Shaping the Future
of Intellectual Disability Nursing in Ireland

**Supporting people
with an intellectual disability to live
ordinary lives in ordinary places**

HSE | Seirbhís Sláinte Níos Fearr á Forbairt | Building a Better Health Service

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January 2018

Foreword

It is with great pleasure that we present this document "Shaping the Future of Intellectual Disability Nursing in Ireland" which sets out a clear direction for the future role of intellectual disability nursing in delivering on a key priority for the HSE; ensuring the best possible health and social care is delivered to individuals with an intellectual disability.

Recent studies have shown, people with an Intellectual Disability are living longer and for some they develop complex health issues earlier in life than the general population. We must also bear in mind children, born with an intellectual disability are surviving into adulthood and old age. These adults and older people experience a range of physical and psychological health and social care complexities, highlighting the critical need for highly skilled intellectual disability nursing care across their lifespan.
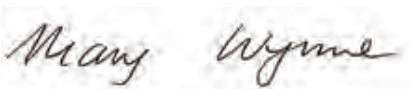
To achieve safe, high quality, modernised health and social care within community based services, a core ingredient is the availability of competent and skilled registered nurses in the field of Intellectual Disability supporting individuals with a disability achieve and maintