This resulted in the formation of the Nursing Network in Intellectual Disability Ireland (NNIDI). The network was developed by a steering group, comprising representatives from the third level education sector, service providers, nurse practice development teams and professional development units.

The overall purpose of the NNIDI is to promote an intellectual disability network in Ireland and facilitate events and publications which support this.

2009 saw the 50th anniversary of the establishment of Intellectual Disability Nursing in Ireland. The NNIDI marked this historical occasion, by running a unique celebratory event, Intellectual Disability Nursing – Towards the Future supported by the National Council for the Professional Development of Nursing and Midwifery. In 2010 the NNIDI held its first conference Build a Nurse at All Hallows, Dublin. The event, which highlighting the key attributes of the RNID, was facilitated by Helen Laverty, a Lecturer at the University of Nottingham. Following which in 2012 we held a very successful Conference Celebrating Intellectual Disability Nursing in Stewarts Care Services, Palmerstown, Co. Dublin, funded by HSE NMPDU Dublin Mid Leinster with over 150 participants attending the daylong event. Key international and national contributors included; Professor Bob Gates, Prof Michael Browne, service users, Dr Maura Pidgeon, Dr Cate Hartigan, Dr Kathleen McLellan and Lassarina Maguire That year also saw the launch of our very first publication Nursing and Networking in Ireland: A guide for nurses working in Intellectual Disability Services. This guide, which was very well received within academia and practice, both here and in the UK, is accessible free at http://www.nnidi.com/.
Furthermore in 2014 we ran a very well attended masterclass event *Making Connections to enhance Professional Practice* at the School of Nursing and Midwifery, Trinity College, University of Dublin. Contributions included Professor Ruth Northway, Kathleen Walsh and Dr John Sweeney. In 2016 we commenced the process of producing this e-book, which the NNIDI Committee hope is just the first in a series. The book was launched at *NNIDI Research Seminar*, Tullamore Hospital 30th June 2017. Topics on the day were assisted decision making, advanced nurse practice, end of life care, and the clinical nurse specialist’s role.

The NNIDI continually strive to provide information and run conferences, masterclasses and research seminars that will bring people from professional, academic and political arenas together to discuss and develop the vision for intellectual disability nursing in Ireland now and into the future. We welcome you, the reader to be a part of this by joining us, recommending NNIDI to colleagues and linking in with our service as often as possible. For further information please contact info@nnidi.com or log onto our website http://www.nnidi.com.

Dr Owen Doody and Paul Keenan
Co-Chairpersons NNIDI
30th June 2017
INTRODUCING NURSING IN INTELLECTUAL DISABILITIES: IRISH AND INTERNATIONAL PERSPECTIVES

Paul Michael Keenan and Owen Doody

The search for professional knowledge, skills and values is a continuous and rewarding endeavour. Although the world of care for people with an intellectual disability is in a state of flux, there is little doubt that significant milestones have been reached at a national level in recent decades. For example, Ireland now has a disability act and national strategy, and it is hoped intellectual disabilities will also have its own strategy. Quality of care is measured against basic international standards and where a service is deemed not to have reached acceptable levels genuine efforts are more often than not made to address them. Equally, at the time of writing this forward, the profession of Intellectual Disability Nursing will soon have a contemporary and forward focused strategy, which has recently been developed in partnership with RNIDs, people with an intellectual disability and their families/significant carers, as well as a host of governmental and non-governmental interest groups.

The primary aim of Nursing in Intellectual Disabilities – Irish and International perspectives is to provide scholarly perspectives on key contemporary areas relevant to person-centred nursing care for people with an intellectual disability.

It is hoped that this will be the first in a series of books focusing on evidence based practice relevant to the Irish, as well as the international, context and the various branches of nursing. We welcome suggestions for future chapters and submissions through the Nursing Network in Intellectual Disabilities Ireland.

The editors wish to thank the authors for contributing substantial amounts of their time to undertaking extensive research and preparing informative, insightful chapters. We express our gratitude to them for sharing their expertise.

The editors would also like to thank the committee members of the Nursing Network in Intellectual Disabilities, Ireland (www.nnidi.com) for their unanimous encouragement, support and approval throughout the process of developing and producing this project.
Overview of chapters, Chapter one introduces the concepts and meaning of intellectual disability. Chapter two presents an overview of social policy, while chapter three introduces the reader to the domains of competence in intellectual disability nursing as set out in the standards and requirements for registered nurses in Ireland. Chapter four focuses on the development of intellectual disability nursing in Ireland through specialist roles. Chapter five presents person-centred planning within intellectual disability. Chapter six addresses nurse prescribing and chapter seven addresses the liaison role of the intellectual disability nurse. Chapter eight presents the relevance of networking and developing networks. Chapter nine presents two students reflection of their experience volunteering in Malawi and Chapter ten presents a student’s experience of volunteering in Belarus.

We are delighted to have contributions from Lynn Marsh, Ruth Northway, Michael Brown, Suzanna Weedle and Eloise Sheerin. Their work adds greatly to the book in presenting on topics related to volunteering, competence, liaison and networking.

Finally, we hope you the reader will benefit personally and professionally when reading and reflecting on the book’s content in the context of your service to people with an intellectual disability.
CHAPTER ONE

Intellectual Disabilities – Concepts and Meanings

Paul Michael Keenan and Owen Doody

1.0 Introduction

For the purpose of this book the term *intellectual disability* is employed when referring to nursing and service provision, as this is the term enshrined in the Nurses and Midwives Act (GoI 2011), and utilised by the Department of Health (DoCH 2010), the Health Service Executive (HSE 2013) and Health Information and Quality Authority (HIQA 2013). The use of labels has been dynamic; thus in the past twenty years, the term ‘intellectual disability’ has replaced the term ‘learning disability’, which had previously replaced the terms ‘learning difficulties’ and ‘mental handicap’ (Begley et al., 2009).

1.1 Defining Intellectual Disability

People with an intellectual disability do not constitute a homogeneous group, nonetheless in terms of diagnosis and classification there are a number of features that have gained widespread professional acceptance internationally. There are many and varied reasons why an individual may be identified as having an intellectual disability and causes may be of unknown, multi-factorial or specific origin and have biological, sociological and psychological influences (Begley et al., 2009; Doody et al., 2012; Griffiths and Keenan 2015). Although disability is defined in Irish legislation (GoI 2005), intellectual disability is not defined (Keenan 2007). For the purpose of this book the definition recognised by the Department of Health and the Health Service Executive (2013) is adopted and is identified as:

“A significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social function), which started before adulthood and has a lasting effect on development.”

(DoH 2001:14; HSE 2013: 6)
This definition is broadly in line with the WHO International Classification of Disease ICD-10 (WHO 2010), but excludes the latter’s term ‘mental retardation’, which is now generally viewed as ‘insulting and undignified’ (Begley et al., 2009: 41).

The precise population of people with an intellectual disability in Ireland is not known (Ryan and Rice 2012). In December 2015 there were 28,108 people registered on the National Intellectual Disability Database (NIDD) receiving, or identified as needing services for a diverse range of health and social needs, some of which are complex (Doyle & Carew 2016). This represents a prevalence rate of 0.6% of the population in the Irish Republic, which is in marked contrast to the UK prevalence rate which is estimated to represent 2% of the population (DoH 2001). However, it is estimated that only about a third of people with a mild intellectual disability in Ireland are normally recorded on the NIDD database (DoHC 2006). In comparison the Central Statists Office indicates a population of 50,400 people in Ireland have a diagnosis of disability in their national disability survey (NDS) (CSO 2008). Reasons for differences in the statistics from the NIDD and NDS include variations in definitions used, methods of data collection and criteria for registration (table 1.1). Furthermore Ryan and Rice (2012) highlight that the increasing ethnic diversity of the Irish population may lead to variations in the number of people with intellectual disabilities. For example, according to the DoH (2001) Pakistani and Bangladeshi communities have significantly higher rates of people with an intellectual disability.

Since the Health Research Board’s first census in 1974 the number of individuals with moderate, severe or profound intellectual disability has increased by 46%, and the number of individuals over 35 years of age has increased from 29% to 49%. In addition the birth rate has also increased significantly in recent years due to increased medical advances and intervention and sixty six per cent of people receiving services live at home (Doyle and Carew 2016). Similarly within the international context the population of people with intellectual disability is growing with increased survival and longevity rates resulting in changing patterns of morbidity and mortality (MHC 2009). This increase has occurred due to the rise in pre-term infants surviving and increased longevity across all age groups. The rise in pre-term infants’ as a consequence of medical advances, socio-economic factors relating to living standards.
Table 1.1: Reasons for different statistics between the NIDD and NDS (Doody and Doody 2012)

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<th>National Disability Study</th>
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<td><strong>Definition used</strong></td>
<td>The NIDD definition is based on the WHO International Classification of Diseases (10th edn - ICD-10) (WHO 2007).</td>
<td>The NDS definition is based on the WHO International Classification of Functioning (ICF) (WHO 2001).</td>
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<td><strong>Data collection method</strong></td>
<td>The NIDD based their data collection on the fact that a person was assessed by a multidisciplinary team, and on his/her level of intellectual disability identified (mild, moderate, severe or profound).</td>
<td>The NDS based their data on whether or not the individual had a diagnosis of intellectual disability and was self-interpreted in a guided interview context.</td>
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<td><strong>Criteria for registration</strong></td>
<td>The NIDD registers data only on individuals with an intellectual disability for whom specialized health services are being provided or who, following a needs assessment, are considered to require specialized services in the next 5 years.</td>
<td>The NDS included all individuals who defined themselves as having an intellectual disability, regardless of whether they were in receipt of or requiring intellectual disability services.</td>
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Housing and deprivation has led to a significant increase in children with multiple disabilities and children diagnosed with Foetal Alcohol Spectrum Disorder, Attention Deficit Hyperactive Disorder and Autism Spectrum Disorder (Cooper et al., 2011; Lange et al., 2010; Baron-Cohen et al., 2009; Emerson 2009; Emerson and Hatton 2007). Within the age spectrum the number of children and young people with profound and multiple intellectual disabilities has increased by nearly 120% in recent years (Glasper 2011) as well as the proportion of people with intellectual disability living into older age (Burke et al., 2014; Keenan and McIntosh 2000). The increasing and ageing intellectual disability population poses significant challenges for policy, services and professions both in Ireland and internationally (Griffiths and Keenan 2015; McCarron et al., 2011).

1.2 Conclusion

While the exact population of individuals with an intellectual disability is unknown, internationally and within Ireland, because of the under representation of people with mild intellectual disabilities within statistics, they represent a significant and growing number of people who are living longer. Their unique needs are becoming better understood, but further research is required if health and social care professionals are to provide enhanced quality care.
Chapter One References


education. School of Nursing and Midwifery, University of Dublin, Trinity College Dublin. 5 November 2015.

Health Information and Quality Authority (2013) National Standards for Residential Services for Children and Adults with Disabilities. Dublin: Health Information and Quality Authority.


CHAPTER TWO

Intellectual Disability Social Policy: An overview

Paul Michael Keenan and Owen Doody

2.0 Introduction

The purpose of this chapter is to provide readers supporting people with an intellectual disability in Irish health and social care with a convenient reference tool for legislation/policy, followed by a discussion, rather than an exhaustive documentary analysis, of relevant current social policy. The documents listed in Tables 2.1, 2.2 and 2.3 below are freely available on the World Wide Web and from the respective governmental publishers*.

2.1 Themes

The key themes emerging from Irish social policy include the development of equal citizenship and social inclusion, increased self-determination and quality of life, the development of high quality care enhancing access to and active participation within the community, an increasing and ageing population, requirements for person-centred funding and supports incorporating natural formal and informal supports, higher client expectations and the widest possible choice such as supported individual and smaller community residential settings, a strong focus on cost-effective services, and the development of primary health care and specialist support teams to assist people to live ordinary lives which they value (Griffiths and Keenan 2015; Keenan 2008; Keenan 2007).
Table 2.1: Irish Intellectual Disabilities Social Policy

- Mental Treatment Act (Government of Ireland 1945)
- Commission of Inquiry on Mental Handicap (Government of Ireland 1965)
- Commission of Inquiry on Mental Illness (Government of Ireland 1966)
- Towards a Full Life (DoH 1983)
- Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland (DoH 1983)
- Planning for the Future (Government of Ireland 1984)
- Needs and Abilities (DoH 1990), Towards an Independent Future (DoH 1996)
- A Strategy for Equality (National Federation of Voluntary Bodies 1996)
- National Disability Strategy (GoI 2004)
- Disability Act (GoI 2005)
- Report of the National Reference Group on Multidisciplinary Disability Services for Children aged 5-18 (HSE 2009)
- National Housing Strategy for People with a Disability 2011-2016 (DECLG 2011)
- Developing Services for People with Disabilities (NDA 2010)
- New Directions – Review of HSE Day Services and implementation plan 2012 – 2016 (HSE 2012)
- Value for Money and Policy Review of Disability Services in Ireland (DoH 2012)
- Progressing disability services for children and young people (HSE 2012)
- Respite/Residential Care with Host Families in Community Settings Working Group Report (HSE 2012)
- The National Standards for Residential Services for Children and Adults with Disabilities (HIQA 2013)
- Safeguarding Vulnerable Persons at Risk of Abuse (HSE 2014) ) (See table 2.3. below)

Table 2.2: Irish Health Policy related to Intellectual Disability Care

- Tackling Chronic Disease – A Policy Framework for the Management of Chronic Diseases (DoH 2008).
- Palliative Care For Children With Life-Limiting Conditions In Ireland- A National Policy (DoHC 2009)
- National Carers’ Strategy (DoH 2012)
- National Review of Autism Services (HSE 2012)
- National Positive Ageing Strategy (DoH 2013)
- Irish National Dementia Strategy (HSE 2014)
- Risk assessment and safety planning in mental health nursing services – an exploration of practices, policies and processes (HSE 2015)
- Risk Assessment and Safety Planning in Mental Health Nursing Services An exploration of practices, policies and processes (HSE 2015)

Table 2.3: Policies used in conjunction with Safeguarding Vulnerable Persons at Risk of Abuse (HSE 2014)
• National Standards for Residential Services for Children and Adults with Disabilities, (Standard 3) (HIQA 2013).
• National Quality Standards for Residential Care Settings for Older People in Ireland, (Standard 8) (HIQA 2009).
• HSE Policies for Managing Allegations of Abuse against Staff Members - Trust in Care (HSE 2005)
• HSE Elder Abuse Policy (HSE 2012)
• HSE National Consent Policy (HSE 2013)
• HSE Policy on Domestic, Sexual and Gender Based violence (HSE 2010)
• Children First: National Guidance for the Protection and Welfare of Children (DCYA 2011)
• HSE Safety Incidence Management Policy (HSE 2014)
• HSE Best practice principles for risk assessment and safety planning for nurses working in mental health services (HSE 2015)

Services for people with an intellectual disability are and will continue to evolve within Ireland based on Irish and International policy thereby, despite substantial increases in Irish service provision over the past decade, in the future there will be significant and increasing requirements for:

• Community based residential placements with a range of community based housing options such as supported and independent living models.
• Specialist children and young people services.
• Community therapeutic support services designed to meet the assessed needs of people who chose to live with their families or in supported living arrangements in the community e.g. Community Intellectual Disability Teams and Intellectual Disability/Mental Health Teams.
• Family and carer support.
• Respite services.
• Meaningful employment and day activities.
• Intensive specialist support services such as the assessment and treatment of mental health, autism and behaviours that may challenge.
• Services designed specifically to meet the needs of the older person with an intellectual disability and End of Life care.
• A range of consumer-directed approaches which offer people with an intellectual disability more choice and opportunities to manage their own care.
• Specialists in the range of health issues experienced by people with an intellectual disability.
• Greater access to mainstream health, mental health and social care services.

(Griffiths and Keenan 2015; McDermott and Keenan 2014; Keenan 2008; Keenan 2007)

Services and supports, both formal and informal, for people with an intellectual disability are and will continue to evolve within Ireland. A shift from agency/professionally managed group
service packages to individualized budgeting and supports is currently being examined and may allow for the development of what Koder (2003) describes as integrated models of care which offer both health/social care agencies/professionally managing service packages and consumer-directed approaches to care. Examples of the later may include individualised, outcome driven budgets and direct payments which may provide individuals with an intellectual disability with a wider choice and personal management over which services they utilize (DoH 2012; NDA 2010; Koder 2003), although it is not without its challenges.

2.2 Conclusion

What appears clear from exploring Irish social policy issues over the past decade is that in the future the person with an intellectual disability and their family/significant cares will play an increasing role in developing, directing and evaluating their care and the supports they receive.
Chapter Two References


National Disability Authority (2010) *Developing Services for People with Disabilities: A synthesis paper summarising the key learning of experiences in selected jurisdictions*. Dublin: NDA.

CHAPTER THREE

Domains of competence in Intellectual Disability Nursing

Lynn Marsh

3.0 Introduction

Over the last few decades, Irish nursing education has experienced significant restructuring in both its content and academic delivery level since entering third level institutions in 2002 (Fahy et al., 2011; Deasy et al., 2010). In this time nurse education has witnessed a transition from a three-year apprenticeship model to a four-year degree model linked to higher education institutions (McCarthy and Murphy 2008). Notably, the progression in information technology and science and additional shifts in cultural and economics, have changed the future of the already complex healthcare service, impacting significantly on Irish nurse education (Government of Ireland 1998). As many challenges therefore lie ahead for the nursing profession and the drive for professional advancement, it is vital that nurse education and practice, including intellectual disability nursing education and practice, changes to meet future challenges in terms of supporting people with intellectual disabilities and their families.

Arguably, intellectual disability nursing has remained a profession under scrutiny and a profession that seems to be constantly on the periphery of nursing (Laverty et al., 2005; Mitchell 2004). Yet intellectual disability nursing is one of the primary professions which supports people with intellectual disabilities and their families across the lifespan. Therefore, intellectual disability nursing must evolve and develop on a par with other nursing professions to maintain its professionalism. Consequently, the emergence of key Irish policy documents such as ‘Time to move on from Congregate Settings’ (HSE 2011), ‘Growing Older with an Intellectual Disability in Ireland’ (McCarron et al., 2011) and the New Directions report (HSE 2012) are largely responsible for shaping, informing and transforming intellectual disability nurse education and practice in Ireland.

However, in developing nursing education programmes, educators in particular must be cognisant of the challenges posed in the preparation and production of nurse graduates who have the knowledge, know-how and skills to function effectively in an ever changing...
healthcare environment (Hegarty et al., 2009). Of note, the attainment of nursing competence must meet professional standards (ABA 2000) given that nursing as a practice based profession involves the linking of theory and practice. Interestingly, Shulman (2005) suggests that in order to understand a profession, one needs to examine its’ professional preparation i.e. the teaching and learning approaches. In doing this one can identify pedagogical forms of teaching and learning which are modes of teaching that are designed specifically for the discipline. Shulman (2005) posits that students are instructed on three core dimensions; to think, which basically relates back to the theory or the content; to perform: which relates to the doing or the acquisition of skills and lastly, to act with integrity; which is a dimension that is underpinned by the beliefs/values or morals of that profession. Indeed, there is a general consensus that the core criterion of competence is the platform on which to incrementally build the nursing profession across the four years of a Batchelor degree. Without these core criterion, intellectual disability nursing would lack the essential element of being both an art and a science committed to the care and support of people with intellectual disabilities and their families.

As background, and notwithstanding that the discipline of nursing is complex and varied in its preparation of undergraduate nurses, nursing students acquire and develop skills through both academic preparation and skill-based apprenticeship of practice (Benner and Sutphen 2007). Therefore, nursing, and intellectual disability nursing specifically, have core criterion embedded in nurse education programmes which are founded on achieving competence, which is not only explicit in the Standards and Requirements for Registered Nurses in Ireland but is embedded across the undergraduate nursing programmes (NMBI 2016; ABA 2005).

In Ireland, competence is defined by the Nursing and Midwifery Board of Ireland (NMBI 2016 p.17) as ‘the attainment of knowledge, intellectual capacities, practice skills, integrity and professional and ethical values required for safe, accountable and effective practice as a Registered Nurse’. However, even though the NMBI (2016) have provided a definition of competence, sometimes difficulties can be experienced as often differences exist between the definition of competence, the assessment methods used to assess competence, differences between third level Higher Education Institutes (HEI) and the complexities of the practical experiences available to each student (Butler et al., 2011; Cowin et al., 2008; McCarthy and Murphy 2008) further compounding the theory-practice gap. Cowin et al., (2008) however argue that the term competence ‘does not have a globally accepted definition and this has the
potential to create controversy, ambiguity and confusion’ (p.272). However, as highlighted by Butler et al., (2011), Irish nure preceptors ‘adhere to, and are largely committed to facilitating the processes involved in students’ competence assessment’ (p.302), irrespective of a globally accepted definition of competence. However, the significant restructuring of Irish nursing curricula has seen the emergence of competency based education and assessment, the primary focus of this chapter. Indeed, the emergence of competency based education and assessment is evident internationally (Windsor et al., 2012) and how it impacts on the role of the RNID in an Irish context warrants further discussion.

3.1 Standards and Requirement for Registered Nurses in Ireland

The Standards and Requirements for Registered Nurses in Ireland first came into effect in 2005 (ABA 2005) and identify the key functions of the registered nurse (Fahy et al., 2011). Within these Standards are the framework for competency based education and assessment encompassing five domains of practice as identified by ABA (2005). These are Professional and Ethical Practice; Holistic Approaches to Care; Interpersonal Relationships; Organisation and Management of Care; and Personal and Professional Development (ABA 2005). More recently, the NMBI revised, updated and expanded the Standards and Requirements for Registered Nurses into six domains of practice rather than five (NMBI 2016). The six domains of competence are Professional values and conduct of the nurse; Nursing practice and clinical decision making competences; Knowledge and cognitive competences; Communication and interpersonal competences; Management and team competences; and Leadership potential and professional scholarship competences (NMBI 2016) (See Table 3.1), which are expected to be implemented by 2018. As a consequence, there are now sixteen broad competence statements, all of which have a number of indicators and which have been benchmarked against the Australian, Canadian (British Columbia), New Zealand and United Kingdom Nursing and Midwifery Councils regulatory standards for Registered Nurses and against the European Federation of Nurses Associations Competency Framework (2015 p.6) and once attained, allows entry to the Professional Register of Nurses in Ireland.

Notably, a key difference between the Standards and Requirements for Registered Nurses 2005 and 2016, is that the word competence is now explicit in almost all of the domains and have been mapped for each year of BSc programme rather than a terminal characteristic at the end of the four-year degree programme. While the standards and requirements for evaluating
curricula for undergraduate nursing education programmes are set by the Board, there is no consensus by the Board on the form of competence assessment. Rather it is left to the remit of the third level institutions and their associated Health Service Providers (HSP) to agree and implement competence assessment tools (Fahy et al., 2011). Arguably this is perhaps a weakness of the Irish undergraduate nursing curricula as inconsistencies can arise in which a new graduate from one jurisdiction attains a different level of competence that their counterpart in another jurisdiction. This is perhaps a cause for concern given the complexities of intellectual disability nursing at a time when the profession is revaluating its’ role and attempting to meet the complex care delivery of people with intellectual disabilities and their families.

Table 3.1: Domains of competence

<table>
<thead>
<tr>
<th>Domains of Competence</th>
<th>An Bord Altranais (ABA) 2005</th>
<th>Nursing and Midwifery Board of Ireland (NMBI) 2016</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Professional / ethical practice</td>
<td>Professional values and conduct of the nurse</td>
</tr>
<tr>
<td>2.</td>
<td>Holistic approaches to care and the integration of knowledge</td>
<td>Nursing practice and clinical decision making competences</td>
</tr>
<tr>
<td>3.</td>
<td>Interpersonal relationships</td>
<td>Knowledge and cognitive competences</td>
</tr>
<tr>
<td>4.</td>
<td>Organisational and management of care</td>
<td>Communication and interpersonal competences</td>
</tr>
<tr>
<td>5.</td>
<td>Personal and professional development</td>
<td>Management and team competences</td>
</tr>
<tr>
<td>6.</td>
<td>------------------------------</td>
<td>Leadership potential and professional scholarship competences</td>
</tr>
</tbody>
</table>

While competence assessment is undoubtedly a complex process in nursing (Butler et al., 2011) it would be remiss not to question what could or should be reasonably expected of a newly graduating Registered Nurse in Intellectual Disability (RNID) in Ireland in terms of competence? In addition, the Standards and Requirements for Registered Nurses (NMBI 2016) presumes that the competencies expected can be achieved and transferred to different client/patient population groups and in effect, to different nursing professionals and roles i.e. intellectual disability nursing. Arguably, and from an Irish context, it appears that the application of these competencies across the HEI’s and HSP’s needs to be considered in the preparation of undergraduate nurses for life-long learning as nurse education must commit to practice based learning as advised by the Royal College of Nursing (RCN 2011).

Interestingly, a 2011 quantitative Irish study by Butler et al., of 255 general; mental health; and intellectual disability nurse preceptors (general (n= 159); mental health (n= 43); and intellectual disability (n= 43)) revealed that nurse preceptors ‘either always or usually assessed students’ knowledge (90%), attitudes (89%) and to a lesser degree skills (77%)’
Of note, the majority of nurse preceptors (53%) in Butler et al., study (2011) were educated to Batchelor level but reported challenges in their understanding of the competency descriptors, a finding similar to another Irish study by Cassidy et al., (2012) which explored general, mental health and intellectual disability nurse preceptors’ \((n = 16)\) views and experiences of assessing undergraduate nursing degree students using a competency based approach.

As part of a larger qualitative study by Brown and Crookes (2016) of competency assessment in nursing the ‘skills’ that could reasonably be expected of a newly graduating registered nurse in Australia were identified. This study was representative of a total of 495 participants including academics \((n = 139)\); clinicians \((n = 123)\); educators working with health services \((n = 100)\) and Directors or Assistant Directors of Nursing \((n = 54)\). The findings revealed that thirty skills areas were perceived to be ‘necessary’ of the new graduate with the top five skills set being efficient and effective communication, professional nursing behaviours, privacy and dignity and managing medication administration. Notably leadership skills ranked 30 in the list (Brown and Crookes 2016), and which has now been made explicit in domain six of the revised Standards and Requirements for Registered Nurses (NMBI 2016).

Interestingly, from the reading of the literature, it seems that competence and competence based assessments are driving eligibility for entry to the Professional Register of Nurses in Ireland irrespective of the division. Thus it could be argued that this refocus on the achievement of core competence has inadvertently encouraged the intellectual disability nursing to lose sight of what people with intellectual disabilities and their families want from their intellectual disability nurse.

Interestingly, a descriptive qualitative focus study with people with intellectual disability conducted by Laverty \textit{et al} in the United Kingdom (UK) in 2005 titled ‘Build a nurse’ asked participants what skills and qualities they would like the intellectual disability nurse to possess in order to care for and support people with intellectual disabilities effectively? The four themes that emerged were as follows; firstly, Personal attributes/personality (i.e. a smiley face; to look and smell clean; be more interested in the person than themselves; secondly, knowledge (of human rights; medication and hygiene; epilepsy; first aid and to cook nice food); thirdly, skill (i.e. give opportunity - not just boring walks; to be patient - don't put time limits on things; know when to take someone to the doctor and when just to give a
paracetamol; and finally attitude (i.e. don't make fun of the person's disability; shouting doesn't work; explain when things are going to happen such as rinsing your hair; have faith in the person you are nursing; remembering they are just people too) (Laverty *et al.* 2005 p. 33/34). Significantly, the key take home message was not about nursing competence per se but about respect, values, advocacy and effective and appropriate support of the person with an intellectual disability.

Therefore, in order to support people with intellectual disabilities effectively the voices of those who the RNID supports must be heard and this should be one of the key guiding principles to intellectual disability nurse education. While it is imperative to have clinicians, academics and students involved in developing curricula it is vital that the qualities expected of any nurse include being caring, compassionate, kind, safe and knowledgeable practitioners who each recognise that each and every individual should not be defined by their ability but supported to achieve irrespective of a disability. Indeed, the person best placed to support this population group in Ireland is the RNID and while competencies and the achievement of same will progress the profession, listening and hearing what is expected form those whom we support is critical to the advancement of intellectual disability nursing.

### 3.2 Conclusion

Undoubtedly, the need for undergraduate nursing students to achieve competence is vital for the progression of the nursing profession in Ireland. Rather than focusing on achievement of particular skill sets, the overall competence of the new graduate must focus on transferable skills that allow them to work across a variety of settings and across the lifespan of an individual with an intellectual disability and their family. Perhaps there needs to be a call for a shared understanding and agreement in Ireland and internationally of what competence is and how nurse preceptors can reliably and objectively assess levels of nursing competence. However, in order to prepare undergraduate nurses for intellectual disability nursing in particular, we have to be mindful of what people with intellectual disability want of the RNID. While intellectual disability nursing in Ireland is one of the primary professions which supports people with intellectual disabilities and their families across the lifespan, intellectual disability nursing also must evolve and develop on a par with other nursing professions to maintain its professionalism cognisant of those whom we support.
Chapter Three References


CHAPTER FOUR

Advances in Intellectual Disability Nursing in Ireland

Owen Doody

4.0 Introduction

Since the commencement of Intellectual Disability Nurse education in 1959, the registered intellectual disability nurse (RNID) has played a pivotal role in care provision for people with ID in Ireland (Doody et al., 2012a; Sheerin and McConkey 2008). Since its development ID nursing as a profession adapted and developed its philosophy in line with care, social and rights based policy and this has created much debate regarding its identity and existence, and these debates re-emerge over time (Doody et al., 2012a). This uncertainty has been exacerbated by inadequate utilisation of nursing skills in Irish ID services (Sweeney and Mitchell 2009) and the fact that the UK and Ireland are the only countries providing a specialist pre-registration programme for nurses caring for people with ID (Sweeney and Mitchell 2009; Horan, 2006). The future of ID nursing exists within a changing landscape where current direction is towards the closure of congregated settings in Ireland (HSE 2011), and the economic climate.

Since the 1980s ID public policies in Ireland show a clear path favouring the development of community-based services and as Ireland moves towards the final stages of this paradigm shift away from congregated settings, a complex landscape of service delivery will be created (Malin and Race 2010). Within this changing landscape of service provision it is likely that supported living, independent living, in-home support, community based support, primary care and specialist supports will be required (HSE 2011). Placing a focus on employment, education and personalisation but specialist settings may also be required, such as; treatment and assessment services, challenging behaviour units, specialist health or social care settings, such as homes for older people, hospices providing care for life limiting conditions, or respite services for persons with complex health or social care needs (Gates 2011). This changing landscape provides many opportunities for ID nurses to embrace a range of new roles for example supporting secondary healthcare in acute hospitals, mental health services as well as in primary care (Doody et al., 2012a). While the advancement of nursing practice has gained
significant momentum over the years (Griffin and Melby 2006; McKenna et al., 2006), the future of ID nursing can be seen as lying in the hands of the nurses themselves and in their willingness to make their contribution visible (Doody et al., 2012a).

4.1 Development of specialist roles in Ireland

The development of clinical nurse specialist (CNS) posts commenced in 2001 across all disciplines of nursing in Ireland. Ireland may be seen as arriving late to the concept of nurse specialist which was first documented in the American Journal of Nursing by an American private duty nurse, describing specialists in three areas: surgical, paediatric and obstetrical nursing (De Witt 1900). Specialisation initially referred to the long experience of the nurse in a specific speciality and developed to ‘improve the quality of nursing care delivered by bringing a nurse with specialised experience and advanced formal education to the direct care interface’ (Hamric 1998: 57). In addition it has been recommended that in order to specialise, a nurse must have practised nursing, must continue to practise, and must continue to evolve through practising nursing (Richmond 2004; Castledine 1991).

There is a wide variation in the CNS role and in addition a proliferation of nursing positions referred to collectively under the umbrella term of ‘advanced nursing practice’ leading to confusion and ambiguity (Potter and Coey 2003; Dyson 1997). This ambiguity and confusion appears to be universal as CNS posts developed across a wide range of practice areas in adult, children, mental health and midwifery practice (Doody and Bailey 2011). However, this frequently occurred in an unplanned and reactive manner, with reported differences regarding the preparation, criteria for eligibility and implementation of the role (Bailey 2004).

The development of the CNS posts in Ireland was a component of the strategic development of the health service (Ryan et al., 2006) and took place against the backdrop of health and social policy (Doody and Bailey 2011; NCNM, 2006). The origins of CNS in Ireland may be traced to the Working Party on General Nursing Report (DoH 1980). However, it was not till the collaborative report between the Nursing Board and the Health Service Employers the Report of the Commission on Nursing: A Blueprint for the Future (GoI 1998) was published which recognised both fundamentals and roles for the nurse specialist (Table 4.1). However, while the recognition of the fundamentals and roles were helpful there was no formal
recognition of the CNS post and, in the absence of an agreed framework, a diverse group of individuals evolved, practising with minimal support (NCNM 2001; ABA 2000b).

Table 4.1: Fundamentals and Roles of nurse/midwife specialists (GoI 1998)

<table>
<thead>
<tr>
<th>Rationale</th>
<th>Qualification / function</th>
<th>Timescale</th>
</tr>
</thead>
<tbody>
<tr>
<td>To recognize nurses already functioning as CNSs at the time of implementation of the framework.</td>
<td>Holds an appropriate post registration qualification and/or a minimum of 5 years’ experience in the area of specialty</td>
<td>Closing date for applications 30th April 2001.</td>
</tr>
<tr>
<td>To identify the academic qualifications and professional experience which a newly appointed CNS must achieve within a specified time frame of appointment agreed locally.</td>
<td>The NCNM (2002) published guidelines for higher level education programmes for the CNS in order to meet the learning needs of these nurses.</td>
<td>With effect from the 1st May 2001</td>
</tr>
<tr>
<td>To identify the academic qualifications and professional experience which a newly appointed CNS must hold prior to appointment.</td>
<td>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 National Qualifications Authority of Ireland NQAI) related to the area of specialist practice.</td>
<td>With effect from the 1st September 2010</td>
</tr>
</tbody>
</table>

Based on the GoI (1998) report the NCNM was established as an independent statutory body with responsibility for post-registration development of nursing/midwifery in Ireland in 1999. The NCNM promoted and developed the professional role of nurses/midwives in order to ensure the delivery of quality nursing/midwifery care to patients/clients in a changing healthcare environment. A key purpose of the NCNM was to establish a clinical career pathway for nurses/midwives facilitating the progression from staff nurse to CNS (NCNM, 2002). Thereby they introduced an initial framework for the national development of the CNS role (NCNM, 2001) identifying three independent pathways (see Table 4.2) through which nurses could achieve recognition of their experience and learning (NCNM 20008; 2007; 2004a; 2001).

Table 4.2: Career pathways for CNS (NCNM, 2008; 2007; 2004a; 2001)
The NCNM define CNS as:

“A nurse or midwife specialist in clinical practice has undertaken formal recognised post-registration education relevant to his/her area of specialist practice at level 8 or above on the NQAI framework. Such formal education is underpinned by extensive experience and clinical expertise in the relevant specialist area. The level of practice of a CNS is higher than that expected of a staff nurse or midwife” (NCNM 2008).

Additionally, the area of specialty is defined as:

“As an area of nursing/midwifery practice that requires application of specially focused knowledge and skills, which are both in demand and required to improve the quality of client/patient care” (NCNM 2008; 2007).

Within this framework, the NCNM described five core concepts of the CNS role (Table 4.3) and the framework and descriptors facilitated the national development of CNS roles across the nursing profession in services/organisations throughout Ireland (Doody and Bailey 2011).

Table 4.3: Core Concepts for the CNS specialist role (NCNM, 2008; 2007; 2004a)

<table>
<thead>
<tr>
<th>Core concept</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical focus</td>
<td>The CNSs work must have a strong patient focus whereby the speciality 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. Direct care comprises the assessment, planning, delivery and evaluation of care to patients and their families. Indirect care relates to activities that influence others in their provision of direct care.</td>
</tr>
<tr>
<td>Patient/Client advocate</td>
<td>The CNS role involves communication, negotiation and representation of the patient/client values and decisions in collaboration with other health care workers and community resource providers.</td>
</tr>
<tr>
<td>Education and training</td>
<td>The CNSs remit for education and training consists of structured and impromptu educational opportunities to facilitate staff development and patient/client education. Each CNS in tandem with his/her line manager is responsible for his/her continuing professional development, including participation in formal and informal educational activities, thereby ensuring sustained clinical credibility among nursing, medical and paramedical colleagues.</td>
</tr>
<tr>
<td>Audit and research</td>
<td>Audit of current nursing practice and evaluation of improvements in the quality of patient/client care are essential requirements of the CNS role. The CNS must keep up to date with relevant current research to ensure evidence based practice and research utilisation. The CNS must contribute to nursing research which is relevant to his/her particular area of practice. Any outcomes of audit and/or research should contribute to the next service plan.</td>
</tr>
<tr>
<td>Consultant</td>
<td>Inter and intra-disciplinary consultations, across sites and services are recognised as key functions of the clinical nurse specialist. This consultative role also contributes to improved patient/client management.</td>
</tr>
</tbody>
</table>
4.2 CNS development in ID Nursing

The development of the ID CNS was part of the overall development of clinical career pathway development in Ireland as outlined in the previous section. Many titles exist (Table 4.4) for ID CNS posts in Ireland and overlap and terminology is an issue that creates confusion and ambiguity with CNS roles across services and the Ireland.

Table 4.4: Example of titles in intellectual disability CNS practice

<table>
<thead>
<tr>
<th>Community nursing</th>
<th>Challenging behaviour and behaviour management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early intervention</td>
<td>Creative, recreational and diversional activation</td>
</tr>
<tr>
<td>Autism spectrum disorders</td>
<td>Supported living, and vocational rehabilitation</td>
</tr>
<tr>
<td>Complementary therapies</td>
<td>Health promotion with or without intervention</td>
</tr>
<tr>
<td>Continence promotion</td>
<td>Older people with intellectual disabilities</td>
</tr>
<tr>
<td>Feeding and nutrition</td>
<td>Alternative and augmentative communication</td>
</tr>
<tr>
<td>Infection control</td>
<td>Personal development and therapeutic programmes</td>
</tr>
<tr>
<td>Mobility</td>
<td>Physical disability and special needs</td>
</tr>
<tr>
<td>Palliative care</td>
<td>Epilepsy and health promotion</td>
</tr>
<tr>
<td>Ageing and dementia</td>
<td>Sensory integration</td>
</tr>
</tbody>
</table>

The Commission (GoI 1998) suggested seven broad bands to be used to group relevant sub-specialist areas and following the establishment of the NCNM and the issuing of a definition for CNS (Doody et al., 2012b). The DoHC (2002) commissioned a report to explore the CNS in ID nursing which proposed a framework for the development of clinical specialism and advanced practice in intellectual disability nursing and identified a clear pathway for the ID CNS and aided the development of CNSs in ID nursing. This report endorsed specific suggestions relating to education and broadened on the Commission report (GoI 1998) through listing themes or areas of practice for specialism to occur. Furthermore the ERHA (2004) in their report ‘Looking into the future: maximising the nursing contribution to a comprehensive intellectual disability service’, identified areas of practice for ID nurses to specialise. Table 4.5 identifies the areas for development as considered by GoI (1998) and areas of practice for specialisation as considered by both the DoHC (2002) and ERHA (2004).

Table 4.5: Clinical Career Pathways for CNS and Proposed Role (Doody et al., 2012b)

<table>
<thead>
<tr>
<th>Clinical Career Pathway CNS</th>
<th>Proposed Role</th>
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</thead>
<tbody>
<tr>
<td>Report of the Commission on Nursing: A Blueprint for the Future (GoI 1998) – 7 broad bands</td>
<td>High dependency nursing</td>
</tr>
<tr>
<td></td>
<td>Rehabilitation and habilitation nursing</td>
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<td></td>
<td>Medical surgical nursing</td>
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<td></td>
<td>Maternal and child health nursing</td>
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<td></td>
<td>Community health nursing</td>
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<td></td>
<td>Mental health nursing</td>
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<tr>
<td></td>
<td>Disability nursing</td>
</tr>
<tr>
<td>Proposed Framework for the development of Clinical Specialism and Advanced Practice in Mental Handicap Nursing (DoHC 2002)</td>
<td>Sensory development</td>
</tr>
<tr>
<td></td>
<td>Management of behaviour</td>
</tr>
<tr>
<td></td>
<td>Multiple and complex disabilities</td>
</tr>
</tbody>
</table>
The activities of the ID CNS and within individual roles have rarely been explored. Evidence that exists regarding the ID CNS in Ireland comes from the NCNM own evaluations of the role across all disciplines in nursing (Begley et al., 2010; NCNM 2004b). The NCNM (2004b) evaluation report identifies some interesting factors, such as the active role of the CNS in client care, education, advocacy and the limited evidence of a research role. In addition the NCNM evaluation (Begley et al., 2010) highlights that developments in the clinical career pathway of ID nurses have not taken place at the same pace as that of the other disciplines of nursing. The report also addresses the difficulties of the CNS concept in ID services, unlike in acute care services, where care is mostly comparable in each acute care hospital; this is not the case in ID services (Begley et al., 2010). Nevertheless, education and health promotion roles of CNSs were viewed as contributing to upholding quality standards of care and serving as a role model for nursing and staff. In ID services, in particular, it was identified that the CNS impacted on wider outcomes related to quality of life for clients and families (Begley et al., 2010). From an ID CNS perspective Doody (2013) identifies the
contribution of ID CNSs from the CNSs perspectives, nurses/managers and MDT perspective and families’ perspective. Table 4.6 presents a summary of the development in CNS in Ireland from 1980-2011.

**Table 4.6: Summary of the development in CNS in Ireland related to ID 1980-2016**

- 1998 - Report of the Commission on Nursing is published and recommended the establishment of the NCNM to guide and direct the development of CNS posts and that the Minister for Health and Children provide for the grades of CNS.
- 1999 - Statutory Instrument No 376 is published and NCNM is established.
- 2000 - NCNM members are appointed and they develop the definition, core concepts and approval process for CNS posts. The Immediate clinical career pathway becomes into operation and CNS post in intellectual disability nursing was approved.
- 2001 - Executive staff of the NCNM take up posts and publish the frameworks for the establishment of CNS posts and the intermediate clinical career pathway commences 1 May.
- 2002 – The Nursing Policy Unit of the Department of Health and Children proposes that CNS posts in intellectual disability develop in accordance with client need and/or lifespan stage.
- 2003 – The NCNM publishes Agenda for the Future Development of Nursing and Midwifery, referring to considerations for CNS roles in intellectual disability nursing.
- 2006 – The NCNM publishes a position paper on clinical nurse specialist and advanced nurse practitioner roles in intellectual disability services, referring to the philosophical, demographic and issues that distinguish the development of such posts.
- 2008 – The NCNM publishes fourth editions of the CNS frameworks and the Profiles of Advanced Nurse/Midwife Practitioners and Clinical Nurse/Midwife Specialists contains a feature on clinical nurse specialists in autism. The NMPDU (HSE, South) and National Council collaborate to produce the second edition of the Clinical Nurse/Midwife Specialist Role Resource Pack, which contains a case study of a clinical nurse specialist in challenging behaviour.
- 2014 - Comiskey, C., Coyne, I., Lalor, J., and Begley, C. (2014). A national cross-sectional study measuring predictors for improved service user outcomes across clinical nurse or midwife specialist,


4.3 Advanced nursing practice

Based on the foundations of intellectual disability nursing theory and practice advanced nursing may be performed by registered ‘autonomous, experienced practitioners who are competent, accountable and responsible for their own practice’ (Begley et al., 2010: xxii). Advanced Nurse Practitioners (ANPs) are professionals holding a master’s degree or higher and registered with NMBI. They demonstrate high levels of clinical excellence in research and evidence based practice specific to their scope of nursing competency e.g. intellectual disabilities. They are deemed central clinicians in coordinating quality person and family centred care to people with an intellectual disability. ANPs support practice through the core concepts of their role; autonomy in clinical practice, expert practice, professional and clinical leadership and research and demonstrate proven competencies at a high level of clinical practice under six domains (NMBI 2015:6-14):

1: Professional Values and Conduct of the Registered Advanced Nurse Practitioner
2: Clinical-Decision Making
3: Knowledge and cognitive competences
4: Communication and interpersonal competences
5: Management and team competences
6: Leadership potential and professional scholarship competences

Advanced Nurse Practitioners must:

- Be a registered intellectual disability nurse
- Use high levels of knowledge and skills in their scope of clinical practice.
- Hold a postgraduate qualification at master’s degree or higher with a substantial clinical assessment module, in an area specific to their area of intellectual disability nursing practice
- Have a minimum of seven years post-registration experience
- Have substantive hours at supervised advanced practice level
- Provide evidence of continuing professional development
- Demonstrate a high level of leadership and management
- Work in an accredited ANP post.

Internationally the CNS and ANP roles are widely recognised. However, confusion exists as entry requirements and role components can differ across countries. In addition, terminology differences exist such as in Northern Ireland and the UK ID or LD CNSs do not exist but the community learning disability nurse (CLDN) is seen as a specialist role and in addition nurse consultant roles with ID exist across the UK. The Nurse Consultant’s primary role is to ensure better quality clinical outcomes for people with an intellectual disability.

4.4 Conclusion

Ireland has seen nursing specialties evolve across a wide range of practice areas with practitioners having a variety of levels of preparation. To attain the vision for advancing nursing practice it is imperative that CNSs/ANPs adopt and satisfy the components of their role to their full potential. Within practice, the CNSs/ANPs are well positioned to adopt a leadership role for the profession. However, as little evidence exists regarding the practice outcomes of CNSs/ANPs in Ireland, increased support is essential to encourage and enable these nurses to publish the outcomes of their care. Given the current restructuring of services, models of service provision and national policy, intellectual disability nursing will continue to
be faced with a challenge to change and respond to meet the needs of services, clients and families.
Chapter Four References


Nursing and Midwifery Board of Ireland (2015) *Advanced Practice (Nursing) Standards and Requirements*. Dublin: Nursing and Midwifery Board of Ireland.


CHAPTER FIVE

Person-centred Planning: A way of being and serving rather than simply saying and doing

Paul Michael Keenan

5.0 Introduction

‘People with disabilities, ... have the right to be safe, to receive person-centred, high quality services and supports and to have access to the services they need in order to maximise independence and choice and enable them to lead a fulfilling life. This basic right is fundamental to their wellbeing and healthy development.’

(HIQA 2013a: 3)

Person-centeredness is a primary focus of current Irish and International social policy and nursing practice in the field of intellectual disabilities (HSE 2012a; HIQA 2013a,b; Valuing People 2017). Social policies which emphasise or allude to person-centred care include: professional documents the Code for nurses and midwives (NMC 2015) and the Code of professional conduct and ethics (NMBI 2014) and governmental policies such as, Expert Reference Group on Disability Policy’ Report of Disability Policy Review (DoHC 2010) Time to Move on from Congregated Settings (HSE, 2011), Value for Money (DoH, 2012), Progressing Disability Services for Children and Young People (HSE, 2012a) New Directions (HSE, 2012b).

5.1 Defining person-centred planning (PCP)

The international literature offers no agreed definition of PCP. In Ireland, the NDA defines PCP as:

“A way of discovering how a person wants to live their life and what is required to make that possible. The overall aim of PCP is good planning leading to positive changes in people’s lives and services” (NDA 2005a: 12).
5.2 Person-centeredness and person-centred planning

This philosophy and way of managing care is perceived as very different from the biomedical model of care which had dominated service provision in the past hundred or so years. PCP is not simply a relabelling of existing structures and processes of care, but requires major cultural and systemic evolutions to more internationally recognised standards of contemporary care (Keenan 2008 & Genio 2012). Nor is PCP a relabelling of existing task-oriented practices. PCP calls upon each nurse to develop their own professional knowledge, skills and values in ways which serves the individual with an intellectual disability rather than simply doing things for them and developing services for them (Keenan 2008; Keenan & Griffiths 2015). Person-centred care requires professionals to identify through in-depth assessment how an individual wishes to live their life and develop their dreams/aspirations, then ensure the necessary support is provided (NARI, 2006; NDA 2005a. & b.; Valuing People 2017). A person-centred care approach enables people with intellectual disability to, at all times, be actively involved in and in control of their care and support to the level of their capacity and choice. Its emancipatory focus respects and facilities personal choice, advocacy and independence. Therefore the nurse is required to be actively engaged in partnership with the person, their family and cares and other professionals through intra-disciplinary and intra-agency practice to plan and shape supports for the person based on the life they want (Keenan & Griffiths 2015, Valuing people 2017).

While there is some proof that the philosophy of person-centeredness is being applied in contemporary nursing practice there still exists limited descriptive and, more importantly, empirical evidence about its practical application, the processes of assessment and management used or its effectiveness for people with an intellectual disability. Therefore there is a need for governmental organisations, such as HSE, DoH and NDA, who are charged with leading and guiding professional care to continue to address this issue. In recognition of this obligation, for example, the NDA are currently in the process of developing a National Framework for Person-Centred Planning in Disability Services. While it is too early to comment on such broad initiatives, it should be noted that ubiquitous approaches to people with disabilities are not always in the best interests of individuals or those with different disabilities. Therefore, a national framework for people with an intellectual disability should also be considered.
Albeit that the research is limited, a small number of studies are available. Claes et al., (2010) in an evaluation of 15 research studies found that person-centeredness improved the service user’s range of choices, extended social networks, enhanced communication and parental engagement. However, they also found that those with severe intellectual disability, challenging behaviour and communication needs were excluded from the person-centred care plans. Robertson et al. (2007) have identified many barriers to person-centred planning, including; the shortage of staff, the movement of staff within a service, insufficient time, a lack of person-centred facilitators, insufficient staff training and the practice of person-centred care in ways which reduce and manage service-user risk in safe ways.

Within Ireland intellectual disability nurses have also demonstrated their role and engagement in person-centred care where; Martin and Carey (2009) described how a woman with moderate intellectual disability was helped to develop her own person-centred approach to her care, Ryan and Carey (2008) described how person-centred planning was used for a young boy with Down syndrome, Ryan and Carey (2009) describe person-centred planning for an older person with intellectual disability and dementia, Smith and Carey (2013) describe person-centred planning for an older person with intellectual and physical disabilities and McCarron et al., (2013) describe a significant collaborative initiative to implement person centred practice within a congregated setting managed by a large Irish health and social care provider.

**5.3 Conclusion**

Person-centred care and person centred planning are central to policies shaping the care and support of people with an intellectual disability. The nurse is required to collaborate with the service user in respectful and dignified ways which facilitate the life the individual chooses and to work in partnership with all those involved in providing care and support, including families and professional cares. While there is limited research to demonstrate the effectiveness of such an overarching approach, its values and principles are grounded in respect of the individual, and the enablement of autonomy, independence and community connectedness, which are professionally viewed internationally as being at the core of good practice.
Chapter Five References


Health Information and Quality Authority (2013a) The National Standards for Residential Services for Children and Adults with Disabilities. Dublin: HIQA.

Health Information and Quality Authority (2013b) *About the Regulation of Residential Services for Children and Adults with Disabilities – Guidebook 2013*. Dublin: HIQA.

Health Service Executive (2012a) Progressing Disability Services for Children and Young People. Dublin: Health Service Executive.


National Disability Authority (2005b) *Person Centred Planning for People in Ireland who have Disabilities Plain English Version*. Dublin: NDA.

Nursing and Midwifery Board of Ireland (2014) *Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives*. Dublin, NMBI.


CHAPTER SIX

Nurse prescribing

Paul Michael Keenan and Owen Doody

6.0 Introduction

The role of the intellectual disability nurse has seen substantial changes in the past decade in terms of clinical nurse specialisms, and to a much less extend with regards to advanced nursing practice and nurse prescribing. An increasing number of nurses now have the opportunity to extend their practice by training to be and then registering to become prescribers of medication within their clinical competence.

6.1 Nurse prescribing

The introduction of nurse prescribing in Ireland has been seen as an essential milestone in the professional development of the nursing discipline (Naughton et al, 2013). Creating an opportunity for RNIDs to become nurse prescribers is in line with the national changes in the professional development of nursing in Ireland. Legislation has developed to support nurses’ authority to prescribe as long as; the nurse is registered with the NMBI, has gained relevant clinical experience, has completed an agreed education programme and has a collaborative agreement with their service provider. The introduction of nurse prescribing in Ireland in 2007 expanded on the understanding of the UK and Australian nurse prescribing experiences and identified that nurses develop specialist knowledge and experience prior to registering on a prescribing course (HSE 2008).

In Ireland, any nurse, with the backing of their employer, is entitled to register on a nurse prescribing education programme leading to a qualification as a Registered Nurse Prescriber (RNP) (An Bord Altranais 2007a) if they meet the following criteria:
(a) Has recognized relevant competencies at Level 8 of the National Qualifications Authority of Ireland framework (equivalent to degree level);

(b) Is registered with the Irish Nursing and Midwifery Board (NMBI);

(c) Has a minimum of 3 years’ experience (in the last 5 years) with a recognized healthcare provider; and

(d) Has been employed in the speciality where they wish to prescribe for one full year.

An essential part of the process in Ireland comprises of the development of a collaborative practice agreement (CPA). CPAs were established and used to guide the clinical supervision of each nurse with prescriptive authority (An Bord Altranais 2007b). A CPA establishes an agreement among a nurse prescriber candidate, a consultant physician and the health service employer and is developed following successful completion of a nurse prescribing education programme. The CPA limits and stipulates the medication an individual nurse prescribing candidate can prescribe. The nurse prescribing candidate then submits their application and CPA to the NMBI to gain entry to the Registered Nurse Prescriber (RNP) division of the professional register. In addition, all RNPs are obliged to retain an electronic record of all their prescriptions on a central database – The Nurse and Midwife Prescribing Data Collection System (Office of the Nursing Services Director Health Service Executive 2008). CPAs must be appraised and updated periodically (ABA 2012).

6.2 Evidence of nurse prescribing

Internationally nurse prescriber roles have been implemented across many countries and systematic reviews exist such as Gielen et al., (2014) and Kroezen et al., (2011). However, the literature is sparse relating to nurse prescribing in intellectual disability nursing. This has to be considered within the context of intellectual disability nursing and the fact that Ireland and the UK are the only countries training nurses within this discipline. Therefore we need to consider other nurses such as community nurses, mental health nurses and nurses within the primary care in other countries if we are to gain information on nurse prescribing for the intellectual disability population.
Within Ireland, Creedon and O’Connell (2009) described the introduction of nurse prescribing. From a research perspective Lockwood and Fealy (2008), Wells et al., (2009) and Naughton et al., (2013) have looked at the views of CNS’s, community mental health nurses and evaluating the appropriateness and safety of nurse prescribing. However, these studies did not include intellectual disability nurse prescribers and the information gained may not be generalizable. Condell et al., (2014) investigated the knowledge and experience of newly qualified prescribers. While intellectual disability prescribers were included it is difficult to identify the sample size of intellectual disability nurse prescribers as included in the reported ‘other’ category (n=14). Nonetheless, while it may be difficult to identify findings specific to intellectual disability nurse prescribers the study recognises the benefits of education and those who attaining higher academic achievements, reported increased confidence and better patient care, which resulted in enhanced engagement in the process of prescribing. In addition, what is importance is working within one’s scope of practice (Carey et al, 2014) and even with increased autonomy one needs the ability to recognise their limitations and seek advice (Condell et al., 2014).

6.3 Conclusion

As regulations and requirements evolve over time, it is the registered nurse’s responsibility to keep up to date at all times. This may be achieved by regularly visiting the Nursing and Midwifery Board of Ireland website: www.nmbi.ie, reading their guidelines, correspondence and newsletters and keeping up to date with nursing news and good practice developments in the nursing press. The nurse prescribing qualification is not restricted to CNS’s and ANP’s with the minimum requirements for registered nurse prescriber (RNP) including:

- Registration as an intellectual disability nurse on the live register of NMBI
- Minimum of 3 years post-registration clinical practice (within the last five years with a minimum of one year in the area in which the person will practice prescribing e.g. intellectual disabilities)
- Hold accredited competencies at Level 8 of the National Qualifications Authority of Ireland framework
- Evidence of continuous professional development and competent to study at graduate level.
- Provide suitable evidence that the individual possess a competent level of information technology (IT) literacy.
Chapter Six References


CHAPTER SEVEN

Intellectual Disability Liaison Nursing

Professor Michael Brown

7.0 Introduction

The first Liaison Nursing service for people with intellectual disabilities was established in Edinburgh, Scotland at the Western General Hospital in 1999 and places experienced Registered Intellectual Disability Nurses exclusively in the general hospital setting to ensure that there is access to additional support and expertise regarding the specific health needs of people with intellectual disabilities throughout the care journey. The role seeks to ensure that the care and support of people with intellectual disabilities is both safe and person-centred during pre-attendance, attendance, admission and discharge. Liaison Nursing roles have been developed in many general hospital services, particularly across the United Kingdom, with a focus on supporting people with intellectual disabilities, their family and carers throughout the care journey. They have an important role to play in ensuring that care and support needs are identified and met, that additional support is available for people with intellectual disabilities, their families and carers and professionals in general hospitals.

7.1 Health needs of people with ID necessitating general hospital access: An overview

There is now a well-established body of research evidence regarding the extent of the complex health morbidities and inequalities experienced by many people with intellectual disabilities (Cooper et al., 2015). People with intellectual disabilities are high and frequent users of all universal health services, including general hospitals, due to their range of health needs. Due to such needs, many require to attend general hospitals for assessment, clinical investigations and treatments. It is also important to recognise that people with intellectual disabilities can and do experience the same, and often a greater range of health conditions as the non-disabled, thereby necessitating access to general hospitals for assessment, clinical investigations, treatment and care. There is a growing body of evidence regarding the extent of people with intellectual disabilities health needs and actions necessary to ensure that they
are met in a way that is both safe and person-centred within the general hospital environment and the important role of the intellectual disability liaison nurse. People with intellectual disabilities have a range of specific health conditions that may result in their need to access general hospitals for assessment, investigations, treatments and care and support (Glover et al., 2016a).

Epilepsy is very common and results in the need for clinical investigations such as Electroencephalogram (EEG), CT and MRI scanning to assist with diagnosis (Haveman et al., 2010). Attendance at neurology and x-ray departments may be necessary as part of the assessment, clinical investigations and treatment processes. As a result of seizures, people with intellectual disabilities may lose consciousness suddenly and fall to the ground or onto objects that lead to injuries including, burns and scalds and dislocations, subluxations and fractures, all of which may contribute to premature and avoidable deaths (Camfield and Camfield 2015; Finlayson et al., 2015). Therefore, some may need to attend an accident and emergency departments, with the need for admission for further clinical investigations and anticonvulsant medication review (Robertson et al., 2017).

Sensory impairments are common such as vision and hearing conditions which can necessitate attendance at a general hospital. Conditions such as congenital cataracts, retinal abnormalities, optic atrophy, or abnormalities of the eye structure can occur and lead to visual impairment (Evenhuis et al., 2001). Access to assessment and treatments such as cataract surgery may be indicated as well as regular review to reduce complications and reduce accidents, falls and injury resulting from visual impairments (Finlayson et al., 2015).

Endocrine disorders including thyroid disorders and diabetes are also common and may require assessment, investigation and treatment at a general hospital. There are higher prevalence rates of diabetes within the intellectual disability population; with some 10% experiencing the condition. There is therefore associated risk of complications, such as cataracts and cardiovascular and peripheral vascular disease that requires monitoring and treatment (MacRea et al., 2015). Thyroid disorders, notably hypothyroidism in people with Down Syndrome, is common and can result in a range of physical and mental symptoms, such as skin changes, lethargy, tiredness and depression (Prasher and Gomez 2007).
Cardiovascular disease is a leading cause of death of people with intellectual disabilities (Emerson et al., 2016). Heart disease is common in people with intellectual disabilities and as the population lives into older age, more will experience the complications of cardiovascular disease associated with the ageing. Conditions such as hypertension, vascular dementia, myocardial infarction, diabetes, dyslipidaemia and cerebral vascular accident may be evident, necessitating access to assessment, investigation and treatment in general hospitals (Wee et al., 2014).

Respiratory disease is the most common cause of death for people with moderate to severe intellectual disabilities and is a significant factor in relation to premature death, which in many cases is avoidable with access to appropriate and timely healthcare (Hoskings et al., 2016; Heslop et al., 2014; Tyrer and McGrother 2007). Asthma is a common respiratory condition experienced by people with intellectual disabilities as are chest infections that if untreated can result in pneumonia and lead to premature and avoidable death (Tyrer and McGrother 2009). Pneumonia is common in people with intellectual disabilities and is often secondary to gastric aspiration and increases with the severity of the intellectual disability. Pneumonia is particularly common in people with Down Syndrome and results in their death (Uppal et al., 2015). Admission to general hospitals may be necessary to enable clinical investigations to be undertaken such as x-rays and scans, endoscopy to identify and treat or exclude contributing conditions such as gastrooesophageal reflux disorder, gastric erosion and ulceration linked to helicobacter pylori infection in the stomach, which may be associated with oesophageal and gastric cancers (Galli-Carminati et al., 2006).

Constipation is common in people with intellectual disabilities and increases with the severity of the disability. Prevention by way of good fluid intake and nutrition and physical activity and health screening is important (Robertson et al., 2014). Attendance at a general hospital may be required in cases of chronic constipation and faecal impaction, due to the need for interventions to remove the faeces from the impacted colon and address potential consequences of faecal aspiration (Timmeren et al., 2016).

Early detection through accessing national cancer screening programmes such as those for breast, cervical and bowel cancer is important, as is the possibility of cancers associated with gastric conditions such as helicobacter pylori. People with intellectual disabilities experience a different cancer profile from the general population, with oesophageal, stomach and gall
bladder cancers being more common, with lower levels of prostate cancer, respiratory cancer and urinary tract cancer (Heslop et al., 2014). As people with intellectual disabilities age, there is a need to recognise the potential increase of other cancers associated with general ageing (Haveman et al., 2010).

Oral diseases and poor dental health is common in people with intellectual disabilities and can necessitate attendance at a general hospital for emergency treatment or planned admission for examination and treatment, sometimes under sedation or general anaesthetic. Regular dental review is important as is dental education to ensure that people with intellectual disabilities, their families and carers recognise the need for good oral care and identify and treatment issues promptly (Finkleman et al., 2014). Dental caries, gum disease, periodontal disease and root caries are common and leading to poor nutritional intake, pain and discomfort and therefore higher number of extractions and the use of sedation and general anaesthetics (Morgan et al., 2012). Gastric oesophageal reflux disorder (GORD) if untreated results in pain and discomfort and can contribute to dental disease.

Accidents are common in people with intellectual disabilities and can necessitate attendance at a general hospital and clinical investigations and treatments. As a population, they experience falls, fractures, and injuries (Finlayson et al., 2015). Injury may for example result from falls associated with seizures that can cause fractures, head injuries, dislocations and subluxations (Camfield and Camfield 2015). Accidents may also be due to factors associated with the side effects of medication, such as anticonvulsants. Conditions such as hearing and visual impairments, impulsivity, and epilepsy can result in falls, road traffic accidents, accidents in the home such as scalds and burns. People with profound and multiple intellectual disabilities are at significant risk from fractures (Glick et al., 2005).

People with intellectual disabilities experience significant mental disorders which can contribute to their need to access general hospital treatment and care or may impact on their care journey. Anxiety disorders and challenging behaviours are common in the intellectually disabled and may be exacerbated by physical illness and an unfamiliar environment such as a general hospital and need to recognised and supported appropriately when attending general hospitals (Pruijssers et al. 2014). Attempted suicide can be the consequence of a range of complex factors including depression, psychosis and schizophrenia, for example and is a cause of death in younger people with intellectual disabilities (Glover et al., 2016b; Osugo
and Cooper 2016). Given the high prevalence of mental disorders within the intellectually disabled population, there is a risk of attempted suicide which may result in assessment and treatment in a general hospital. Close liaison between general hospital and specialist intellectual disability professionals is therefore necessary to ensure that treatment, care packages and supports are appropriate to the needs of the individual.

General hospital care can be particularly challenging for people with intellectual disability and autism spectrum disorder due to impairments in communication that effect their ability to communicate pain and distress and may affect their interactions with professionals involved in their care and treatment. When coupled with the complexity and unfamiliarity of the general hospital environment, there is an increase in the possibility of anxiety and agitation, as well as hypersensitivity to visual, auditory and sensory stimulation. Issues regarding tolerating medical equipment such as cardiac monitors and blood pressure monitors need to be considered and how cooperation can be gained and support provided during clinical investigations and treatments (Broder-Fingert et al., 2016).

7.2 Investigations and Inquiries

There has been a range of high profile investigations regarding the care of people with intellectual disabilities in the general hospital environment in the United Kingdom, where issues related to the poor quality of care have been identified that in some cases lead to avoidable deaths. Mencap, a leading charity for people with intellectual disabilities and their carers, published 2 reports Death by Indifference and Death by Indifference: 74 Lives and Counting (Mencap 2012, 2007). The reports set out systems failures that lead to the deaths of people with intellectual disabilities and the failings of health services to meet their needs.

As a consequence of the issues identified and highlighted by Mencap, the Department of Health in England held an independent inquiry, chaired by surgeon Sir Jonathan Michael. The outcome of the inquiry was the publication of Healthcare for All (Department of Health 2008). Healthcare for All made a series of recommendations, set out in Table 7.1:

<table>
<thead>
<tr>
<th>Table 7.1: Summary of Healthcare for All recommendations</th>
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<tr>
<td>The collection of data to enable the identification of people with learning disabilities</td>
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<tr>
<td>The identification of needs through Joint Strategic Needs Assessments</td>
</tr>
<tr>
<td>The review and monitoring of general health services for people with learning</td>
</tr>
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Nursing Network in Intellectual Disability 44
The Department of Health in England commissioned *The confidential inquiry into premature deaths of people with learning disabilities* (CIPOLD) in 2010 (Heslop et al., 2013). The purpose of the inquiry was to investigate the avoidable or premature deaths of people with intellectual disabilities through retrospective reviews of deaths in the West of England. The Confidential Inquiry reviewed the cases of 247 children and adults with intellectual disabilities and identified the need for actions across care services in the West of England (Heslop et al. 2014). It identified the need for sustained action across care services and actions that need to be taken forward to help ensure that care is safe and deaths that are available prevented in the future; an overview is presented of the recommendations in Table 7.2.

### Table 7.2: Overview of actions required from The Confidential Inquiry recommendations.

- Strong national and local leadership to effect change
- The development of alert systems to identify people with learning disabilities in general health services
- The making reasonable adjustments to ensure safe, person-centred care
- The sharing of best practice
- The implementation of clinical guidelines to take account of multi-morbidities
- The allocation of a named healthcare coordinator for people with learning disabilities with complex needs with two or more long-term health conditions
- The introduction of patient-held records for those with multiple health conditions
- Ensuring equal access to clinical investigations and treatments to achieve the same health outcomes as for the non-intellectually disabled;
- Ensure adherence to capacity legislation
- mandatory updates for practitioners in health and social care regarding the care and support needs of people with intellectual disabilities
- A review of the Do not attempt cardiopulmonary resuscitation guidelines

(Department of Health 2008)
7.3 General hospital care and people with ID

Backer et al., (2009) undertook a systematic review of the literature to identify the experiences of people with intellectual disabilities in the secondary, general hospital, environment. Thirteen research papers were included in the review and analysed to identify the possible actions necessary to improve care. The review identified 5 solutions to overcome the barriers to care provision.

(i) The development of liaison nursing models in general hospitals.
(ii) Improving healthcare systems to ensure care is person-centred.
(iii) Improving communication and information sharing across care systems.
(iv) Ensuring that additional support is available for family carers.
(v) Education and practice development to ensure that professionals have appropriate attitudes and values towards people with learning.

Bradbury-Jones et al., (2013) conducted a systematic review of the literature to identify the factors that influence the health care experience of people with learning disabilities within the general hospital setting. The review identified 6 key factors, set out in Table 7.3.

Table 7.3: Risk factors associated with general hospital admission for adults with intellectual disabilities

<table>
<thead>
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<th>Factor</th>
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<tr>
<td>The provision of care and meeting of individual health and personal needs.</td>
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<td>Communication at an individual and organisational level.</td>
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<tr>
<td>Staff attitudes towards people with intellectual disabilities and their carers.</td>
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<tr>
<td>Staff knowledge of the care and support needs of people with intellectual disabilities.</td>
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<tr>
<td>The need to recognise and value the role of supporters and carers.</td>
</tr>
<tr>
<td>Adjusting the physical care environment to meet the needs of people with intellectual disabilities.</td>
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</tbody>
</table>

Arising from the analysis of the research literature, Bradbury-Jones et al., (2013) developed a new model that identifies the factors that need to be addressed directly and indirectly when people with intellectual disabilities attend a general hospital. The inner layer of the model sets out the issues directly linked to the individual patient experience, namely, care provision, communication, staff attitudes, staff knowledge, support and carers and the physical environment. The next layer of the model details the factors that indirectly influence the individual patient experience, relate to education and training and the role of liaison services. Sitting at the outer part of the model are the wider influencing factors that relate to social, economic and political issues. The model sets out the interrelated and complex nature of the
factors that influence the health, safety and welfare of adults with intellectual disabilities in the general hospital setting and is useful in highlighting the issues that need to be addressed to ensure that care needs are appropriately met.

Iacono et al., (2014) undertook a systematic review of the research literature to identify the acute hospital experiences of both people with intellectual disabilities and their carers, and to identify areas for future research. The review identified seven themes: failure to meet care needs, fear experienced by people with intellectual disabilities when attending general hospital, the role of carers in providing direct care, negative staff attitudes towards people with intellectual disabilities, lack of staff knowledge about care and support needs, problems associated with delivery of care in the general hospital setting and hospital systems not being responsive to the needs of the individual.

What is apparent from the investigations that have been undertaken and the evidence from the systematic reviews of the research literature are common themes and issues regarding the care and support of people with intellectual disabilities when attending for assessment, treatment and interventions in general hospitals. There are recurring themes about lack of individualised care and support, valuing the role of families and carers, poor attitudes and limited knowledge and understanding of the care and support needs of people with intellectual disabilities and failure to make adjustments to the care environment to support person-centred care. There are therefore opportunities for Intellectual Disability Liaison Nurses to make significant contributions to ensure that care and support is person-centred and that the needs of individual patients are met throughout the care journey and in the wider organisational and education needs of professionals in general hospitals. Central to this is person-centred care and support.

7.4 Promoting person-centred care and support

There is a growing interest and focus on person-centred care and the role that it plays in informing and guiding professional practice to ensure that care is both safe and compassionate. The concept is particularly relevant in relation to people with intellectual disabilities when attending the general hospital environment. From the perspective of the Intellectual Disability Liaison Nurse, person-centred care and support focuses on the ability of the nurse, the patient and their family and carers to connect during times of vulnerability, uncertainty and anxiety, such as when attending a complex and bewildering general hospital.
(Scottish Government 2010). Person-centred care is therefore at the very heart of the role of the liaison nurse for people with intellectual disabilities, aiming to ensure that the provision of care and support meet the needs of the individual and in a way, that ensures their safety. Therefore, the essence of the role is the provision of safe, person-centred care and support that requires the nurse to work at the interface between personal and professional relationships within the context of a complex healthcare system that responds to the human experience of the individual with intellectual disabilities by practicing in a way that is respectful, efficient and transparent (Brown and Chouliara 2016). Person-centred care in relation to people with intellectual disabilities therefore requires the provision and consistent delivery of care and support that builds trust, is safe and effective and is delivered competently by practitioners who recognise and respond at times of psychological and physical vulnerability (Brown et al., 2016).

Intellectual Disability Liaison Nurses are therefore well placed in the general hospital to work collaboratively with people with intellectual disabilities, their families and carers and the professionals involved in providing the assessment, clinical investigations and treatments to ensure that care and support provided are person-centred and enable adjustments to be made to meet the needs of the individual (Brown et al., 2016).

7.5 Disability Liaison Nursing

Part of the solution to improving the care and support that people with intellectual disabilities, their families and carers received when attending general hospitals is the Intellectual Disability Liaison Nurse. The role was first established at the Western General Hospital, Edinburgh in 1999 to ensure that there was access to additional support for people with intellectual disabilities when attending for assessment, clinical investigations and treatment. Since the first post was established there has been the development of liaison nursing roles across the United Kingdom, with the recommendations that all general hospitals have in place such roles (Royal College of Nursing 2014; World Health Organisation 2010). Intellectual Disability Liaison Nursing can be defined as:

‘A Registered Nurse with extensive knowledge, skills and practice expertise of the specific health and support needs of people with intellectual disabilities at the point of pre-attendance,
Nursing Network in Intellectual Disability

Research undertaken into the role of Intellectual Disability Liaison Nurses identified the complexity of the role and three main areas of impact (Gibbs et al., 2008).

(i) **Supporting and enabling direct clinical patient care** by contributing to the assessment and identification of needs and additional supports, information sharing across care systems, facilitating pre attendance planning, providing support and coordination of care throughout the care journey, advice on making reasonable and achievable adjustments to ensure the provision of person-centred care and advising on issues related to capacity and consent and behaviour management, contributing to discharge planning and care coordination.

(ii) **Education and practice development** of professionals working in general hospitals by contributing to induction programmes and continuing professional development sessions and opportunistic education in clinical areas about specific are issues and problems.

(iii) **Strategic organisational developments** such as contributing to the development of care pathways and policies and procedures to promote safe and effective person-centred care and support are provided and acting as an advocate and role model within the general hospital to ensure the care and support needs of people with intellectual disabilities are reflected and met.

Further research undertaken by Castles et al., (2014) identified the benefits from the perspectives of people with intellectual disabilities and their families and the value of the role in enabling and facilitating the planning of care and facilitating discharge planning, assisting in making reasonable adjustments to care and support, liaison work across the general hospital and with professionals from community services prior to admission and at the points of discharge and assisting with the assessment of capacity to consent.

Tuffrey-Wijne et al., (2016) identified important issues regarding the role confusion in relation to carers in terms of contributing to meeting the care needs of their family member with an intellectual disability when attending or admitted to a general hospital. From their research a new model has been proposed that seeks to clarify the role of and contributions
made by carers and the extent to which they can and are able to meet the care and support needs within the general hospital environment. This is an important development given the limited value placed on the knowledge and skills of carers regarding their family members and the poor attention that is often paid to their expertise and experience or the assumption that they can and will provide all direct care and support, whether willing or not. Clarifying the nature of carer support and the contribution they wish to make is therefore an important area for the Intellectual Disability Liaison Nurse to focus on.

Intellectual Disability Liaison Nurses have an important role in facilitating the making of reasonable adjustments to care and support throughout the care journey for people with intellectual disabilities. Reasonable adjustments involve working in a way that is person-centred to ensure that the needs of the individual are assessed and met across the organisation, thereby seeking to reduce the possibility of poor outcomes and harm and improve the patient experience. From the perspective of Intellectual Disability Liaison Nurses, facilitating reasonable and achievable adjustments to care and support is a central component of the role enabling access to information; advising on the making of reasonable and achievable adjustments to care and the care environment; working with carers and professionals in general hospitals to identify care needs and promote person-centred care throughout the care journey and advised on the use of specialist assessment tools and resources, such as DisDAT to assessment for distress (MacArthur et al., 2015; Regnard et al., 2007). Many of these adjustments are cost-neutral and can be easily achieved with little additional time and effort, yet they can make a significant difference to the care experience of the person with intellectual disabilities and their family.

From the perspective of people with intellectual disabilities, their families and carers and the professionals in general hospitals, Intellectual Disability Liaison Nurses are viewed as making a valuable contribution in achieving person-centred outcomes (Brown et al., 2016). The Intellectual Disability Liaison Nursing role is valued for the expert knowledge about the wider, specialist care and support needs of people with intellectual disabilities and for the role in developing effective communication and care systems within the general hospital environment, thereby promoting person-centred care (Brown et al., 2012). However, it is recognised that the role is complex and challenging with the possibility of tensions between the competing demands of supporting clinical care, meeting education and professional
development needs and working strategically across care systems and boundaries, in and out with the general hospital (Brown et al., 2012).

Central to the role of the Intellectual Disability Liaison Nurse is direct work with people with intellectual disabilities, their families and carers and other professionals. The aim being to ensure that support needs are identified and plans put in place to ensure that care is both safe and person-centred:

- Pre-attendance assessment and care planning.
- Assessment, advice, support and education during attendance.
- Discharge planning assessment and care coordination and aftercare support.

Additionally, the Liaison Nurse may undertake wider roles including the development and delivery of education programmes about the health and care and support needs of people with intellectual disabilities, working with services such as primary care, care providers and social work to ensure that the attendance at a general hospital is smooth and efficient and to support the development of new networks that enable communication, coordination and collaboration across agencies. Another area where the knowledge and skills of the Liaison Nurse can be exploited is in collaborating and facilitating in service review and evaluation, clinical audit and standard setting and the development, implementation and evaluation of care pathways and strategies aimed at improving care and the patient experience (Castles et al., 2014; Brown et al., 2016, 2012).

### 7.6 A practice example

Sean is 45 years old and has Down Syndrome and a moderate intellectual disability. He lives in supported living accommodation in the community which has 24-hour on-site staff support. Sean moved to the supported accommodation as part of his planned transition from his family home due to his mother’s increasing care needs; she wished to see Sean ‘settled’ and happy in his own home. Sean attends a work placement in a garden centre 4 days per week and participates in a range of community activities in his local area where he is well known.

From a health perspective Sean has hypothyroidism and takes Thyroxin tablets orally. Overweight, he was diagnosed with diabetes which is controlled by diet and Metformin medication, with a support plan in place to encourage increased physical activity. Sean’s family and key worker noticed that in recent months he has become forgetful and confused at
times, forgetting where he has left things and where he is, which has left him anxious at times when in unfamiliar settings and situations. He has been referred by his GP for a clinical psychology and psychiatric assessment from the specialist intellectual disability team.

At a routine health check undertaken by Sean’s GP, it was noticed that he has developed a cataract in his right eye which has started to affect his vision and confidence. He has been referred by his GP to his local general hospital for assessment for cataract surgery. His key worker made a referral to the Intellectual Disability Liaison Nurse prior to Sean’s attendance for assessment at the general hospital.

Reflecting on the case scenario about Sean and his family, consider the following points and the actions necessary to facilitate and enable his care and support:

**Pre-attendance assessment and care planning**
- Identifying the pre-attendance assessments and information that needs to be gathered by the liaison nurse – who from and how it will be used to inform care.
- Identifying the people and agencies that the Liaison Nurse will need to liaise with to ensure that there is effective communication, coordination and collaboration before attendance.
- Identifying potential issues related to capacity to consent to investigations and procedures and assessments and required and the sharing of information.
- Identifying the reasonable adjustments that may need to be made to before Sean attends the general hospital for assessment, interventions and procedures.
- Identifying Sean’s his families, carers and professional’s education and support needs.

**During attendance**
- Identifying and coordinating assessments that may be required during Sean’s attendance in the general hospital.
- Identifying the information necessary to ensure that Sean’s care episode is both safe and person-centred.
- Identifying to whom information about Sean’s care and support needs should be communicated too.
- Identifying how Sean’s family and home-based support workers can, if they wish, be involved in his care and support.
- Identifying the reasonable adjustments that may need to be made to the care environment to ensure that Sean’s care needs are met in a way that is both safe and person-centred.
- Identifying Sean’s, his families, carers and professional’s education and support needs.

**Discharge planning and care coordination**
- Commencing the discharge planning process before or shortly after admission to ensure a smooth coordinate process.
- Developing an individual discharge planning checklist of all the activities that need to be completed prior to discharge and ensure that information is shared and communicated effectively.
• Liaising with the person with intellectual disabilities regarding their discharge and support needs, such as pain relief and increased assistance with personal care.
• Liaising with family members regarding discharge arrangements and agree their on-going involvement if indicated.
• Liaising with residential care staff to ensure that changes in care needs are communicated and plans developed to meet on-going care needs.
• Liaising with ward staff, primary care, community services and family and carers to ensure that discharge plans are in place and coordinated.
• Liaising with ward staff prior to and up to the date of discharge to ensure that the patient is 'fit for discharge' and the necessary supports are in place.
• Liaising and coordinating follow up appointments and further investigations.

7.7 Conclusion

There is a growing evidence-base of the significant health needs and inequalities experienced by many people with intellectual disabilities which impact on their health and well-being and quality of life. Concerns have been identified that some people with intellectual disabilities are at risk when attending or admitted to a general hospital from poor care that contribute to their avoidable and premature death. Intellectuals Disability Liaison Nursing roles have been developed in many general hospitals to ensure that people with intellectual disabilities, their families and carers and practitioners in general hospitals have access to knowledgeable and skilled practitioners about the specific needs of this often vulnerable group of patients. It is important to recognise that establishing intellectual Disability Liaison Nursing posts within general hospitals is only one element of a range of initiatives that need to be in place. General hospital services also need to ensure that there are policies, procedures, care pathways and education in place that takes account of reflects the needs of this population. By addressing these issues, there is the opportunity to ensure that care is both safe and person-centred.
Chapter Seven References


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CHAPTER EIGHT

Networking in practice

Professor Ruth Northway

8.0 Introduction

Networking has been identified as an important strategy required by nurses and nursing (Nicholl and Tracey 2007). However, what it is, what is its relevance for nursing, and what does it look like in the context of intellectual disability nursing practice? These are the questions that this chapter seeks to address as it aims to assist you to develop your networking techniques and to use them to enhance your practice and professional development.

8.1 What is networking

In a business context networking is often seen viewed as a strategy that is used to gain career advancement or to increase sales and hence it may be associated in people’s minds with individuals who are seeking to serve their own interests. Perhaps the image that comes to mind is one in which an individual seeks an introduction to another not because of who that person is but because of what they may be able to do for them or who they might be able to introduce the individual to. Alternatively there is the image of the individual who, finding themselves in room full of new acquaintances sees this as an opportunity to aggressively introduce themselves to everyone, tell them about their many achievements and to push their business card into everybody’s hands. Neither of these images are ones which many nurses would feel comfortable with probably feeling that such behaviour is just self-serving and at odds with the professional values that they seek to uphold.

It would be misleading to argue that networking is not about personal and professional development but there is more to it than just this. Grant (2013) acknowledges that networking has negative connotations for many people but also argues that, since we come into contact with a range of people with different areas of expertise and interest in both our personal and professional lives, ‘turning to these people to exchange help, advice and introductions’ seems sensible. There is one word in this phrase that sums up the difference in this approach namely
‘exchange’. Rather than seeing networking as simply a one way relationship in which one gains at the expense of the other the notion of exchange implies that the relationship is two way with all parties both giving and receiving. Grant’s approach also acknowledges that, since we all have differing knowledge and skills then there is much to be gained from sharing our different perspectives. In the context of nursing this is very important since our experience and expertise alone may not be sufficient to address many of the issues and challenges faced by those we support. We need to work collaboratively with others and this requires that we have developed effective relationships with them: networking is an important part of developing such connections.

In a similar vein Nicholl and Tracey (2007) suggest that networking:

‘…is a long term project that involves building connections or relationships with people that can help each other’

What this view adds is that networking may not be a ‘quick fix’ but rather is something that requires us to invest in over time. However, but the outcome of such an investment can be beneficial to a range of people including those who use our services. This approach may be therefore be something that nurses may feel more comfortable with and hence its relevance to nursing is worthy of further exploration.

8.2 Why is networking important for nurses and nursing

As noted in the introduction to this chapter Nicholl and Tracey (2007) suggest that networking is an important strategy required by nursing to maintain and enhance its professional position in the context of current healthcare challenges. Such challenges include changing demographics, technological advances, financial constraints and increased demand for services leading to numerous changes in both policy and service provision. In this context effective networking can ensure that the views, knowledge and experience of nurses informs the process of change, that strategic alliances can be formed, and that nurses are able to advocate for those they support.

Jain et al., (2011) argue that the personal and professional relationships developed through networking are some of the most effective means of enhancing patient care as well as enabling nurses to influence the healthcare agenda at local, national and international levels. A number of specific benefits have been therefore been identified within the context of
nursing including professional development through the provision of opportunities for education and research, sharing ideas and reducing duplication of effort which is particularly important in times of economic constraints (Coates and Fraser 2014). Adegbola (2011) adds that it can enable the development of relationships at a variety of levels to solve common problems, it can build relationships with other professionals, it can enhance both professional identity and ‘survival’ and assist in developing global partnerships. She also suggests that it can help nurses to meet their desire to assist and promote the development of others: the reciprocal nature of networking that was highlighted above.

Networking is not, however, without its challenges. Some of these may be personal as not everyone feels comfortable with the idea of developing such relationships with others – what might be referred to as the ‘reluctant’ networker (Munz-Jones 2010). Other challenges, however, have their roots in organisational issues such as networking not being viewed as an effective use of resources when such resources are limited leading to difficulties with prioritising networking within already overloaded work schedules (Coates and Fraser 2014). Intellectual disability nurses have long been regarded as being able to work in partnership with others and hence to effectively network at a range of levels (Northway et al., 2006). Indeed Networking in Learning Disability Nursing: A Guide (Jill Rogers Associates 1999) noted that the importance of making and maintaining contacts with others, on both a formal and informal basis, had been recognised by many intellectual disability nurses when seeking to address the challenges they had faced over the previous two decades. Networking in this field of nursing therefore has a long history and tradition. The continued importance of this was noted in the United Kingdom Learning Disability Nursing Strategy Strengthening the Commitment (Scottish Government 2012). In particular networking was seen as important to promote the sharing of best practice and to advance the profession.

Writing specifically about intellectual disability nursing Horan and Brown (2009) argued that networking had become an essential component of professional practice within this field of nursing. Many of the benefits they identified mirror those discussed as pertinent within the wider profession of nursing namely providing a means of keeping up to date with current evidence, an opportunity for sharing of best practice, and a strategy through which policy development and implementation can be influenced (Horan and Brown 2009). Jain et al., (2011) argue that within nursing networking can be a helpful ay of developing professional identify. This would appear to have particular relevance for intellectual disability nurses since
this nursing speciality does not exist in many countries and its continuation as a field of nursing practice has been challenged a number of times. A further reason why networking is important within intellectual disability nursing has been identified by a number of authors as being due to changing patterns of service provision which mean that such nurses may often work in diverse settings and in relative geographic isolation from their peers (Abdulla et al., 2013; Horan and Brown 2009; Jill Rogers Associates 1999). Finally Abdulla et al., (2013) argue that networks, particularly those facilitated by social media (see comments below) provide an opportunity for people with intellectual disabilities, their families and professionals to communicate and that this has great potential in terms of improving nursing practice.

It is also important to remember that people with intellectual disabilities and their families may require support from a number of different professionals and agencies. As a practitioner it is therefore essential that we are aware of who can offer what, and where and who to go to secure support that may be required. A failure to do this can mean that people with intellectual disabilities experience a lack of appropriate support or support that is poorly coordinated. Development of our professional networks is therefore an essential foundation for providing effective and timely interventions that meet the needs of those we support. Whilst empirical evidence as to the effectiveness of networking within intellectual disability nursing is limited (Horan and Brown 2009) there would appear to be great potential for it to enhance our practice. It is important, therefore, to explore strategies than can be used to develop our networking skills and to extend our professional networks.

8.3 How can ID nurses develop their networks?

Jain et al (2011: 2) note that effective networking is something that requires ‘significant but manageable up-front investment’: it is not something that will ‘just happen’ and thus we need to adopt a strategic and conscious approach if we are to derive maximum benefit from our investment. However, if networking is an approach through which we can promote better care and support others, whilst also facilitating our own personal and professional development, then such an investment would seem worthwhile and a number of strategies are available to assist us in this process. Figure 1 below sets out a strategic approach to networking and each of these stages will be explored in turn.
A strategic approach requires that we are clear about what we want to achieve and that we have a plan for how we will reach our goals. Our starting point therefore needs to be careful consideration of what our aims are in networking and who do we want to network with: one will inform the other. For example if we are seeking to increase our awareness of whether colleagues elsewhere are using a particular intervention and whether they are finding it effective then we are likely to be seeking contacts with practitioners who are working in a similar field of practice to us. If we are seeking to better understand the current evidence base for a particular intervention then we may want to establish links with colleagues working in academic settings who may be researching in this subject area. If we want to influence a policy that is currently in development then we may seek to link with policy makers or to form alliances with other key stakeholders in the process.

Remember, however, that networking should be a reciprocal relationship and hence it is also important to consider what you can bring to any potential relationship. This could encompass a wide range of things such as particular knowledge, clinical experience, links with professional organisations, or specific skills. For example if we return to the situation above in which you want to increase your awareness of whether colleagues are using a specific intervention you will bring your interest in their work but you might also bring the offer of implementing the intervention in your area, of learning from, and supporting each other. In
the policy arena imagine a policy which seeks to change an aspect of healthcare provision which could potentially have a negative impact on people with intellectual disabilities – you could bring your experience of supporting people with intellectual disabilities over a number of years to access health services and knowledge of the barriers that they can face in order to advocate against such a change.

Depending on your aims then there are a number of strategies that can be used to develop your networks. First there are the face to face methods in which you meet with people directly via opportunities such as meetings, visits and conferences. For some intellectual disability nurses these opportunities arise regularly within their everyday work but for others they have to be sought. You might, for example, look for conferences that are being held that will both enable you to update your knowledge but which will also enable you to network with colleagues working elsewhere or people with intellectual disabilities and their families. You could also look out for opportunities to join key committees to both enhance your committee membership skills and to widen your networks. Professional organisations and networks can often be a good starting point for developing such relationships.

Journals can also be a useful starting point for extending your networks. For example many journals include letters sections in which you can either respond to issues that have been raised within the journal (or more widely in the profession) or where you can raise an issue yourself and/or seek information and contacts from others. There may be a paper published in the journal that has a particular resonance for you or about which you would like to know more. Many journals now publish the email addresses of authors which make it relatively easy to contact them or you can use an on line search engine to find their contact details. You may even wish to write something yourself for publication which could be anything from a brief opinion piece to a full article – if you do you may be surprised at how many people contact you thus extending your network.

Today making links with others – even those the other side of the world – has been made so much easier with the advent of social media. Even if you are someone who does not ‘do’ Facebook, Twitter or LinkedIn then most will have access to an email account which means that you can make contact with others and exchange information very quickly. Using social media can also be a cost effective approach compared with other strategies such as conference attendance which can be expensive and hence not accessible for some.
For those of you who do use social media there are a growing number of groups and activities that you can link into to extend your professional knowledge and networks. Facebook has a number of groups that are aimed at intellectual disability nurses and these enable both requests for assistance and a sharing of information – the reciprocal nature of networking. A few examples of such groups are given in Table 8.1:

**Table 8.1: Some Facebook Groups Aimed at Intellectual/Learning Disability Nurses**

<table>
<thead>
<tr>
<th>Facebook Group</th>
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<tbody>
<tr>
<td>Learning Disability Nurse.com</td>
</tr>
<tr>
<td>Positive Choices</td>
</tr>
<tr>
<td>Positive Commitment – a partner to Positive Choices</td>
</tr>
<tr>
<td>LD Nurse Research</td>
</tr>
<tr>
<td>LDnursechat</td>
</tr>
</tbody>
</table>

Twitter can offer a very useful way of keeping up to date with key developments in policy, practice and research. You will find that if you follow key people and groups then they will regularly post about these areas meaning that you can keep up to date with current issues. Many journals also regularly tweet details of new papers that are published enabling you to be aware of current research. Conferences increasingly use social media such as Twitter to enable those not able to attend in person to be aware of what is going on there and the key issues that are being discussed. For example in August 2016 the Word Congress of the International Association for the Scientific Study of Intellectual and Developmental Disability (IASSIDD) asked delegates to use #IASSIDD16 on all of their tweets from the conference so that other people would be able to follow. If you go to Twitter now and search for #IASSIDD16 you will still be able to see the tweets from that event and be aware of the range of research that was presented.

Another way that Twitter can be used to extend your professional networks and knowledge is by joining in what are referred to as ‘Twitterchats’. In these events a topic is set, a time is advertised (usually they last an hour), and someone moderates or leads the discussion. In some instances some specific questions are posed and these are posted before the chat. During the hour anyone has the opportunity to contribute and thus people (sometimes from across the globe) are able to come together to discuss key issues. Throughout the chat a hashtag (#) is used in all responses so that conversations can be followed and often a transcript is made available following the chat so that it is possible to see all the comments made during the discussion. If you are not yet a user of Twitter this may all seem a little confusing – if it does help is at hand as We Communities have very helpfully created a guide for those new to
Twitter. Referred to as Twiterversity it can be accessed by following this link http://wecomunities.org/resources/twiterversity. Further helpful information for those new to Twitter is also provided within the paper by Abdulla et al., (2013).

Within the We Communities there is a specific group aimed at learning (intellectual) disability nurses and their Twitter address is @WeLDNurses. Established in 2012 this group was developed to discuss:

- Best practice
- Problem solving and
- Professional Development (Abdulla et al., 2013)

Table 8.2 provides some starting points for people and groups to follow if you are new to Twitter.

**Table 8.2: Twitter accounts to follow**

<table>
<thead>
<tr>
<th>@WeLDNurses</th>
<th>- connecting learning disability nurses. Talking and sharing with everyone with a passion for learning disability care</th>
</tr>
</thead>
<tbody>
<tr>
<td>@WeNurses</td>
<td>– connecting nurses to share information, knowledge and support to improve patient care</td>
</tr>
<tr>
<td>@PCConf</td>
<td>– Positive Choices is a yearly conference to support learning / intellectual disability nursing students</td>
</tr>
<tr>
<td>@EINursingBMJ</td>
<td>– helping nurses and midwives use evidence in practice</td>
</tr>
<tr>
<td>@IASSIDD</td>
<td>– world-wide group dedicated to the scientific study of intellectual disability</td>
</tr>
<tr>
<td>@JoIDSAGE</td>
<td>– the Journal of Intellectual Disabilities promoting the exchange of best practice, knowledge and research</td>
</tr>
<tr>
<td>@JIDR_Wiley</td>
<td>– the Journal of Intellectual Disability Research</td>
</tr>
<tr>
<td><em>JARID</em></td>
<td>– the Journal of Applied Research in Intellectual Disabilities</td>
</tr>
<tr>
<td>@jadvnursing</td>
<td>- the Journal of Advanced Nursing</td>
</tr>
<tr>
<td>@jclinrnursing</td>
<td>– the Journal of Clinical Nursing</td>
</tr>
</tbody>
</table>

When using social media it is, of course, important for nurses to remember their professional and ethical responsibilities (Levati 2014) since whilst these developments open up tremendous opportunities their very public nature can also bring potential dangers that need to be recognised and avoided. It is for this reason that the Nursing and Midwifery Board of Ireland (2014:7) state in their Code of Professional Conduct and Ethics that ‘You should be aware of your professional responsibility when using social media’. This means using social media in a professional and responsible matter recognising that you are accountable for your actions and for acting with integrity.
8.4 Conclusion

This chapter has argued that networking is an important strategy for nurses and nursing and that it has a particular relevance in the context of intellectual disability nursing. Whilst it is helpful in developing our own professional careers and the wider profession of nursing, most importantly it is a strategy that can improve professional practice and hence the support that is offered to people with intellectual disabilities and their families. However it is not something that just happens – we need to consciously invest time and effort over a period of time. This may seem daunting but it is something we can (and should) all do: hopefully this chapter has provided you with some strategies to try. In conclusion remember the words of Adegbola (2011) and resolve to start extending your networks today:

‘Each day plant seeds in your network relationships. The rewards you reap will exponentially increase the harvest of your benefits. The key is to plant seeds and take deliberate actions every day’.
Chapter Eight References


Nursing and Midwifery Board of Ireland (2014) *Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives*, Dublin: NMBI.

CHAPTER NINE

Disability Perspective in Rural Malawi

*Suzanna Weedle and Eloise Sheerin*

### 9.0 Introduction

Following the second year of our BSc degree in Intellectual Disability Nursing, we travelled to volunteer in Malawi in order to explore disability within a different cultural context and to see what benefit our skill set could bring to this environment. This chapter presents a personal reflection of our experiences, which we have contextualised in the relevant literature, where possible. Malawi and Africa in general, is largely portrayed as a country in need in the media, fundraising campaigns and imagery used to represent it. Despite possibly altruistic intentions, this has led to the creation of a desolate image of Africa as a land in need of saving. However, the reality we came to know was vastly different to our inherent preconceptions. Our experience came as part of a Canadian-Irish project, *Transformative Praxis*, which has been engaging with people in the Chilanga region of Malawi for five years, using a tripartite approach of participatory action research, knowledge transfer and agency/resource support. This project, directed by Prof. Christopher Stonebanks of Bishops University, Canada and co-directed by Dr. Fintan Sheerin of Trinity College, Dublin, involves students from education, development and health backgrounds working on small research-oriented projects in conjunction with local Malawian co-learners.

### 9.1 Students volunteering in Malawi

Being an *azungu* (‘white person’ in the local dialect) in Malawi was undoubtedly a challenging experience. The usual assumption is that people will take you at face value, for the individual you are. However, we all come ingrained within a cultural context; our upbringing and the environment that shaped us have a substantial impact on our innate perceptions and biases. We believed ourselves to be independent beings, hoping to engage with people from another culture to collaboratively work towards social change. Yet we soon came to understand that our skin colour alone was inextricably linked to a history steeped in
oppression. This was something we had no control over and was a reality we grew acutely aware of throughout our time in Malawi.

Fanon (1967: 34) poses the question “Have I not, because of what I have done or failed to do, contributed to an impoverishment of human reality?” Fanon’s question is certainly a pertinent one, especially considering Malawi’s history of colonisation. Memmi (1974: 53) presents us with some interesting insights into the process of colonisation and states that the coloniser not only “succeeds in creating a place for himself but also in taking away that of the inhabitant, granting himself astounding privileges - to the detriment of those rightfully entitled to them”. This was potentially the context within which we were viewed. Thus, we personally may not have felt we had done wrong by the people we encountered but we were members of a race which had significantly contributed to an impoverishment of their reality.

We had to be careful that we were not complicit in the exacerbation of this oppression. Young (1990) propounds that oppression can refer to people experiencing injustice because of the daily practices of a “well-intentioned liberal society” (Young 1990: 41). Thus altruistic intentions did not necessarily preclude us from holding the title of oppressors. There was a tendency among the Malawian people to acquiesce to anything we said, as if our opinion was in some way superior to theirs. Memmi (1974: 53) believed that the coloniser achieves goals by “upsetting the established rules and substituting his own”. Therefore this passivity may have stemmed from their experiences of colonisation. This meant that even conversational dialogue was a complex process. Phrasing and terminology suddenly held so much more meaning. In nursing we are trained to be reflective practitioners, a skill deemed to be a crucial component of health care delivery (Mann et al., 2009). The aim of the reflective process is to critically appraise one’s own thoughts and actions, developing greater self-awareness (Knight 2015). In Malawi, this process was crucial. We had to think about what we were going to say and deliver our message with precision, in case we in any way manipulated their opinions. People would also frequently beg us for money. Again there was an assumption that we were wealthy, superior and powerful. How do you tackle something so strongly ingrained? How do we create an environment where these people no longer felt inferior but worked alongside us as equals? Freire (1993: 45) believes “true generosity lies in striving so that these hands – whether of individual or entire peoples – need be extended less and less in supplication ….”. Yet here were human hands reaching out and begging. There was such powerful dehumanisation evident. The charity’s ethos was to create projects that were meaningful to the
Malawian people, to bring about changes that the people themselves felt were valuable. However, the inherent compliance among the Malawian people meant that not imposing Western viewpoints or standards was a significantly more complicated endeavour than we had anticipated.

Our co-learner for the duration of the trip was Grace Saka (name used with permission), a local woman with a vested interest in both health and disability within her community. With Grace we commenced our search for answers about what it was like to have an intellectual disability in rural Malawi. We had attempted to review the literature on this topic prior to our arrival but there is a dearth of literature published regarding the experiences of people with intellectual disabilities in Sub-Saharan Africa. What has been written, notes a broadly negative contextualisation and stigmatisation of such people (Njenga 2009; Abasiubong et al., 2008; Braathan and Kvam 2008). When we arrived in Chilanga, it also became clear that there was a lack of formal diagnosis within the region, thus the degree and cause of intellectual disability in the community was often speculative. On discussing this topic with members of the local community we found varying opinions on causes of intellectual disability, prevalence rates and available services. Despite these opinions, people with intellectual disability seemed to be largely invisible and so Grace suggested that we might start by visiting the local school for children with visual impairments.

We talked to the headmaster and two teachers within the school and found their thinking to be very progressive. This was evident in the ethos of the school and in their teaching techniques. All adaptations and accommodations had been made for the students in line with government recommendations. These included a football with a bell in it, wooden handrails for guidance, the use of brail and constant verbalisation, while teaching, to ensure all students were engaged. We were quite surprised by these inclusive adaptations. The fact that we were surprised at the progressiveness of the school aroused strong feelings of dissonance within us as we came to terms with our own innate cultural preconceptions. The school operated a system of reverse integration. This meant that children without visual impairments also attended the school because of its reputation for high academic achievement. This was such a thought provoking concept. In Ireland, the focus is on integrating children with disabilities into the mainstream education system, but here the ‘special’ school is seen as superior to some of the mainstream schools. Classes were mixed and the ‘sighted’ students helped and
guided their peers with visual impairment both in the playground and in the classroom (Sheerin and Weedle 2015).

Becoming a teacher for people with visual impairments in Malawi requires specialist training beyond completion of the primary teaching diploma. There are three main specialties of teacher in Malawi: those for people with visual impairments, people with hearing impairments and people with intellectual difficulties. Becoming a specialist teacher is extremely expensive and an unattainable reality for many people, leaving a gap in educational provision for people with disabilities. Furthermore, we encountered people who fell outside these categories and for whose needs the system could not respond. A theme that was evident from the meetings we held with the community and the educators was the paucity of intellectual disability teachers. We also visited a mainstream school and met a special needs teacher. Some of his students with intellectual disability attended mainstream classes, complemented with a few hours of resource teaching per day or week. Yet others were permanently facilitated for in a separate resource class. Although he held very progressive ideals about education for people with disabilities, he was concerned about the lack of specialist preparation and of resources (Sheerin and Weedle 2015).

While engaging dialogically with the teachers from both schools, a suggestion emerged about the potential benefits that sharing knowledge could bring. Once again, we noticed that, despite being students, we were viewed as azungu (white persons) and considered to be experts with all the knowledge and answers. We tried our best to instead be enabling facilitators but there was, at times, an expectation that we would organise and undertake the tasks. In line with the teachings of Freire (1993) we sought to employ dialogue as the method by which knowledge could be transferred between all participants to the discussion. We constantly feared that our ideas would be accepted as the most valid ones. Regular discussions with our academic leaders allowed us to consider our roles in a critical way. Every action we took needed to be empowering and sustainable; it needed to avoid being dependent on input and resources (charity) from outside the local community. The outcome of this approach was that the specialist and mainstream teachers decided to collaborate in order to share ideas and teaching techniques so that people with intellectual disability could receive better education regardless of the availability of a specialist teacher within their village. We were thanked by the teachers for encouraging self-realisation rather than imposing our views. It is our hope that this effort,
which has continued since our departure, will facilitate positive change for the pupils, teachers and families alike.

Next, we engaged with families in the local community. We had the opportunity to visit a number of families who had children with a disability, mainly intellectual disability. These families were so hospitable towards us and generously shared intimate details of their lived reality. It was a real honour to be welcomed into these family spaces. We met a mother and two of her children who had intellectual disabilities. We were struck by the power and strength of this woman who always strived for the inclusion of her children in the local community. She described how she encouraged life skill teaching for her children so that one day they could take care of themselves. She appeared to understand that in order to be valued and included in the community one must contribute. Her children learned how to cook, clean, wash clothes etc. and were observed around the village daily, carrying out tasks along with their peers. Ritzer (2011) highlighted the importance of efficiency, calculability, predictability and control as values of a society. From this perspective, the supports put in place by this mother fostered optimal integration for her children, who could now make a valuable contribution. This in turn meant that they were viewed as active members and would be more likely to be afforded the benefits of holding a socially valued role in this interdependent community (Wolfensberger 1998).

However, with community integration and promotion of independence also comes heightened risk. This mother spoke at length about her concerns around safety. She feared that her children may fall victim to crime, abuse and/or exploitation. Although this is a sentiment mirrored by any parent, it is particularly pertinent for parents of people with intellectual disabilities. Furthermore, the mother spoke of high crime rates in the locality, which only served to exacerbate her fears.

We had great admiration for the lengths people went to in order to achieve an outcome. One mother described the struggle she faced with feeding one of her children due to his difficulty in swallowing the staple food ‘Nsima’ (ground corn). Corn was the main food grown and harvested by the local families and so it was a crucial food source. This mother understood that the sticky, starchy texture was difficult for her son to chew and swallow effectively. In an environment where professional support was not available, she succeeded in resolving the
issue independently. She would use sauces or broths to achieve the exact consistency of food so that he was able to tolerate swallowing it. This was a lengthy process yet figuring out these solutions was simply a necessary part of her everyday life. The resourcefulness among the Malawian people was compelling.

Stigma was also a recurring theme and pervaded many aspects of people’s lives, whether in school, at home or in the local community. The effect of such ‘marking’ has been highlighted elsewhere in the Western world and its effect in relation to marginalisation is well recognised (Wolfensberger 1972). Bullying was a frequent occurrence for children with intellectual disability attending school. Parents indicated that teachers often did not know how to deal with this and schools typically did not have an anti-bullying policy. This led to high dropout rates among students with a disability.

Despite the reliance on community support, some families also spoke of the distancing that accompanied having a child with a disability. Thus, people were expected to take ownership of the ‘problem’ and the responsibility of managing it lay with the family. This, coupled with a culture of not discussing complex issues with others in the community, led to overwhelming strain on the family unit and isolation within the community in some instances. The family members we met also told us that accessing and affording school transport were core issues and that the need for a parent to bring their child to and from school meant that they could not work. This lead to further feelings of isolation as the carer could no longer participate in community duties, a key component of community cohesion. Parents spoke of the difficulties in physically carrying their child over long distances, when the child could not walk. Some people were fortunate enough to have a wheelchair but if this broke they could not get to school. As a result of this a boarding school was deemed to be a preferable option but was often too expensive for families who were just subsisting.

There is a national support network for people with disabilities and their families in Malawi, the Federation for Disability Organisations in Malawi (FEDOMA). However, the families that we spoke with stated that there was no support from government or non-governmental organisations for people with intellectual disabilities specifically in this region. There was some assistance available in certain schools but most people could not access these specialist services. They made it clear that they would greatly value the presence of a disability support
group there. However, networking is challenging, as disability is not openly discussed and so, many families did not know of others around them who experienced disabilities.

Family members expressed fear of what would happen to their loved one with intellectual disabilities, should they themselves die. We can see these sentiments expressed in the Irish context, where the primary carer may become elderly and incapable of caring for the person with an intellectual disability. This leads to fears about the future and the relinquishing of care to a service. In Malawi, the fear surrounding the death of a carer is rooted in survival. Their main concern is whether or not the family has enough community connections established so that the individual can be supported. This again highlights the fundamental interdependence required in this context. We observed situations whereby people were cared for by other members of their community when a family carer died. This mutual understanding of the essence of community among the Malawian people enlightened us and made us reflect on the situation we are faced with in Ireland. Here people with intellectual disabilities are being moved from the once deemed appropriate institutions to community living (HSE 2011). This results in care provision moving into the family and community space. Given the history of mass segregation of people with intellectual disabilities in our society (Sheerin 2011), this is a concept which we are currently trying to rediscover. Perhaps this ethos in these Malawian communities is one that we ourselves could emulate. We questioned our significance and our preconceived assumptions within this context. Did we really have much to offer this community?

In Intellectual Disability Nursing the exploration of alternative communication techniques, such as Intensive Interaction, is a core component of clinical practice. Intensive interaction is “an empirically researched approach to developing fundamental communication and sociability for people with severe and profound learning disabilities and/or autism” (Firth 2009: 43). One of the local women we interviewed had a seven-year-old son, Bless (name used with permission), who could not verbally communicate. A prominent theme while speaking with her was the difficulty she had in communicating with him. On observing Bless in his environment we assessed whether intensive interaction would be an appropriate means by which this mother and son could communicate and bond. Bless showed clear understanding that his actions could influence us; that his actions had reactions. We spoke with her about intensive interaction and she expressed great interest in learning this technique.
We demonstrated the approach to her and conducted a training session. Our Malawian co-learner also took part in the training and translated instructions in Chichewa for the mother, supporting her in implementing this technique herself. Sustainability was always our aim and embedded into all we did. Therefore, we used locally sourced materials to stimulate various senses during the interaction. Bless was very responsive and immense potential was evident as he began to engage more with the world around him and gradually evolve from the self-stimulating world he had created for himself. Many members of the community, as well as his family, observed this interaction and so he was able to demonstrate ability in front of his community.

Bless also experienced lack of mobility. With no wheelchair available, his mother was essentially housebound and unable to work, nor could she bring him anywhere to access education. We wanted to support by paying for and providing him with a wheelchair, however, this posed various challenges. We were acutely aware that anything that came from an ‘azungu’ would not be valued in the same way as it would have if it had come from the local Malawian community. We were advised that given that we may potentially be viewed as oppressors in this environment, anything we contributed may not be respected and could be sold for parts or stolen. If it came from another Malawian community, it would be held in much higher regard. Furthermore, if we were to donate a wheelchair it would serve to exacerbate the existing power imbalance between ‘us’ and ‘them’. The approach needed to be sustainable, drawing on local resources and using local materials and labour. We also wished to promote altruism within the community, something which was suggested by local collaborators to be quite unusual there. As a neighbouring village, Makupo, had access to a development fund, we inquired as to whether the community would be open to investing in a wheelchair for him. The community immediately took on the initiative and sourced a wheelchair which was constructed by a local welder. There were also discussions about continuing this initiative annually, with the community choosing someone in their locality to support each year.

The concept of praxis can be hugely intimidating. However, it was a liberating experience for us to be able to apply theory from our programme in a situation where our profession did not exist. It became clear that the knowledge and skills of intellectual disability nursing are
culturally transferable, especially in areas where need is high and significant benefits can be reaped from the application of those skills and knowledge.

Collaborating with other students from different backgrounds provided a learning environment that was conducive to critical thinking and reflection. We engaged in dialogue with our fellow students about the similarities woven through all our professions. Sociology, community development, education and health; these are all diverse and different fields yet we all shared the vision of social inclusion. As Intellectual Disability Nurses, we hold inclusiveness as paramount in our practice. We realised that we have been taught a skill that allows us to instinctively think inclusively. This quality integrated well into the projects of the other students and allowed us to facilitate the integration of disability perspectives into these projects. For example, we discussed the targeting of stigma in the curriculum being developed by the education students and their co-learners.

People with intellectual disability and the people we met in Malawi both share a history of oppression and power struggles, many of which still exist to this day. Has society created a culture of subservience among people with disabilities, just as colonisation has done among the Malawians? Disability services are making an effort to move from biomedical to socio-educational, from institution to community and from disability to possibility (Sheerin 2004) and projects like Transformative Praxis Malawi are attempting to use progressive approaches to tackle this historic injustice.

9.2 Conclusion

Our time in Malawi has been a formative element of our professional development as intellectual disability nurses. This experience has deepened our knowledge of collaboration, dialogic partnerships and the quintessence of community engagement. It has also strengthened our cultural competence and allowed us to step into the margins and enable the oppressed to assume leadership roles. Ultimately, this praxis approach showed us that meaningful change is an achievable reality.
Chapter Nine References


CHAPTER TEN

Disability in Belarus: Enhancing Practice through Experiential Learning

Suzanna Weedle

10.0 Introduction

This chapter presents the experiences of a final year student studying to become a Registered Nurse in Intellectual Disability (RNID) of volunteering in Belarus. This experience is based on working with two charity organisations and five individual experience of volunteering to work in Belarus. The most recent charity, Chernobyl Children’s Trust (CCT), is a fully voluntary Irish based charity working to meet the needs of children with disabilities, as well as those from disadvantaged and contaminated areas in Belarus (CCT 2016). Within this chapter I hope to convey an insight into some of the work I was involved in with the support of this charity. My reflections are personal and by their very nature subjective, I can only speak of my own experiences and the stories that have been shared with me by the Belarusians I have encountered. My perception of Belarus on my first trip, at 16 years of age, was substantially different to my current perspective. Not only have I gained a more in-depth understanding of Belarusian culture with each visit, but my studies in the field of intellectual disability nursing, and my experience of volunteering in Malawi (discussed in another chapter), have shaped the way I approach not just disability and humanitarian work, but all human engagement. Throughout the chapter I will outline how my training as an RNID has enhanced my voluntary work with people with disabilities in Belarus.

10.1 A students experience in Belarus

Let me begin by painting a picture of Belarusian society as I perceived it. Belarus is a landlocked country in Eastern Europe. As a former member of the Union of Soviet Socialist Republics (USSR), the remnants of communism are still evident within this officially democratic State. Belarus is a land of harsh contrasts. Their climate goes from intense heat in
the summer months to temperatures that drastically plummet in the winter, creating a layer of glistening, powdery snow.

A large proportion of Belarusians work for the State, and in the rural areas this is predominantly on what are referred to as ‘collective farms’. Here you receive a basic wage and are provided with accommodation in return for long hours of manual labour in the frequently severe weather conditions. However, your home is the property of the State which means they can relocate you at any time or in fact withdraw your housing should you display any opposition to their requests.

One family I visited had 3 children ranging from 7 to 13 years old. Their father had passed away 2 years previously and their mother worked on the collective farm. Their wooden house was unbearably cold in minus 23 degrees Celsius of the winter and the children were dressed in scanty, tattered clothing. A tour of their house revealed an absence of any firewood to heat the house and all that was in their fridge was a tub of lard and a half head of cabbage. Not only was their mother absent all day, but the wages she was earning were not even enough to meet their basic physiological needs. This family is but one of many families the charity currently supports who all live in similar impoverished circumstances.

In terms of the political climate in the country, many Belarusian citizens I spoke with expressed a deep rooted sense of powerlessness and believed that voting was a futile endeavour. If you work for the State then your employment is conditional on you re-electing the current government. With the majority of citizens working for the State, a change of government is not a likely occurrence. To me, there appeared to be an inherent adherence to authority within Belarusian society. A Belarusian college student I met spoke of how she had gone to study abroad and was astounded at the audacity of students who would ask questions of their lecturer. In her home society you do not question those in positions of power and it took her quite some time to adapt to this. I got a sense that there were rather cumbersome hierarchical systems in place and that challenging these structures was actively discouraged.

Our focus in Belarus was on how disability fits into this context. For the most part the disability narrative is punctuated by experiences of institutionalisation and marginalisation. This institutionalisation of children with disabilities is, of course, a problem rife with complexity. According to the United Nations International Children’s Fund (UNICEF 2009)
around 33,000 children in Belarus are orphaned or denied parental care, the majority of whom have some form of disability. Many of these children are social orphans, in that they have at least one living parent but are under State care. High divorce rates combined with socioeconomic issues such as substance abuse and family violence (UNICEF 2009) have contributed to mass institutionalisation of people with disability within Belarus. These issues are mirrored in the World Health Organisation’s (WHO) global status report on alcohol and health in which Belarus was listed as the country with the highest alcohol consumption (WHO 2014). Furthermore, the Chernobyl nuclear reactor disaster of 1986 which resulted in radioactive contamination in Belarus led to the relocation of many families. This decimated many social support networks and left numerous families grappling with the challenge of adapting to their new environment (Igumnov and Drozdovitch 2000).

There is also an intense social stigma around disability in the country. This is not to say that every citizen has a stigmatised view of disability. A number of Belarusians work with the charity and constantly strive to create a better quality of life for people with disabilities. Their work is undeniably admirable. However, I have had a number of experiences where it was evident that having a disability involved having a stigmatised identity, a concept Goffman (1963) proffers is a common experience for all those who identify with having a disability. I witnessed one such occurrence on my first trip to Belarus. We were bringing children with disabilities from the orphanage out on a day trip to a local park. As we walked around the park, mothers would shield their children from the sight of the children from the orphanage and would quite clearly avoid being anywhere near us. In addition, most buildings and walkways around Belarus are inaccessible for people in wheelchairs, a clear indication that disability is not an integrated element of their society. Furthermore, people with disabilities are physically marginalised within Belarus with orphanages and institutions located in rural areas, hidden behind large areas of forestry and high walls, shielding them from public view. This is reminiscent of Irish society where, as Sheerin (2011: 31) highlights, “historically, the care of people with intellectual disabilities was provided in institutional services, often situated on the margins of towns or in remote rural areas”. Anecdotally many Belarusian practitioners strongly advise abortion when there is a prenatal diagnosis of disability. If the child is born with a disability, parents are frequently advised to avail of institutional care, consequently undermining their own confidence in their ability to support the child. These stories are not unlike those of many Irish parents, who in the past report being given similar
advice by professionals. In fact, globally, children with disabilities have been and continue to be at much greater risk of being placed in institutions (Gilligan 2016).

The disability model dominating many post-Soviet countries is the academic discipline ‘defectology’ (UNICEF 2012). Inherent in the model is the classification of children into educable and non-educable, whereby those deemed non-educable are destined to a life of institutionalisation (Kalinnikova and Trygged 2014). Gilligan (2016) propounds that this paradigm resulted in an over medicalised approach to disability where the individual’s ‘defect’ became the defining feature of their being. The subsequent impact of this is that disability is conceptualised by authorities and practitioners as an entity requiring treatment that is beyond the capabilities of the lay people, including the child’s parents (Gilligan 2016). This notion of professional dominance and power is a concept we are familiar with in intellectual disability nursing through our study of sociology. Professionals are often characterised as the producers and proponents of certain bodies of knowledge, which are pivotal in forming social policy and the institutions of daily life (Freidson 1986). Categorising a person as a deficit in need of rehabilitation constructs them as not like us, but ‘other’ (Nunkoosing 2011). Illich (1977) propounds that professionals claim ownership over the classification of deviance and dictate the remedies required. Foucault (1975) echoes this same concern in his criticism of the pathological ‘gaze’ of professionals, where people are only seen in the context of medical diagnosis. Thus, professional power can be influential in the societal construction of disability in any environment and the combination of this phenomenon with defectology in the Belarusian context contributing to a notable ‘othering’ of people with disabilities. In fact, UNICEF (2012) even identified defectology as one of the greatest barriers to the implementation of a human rights based approach in Eastern Europe.

Based on this context of disability in Belarus, I would like to take you through some of the work we engaged in. The first week of our volunteer programme in August 2015 was spent in a respite camp for mothers who had chosen to keep their children with disabilities at home. There are over 355,000 families in Belarus where there is only one parent and the vast majority of these are mother-headed families (UNICEF 2009). This was evident in the families that attended the respite camp. The majority of families were single parent families and it was usually the “mamas” that were left to care for the child. Respite is not a service that is provided by the state, nor do these families receive sufficient financial support from the government. To bridge this gap the charity funds year round medical support, specialised
equipment and humanitarian aid, as well as employing Belarusian nurses and physiotherapists to work with the families. Our role within this programme was to give the families a break from the strains of 24/7 care provision and enable them to have a holiday. The camp took place in a fully accessible campus that had been built by foreign charities. The entire programme was completely optional and everything was guided by what the families themselves wished to do. We would run activities for the children from face painting and tie-dying to swimming in the lake and water fights. The mothers had the option of getting their hair done by one of our fellow volunteers who was a trained hairdresser and availing of the massage therapy offered in the centre. Getting their hair done was extremely valuable to the mothers as accessing a community hairdresser with a child with a disability was a difficult feat and finding a hairdresser who would be willing to cut the child’s hair was even more problematic. The families could also get a full medical check-up in the onsite medical facility. In the mornings there were English-Russian lessons given by the translators. These helped to foster enhanced inter-cultural bonding and the inability of the Irish volunteers to pronounce the awkwardly juxtaposed consonants of the Russian language provided a wealth of entertainment for all. In addition to being a form of retreat, the camp served as a disability support group, providing mothers, who were often physically isolated in rural areas, with the opportunity to network with those in similar circumstances. The families shared their stories and together we all engaged in dialogue about what it was like to have a child with a disability in Belarus. Freire (1993: 178) propounded that “leaders who do not act dialogically, but insist on imposing their decisions, do not organize the people - they manipulate them. They do not liberate, nor are they liberated: they oppress”. Thus the dialogue with these families throughout the camp was a vital component of the charity’s work. This dialogue presented us with a means of challenging professional dominance by affirming the value of the lived experience of those with a disability and their support circle.

As well as being involved with families that have chosen to keep their children with disabilities at home, I have volunteered in orphanages and institutions for babies right up to those for the elderly population. Getting involved with these institutions presents quite a moral dichotomy. On the one hand, to engage with these institutions on some level condones their very existence. Yet without physical renovation and cultural change the current reality of thousands of people would remain inhumane. Groark and McCall (2011) grapple with a similar debate, stating that those advocating for deinstitutionalisation may perceive investment in the institutional system as a waste of resources. Sheerin (2011) also highlights
that working within the margins and then returning to mainstream society after one’s shift could itself potentially perpetuate marginalisation. However, McCall (2013) concludes that deinstitutionalisation is a lengthy process, particularly in low income countries, that is susceptible to being prolonged by a myriad of challenges such as cultural sensitivities, lack of support, insufficient resources and the potential unwillingness of families to foster or adopt a person with a disability. This means that it is likely that these institutions will still be home to a significant number of people for a substantial length of time (Groark and McCall 2011). If we comparatively evaluate this from an Irish perspective, the Health Service Executive (HSE 2011) calls for a move from congregated settings to community housing, stating that these settings are a breach of human rights. At the time of writing there were 4,000 people with intellectual disability living in such settings (HSE 2011). Furthermore, recent reports on Irish disability services by the Health Information and Quality Authority (HIQA) reveal many incidents of substandard care for people with disabilities. Evidently, ingrained within our own history and indeed within some areas of our present society is a marginalisation of people with disabilities. Therefore, this dissonance about engaging with a system which contradicts one’s own moral values is not isolated to Belarus, but is an experience potentially felt by anyone who strives to support the integration of those on the margins of society. After much internal dissonance I concluded that meaningful change requires a dual-track approach. While our overall focus is deinstitutionalisation and community development, there is certainly merit in concomitantly attempting to bring about a cultural shift within institutions to prevent human rights violations becoming an integral part of the lived reality of people with disabilities. Likewise, in Ireland, the fact that congregated settings are a violation of people’s human rights (HSE 2011), doesn’t negate the necessity of continuing to improve the conditions within them in the interim of transitioning to community care.

Following the respite camp, my fellow volunteers and I spent 3 weeks in an orphanage that was home to around 300 children and young adults with various disabilities. The orphanage had been renovated by various charities and had a physiotherapy room, a sensory room and a concert hall. It also had playrooms with shelves lined with toys. However, the pristine condition of the toys, all perfectly aligned in the rooms, was an indication that these resources weren’t necessarily being utilised. Everything in the orphanage had to be clean and sterile, so allowing the children to play with the toys correlated to an unfavourable increase in staff workload. The sensory room was also locked the majority of the time so some staff we worked with had never even seen the inside of it, despite it being there for a number of years.
Reports of the former state of the building gave us an insight into the progress that had been achieved through the work of various charities. However, it was also apparent that there was more to change than physical renovation. The greatest concern in institutional settings is the deficient psychosocial environment which can have a detrimental effect on a child’s development (Groak and McCall 2011). This orphanage became our main forum for attempting to utilise the skills we had learned in intellectual disability nursing to bring about positive change. We tried to get involved with all aspects of care within the orphanage from intimate care to assisting with feeding. We also ran programmes centred on sensory stimulation and restraint reduction (Weedle et al., 2016).

Intellectual disability nurses are trained in Multi-Element Behaviour Support, a non-aversive programme aimed at reducing behaviour and enhancing an individual’s skills and overall quality of life (Callan Institute 2010). The objective is to gain an understanding of why the behaviour is occurring, of what the individual is communicating and of how their environment is influencing their behaviour. The model incorporates both proactive and reactive strategies of supporting someone with behaviours that are deemed ‘challenging’ (Baker et al., 1998). This clinical skill proved useful in the orphanage setting. Many children and young adults were restrained in various manners using pieces of cloth. Some were tied to beds or wheelchairs, while others experienced having their arms tied down (Weedle et al., 2016). The motives behind the use of restraint are of course multifaceted and we can only draw on the individual accounts of the people we engaged with and our own speculation to uncover what the reasons for their use were. Perhaps it was the low staffing levels in the orphanage where staff were overworked and underpaid. Maybe there was low staff morale stemming from a society that does not necessarily value work with people with disabilities. It could have been a lack of knowledge about the psychological impact of restraint due to the fact that staff in the orphanages receives no formal training. For some staff, restraint was seen as a means of protecting a child who had self-injurious behaviour or was at risk of falling from their bed. It could also be the fact that restraint, combined with an unresponsive environment, caused some children to withdraw into themselves. This meant that the use of restraint was more convenient for staff who may not have had the time, or desire, to engage with these children and young adults. In fact, many staff members appeared quite disengaged from those in their care. Regardless of what caused the staff to restrain the children, restrictive practices can be hazardous interventions that can impinge on an individual’s fundamental right to freedom (HIQA 2014). Furthermore, Ware (2003) proffers that an unresponsive
environment can stifle a child’s development and that every human being, regardless of age or ability, deserves to be afforded the respect and dignity that a responsive environment embodies. Thus, the reduction of these restraints and the creation of a more responsive environment was a priority for us.

The person who was most heavily restrained was an 18 year old girl I will call Ireena for the purposes of this case study. She is non-verbal and has a severe intellectual disability. She was completely immobilised by restraints. One piece of cloth secured her neck to the top of the bed, another tied her leg to the bed rail and her long sleeved top would be pulled down over her hands so they could be tied together beneath her other leg. She also frequently had a hat pulled down over her face. When questioned about the rationale behind Ireena’s restraint, staff reported that she was too aggressive to be untied.

We had to operate within the hierarchical system of the orphanage in order to achieve any progress otherwise we risked being denied entry to the institution, consequently restricting any chance of change. Therefore we agreed a programme with the doctor of the orphanage whereby we would remove Ireena’s restraints for a set period of time every day, incrementally extending this period of time depending on Ireena’s response to the programme. We frequently encountered opposition from staff when taking Ireena out of bed but once we reassured them that we had the doctor’s permission they would then allow us to proceed. Once again, here we could see the adherence to authority and the reluctance to challenge the status quo. This resistance to change is widely recognised as a dominant feature of institutional culture (Groark and McCall 2011).

The first element of the process entailed developing a therapeutic rapport with Ireena. We spent the majority of our time with her either in the sensory room or out on the grounds of the orphanage. Developing a therapeutic relationship with Ireena was an enriching experience. She exhibited no signs of aggression towards us and she laughed and smiled more with each day of the programme. It appeared as though her behaviours were in response to how she was being treated. We witnessed a number of staff threatening her with restraint and Ireena would often respond to this with self-injurious behaviour, banging her head off the edge of the bed. This seemed to be a means of communicating her opposition.
After we had gained Ireena’s trust, we proceeded to engaging the staff in working with her in an attempt to make our approach as sustainable as possible. This proved extremely challenging. Many staff were reluctant to work with her. In fact, some staff expressed that they were actually afraid of her, reporting previous incidents of her biting people until they bled. One day I brought Ireena, a carer and our translator into the sensory room with me. I showed the staff member how Ireena responded to the sensory room and how calm she became in this environment. The carer was completely disinterested, refusing to come and sit down in the sensory room but instead choosing to stand in the corner of the room. She maintained this acrimony for most of the session. I engaged her in dialogue about how she felt about working with Ireena. She pointed out that I was trained in working with people like Ireena but that she was not. This brought me back to thinking about professional power and the deskilling of society. Illich (1997: 19) proffers that “…these new professions, dominant, authoritative, monopolistic, legalized - and, at the same time, debilitating and effectively disabling the individual - have become exclusive experts of the public good”. This woman had worked with Ireena for years and I had only known her a week at this point. She was the one who possessed the toolbox of extensive experiential knowledge from working alongside Ireena. Yet the fact that I was in the process of gaining a professional qualification had led her to believe that I was more equipped to undertake this engagement. My training as an intellectual disability nurse had taught me not to monopolise intervention and now it was time to apply these concepts in practice. Our goal was sustainability and meaningful change. As intellectual disability nurses, we have a role in empowerment and enhancing independence. In an attempt to disseminate these concepts I emphasised the value of experiential knowledge and how this staff member was capable of enabling others to work with Ireena as she herself was not afraid of her. She had warmed to the idea by the end of the session and even smiled at me, jokingly saying that she could use a massage herself next time! That evening when we went to visit Ireena she was lying in her bed, unrestrained and listening to music. This was a momentous victory for us, staff had never untied her themselves before unless it was for intimate care purposes.

On another occasion we came into the orphanage and staff had not only untied Ireena but had put her in her chair and sat her alongside other people from her group. There were a number of similar moments which gave us hope that we were making progress. However, these results were variable and were dependent on which particular staff were on duty. Our end goal was to take Ireena out to the local cinema. When we originally asked the director about this being a
possibility she was adamant that it would not happen. However, by our third and final week in the orphanage she agreed and we successfully brought Ireena out to the local cinema, along with staff and other children and young adults. It was her first trip out of the orphanage in 10 years.

While we were proud of the progress we had made during our time there, we feared what would happen to Ireena once we left. Would anything have changed? Would staff continue the practice of restraining her? Had we introduced Ireena to an alternative reality only for it to be immediately striped from her? These were serious concerns and ones which the charity continually strives to address.

One positive outcome was that during our time there, we worked with the charity’s team of Belarusian volunteers and discussed the impact of restraint and the benefits of restraint reduction with them. While working with Ireena we discovered that she was capable of feeding herself. This was a sign of incredible resilience. Ireena had not had the freedom to move her arms in years yet she managed to retain so much ability. I showed one of our Belarusian volunteers that Ireena could feed herself. I was quite taken aback by her response. She gazed at Ireena in disbelief and said “She can feed herself? That means she must have a brain!” I reassured her that yes Ireena does have a brain and that she understands you when you speak to her. I explained that just because she cannot verbally speak does not mean she is not communicating and just because she cannot reply in a conventional manner does not mean she is not listening. This realisation was an important breakthrough for this volunteer and a significant lesson for myself to never assume that people understand how extensive communication really is. Working with people who are non-verbal is an integral part of my professional training but it was an alien concept to this volunteer who had been shaped by a society where people with disabilities were largely invisible. These volunteers continue to work with Ireena and other people who are restrained, regularly taking them out of their restraints for sensory stimulation.

In addition to this, Chernobyl Children’s Trust is in the process of implementing a formal training programme for staff on deinstitutionalisation and quality care delivery which will have a strong human rights focus, subsequently addressing the issue of restraint. Altering mentalities is undoubtedly a protracted process but our hope is that our engagement, at least in some way, contributed to its initiation.
10.2 Conclusion

Overall, my experiences in Belarus have been truly fulfilling. It’s certainly an environment where the skill set of the registered nurse in intellectual disability is applicable. My voluntary work has shed a whole new light on how I view Irish service provision. The commonalities between our own history and the current reality in Belarus provide a much more comprehensive insight into the core issues to be addressed as we progress from institution to community. Gaining experience in challenging the institutional mind-set is invaluable. Institutions are not physical buildings but are thought processes we, as individuals, have been shaped to act upon. I firmly believe that no one is immune to the powerful process of institutionalisation. Our priority as intellectual disability nurses should be identifying what factors create the environments necessary for this mentality to flourish and how we can promote humanisation and person-centred care. Actively engaging with individuals from a different culture has been an enriching experience and I am thankful to the many individuals and families who have welcomed me into their lives.
Chapter Ten References


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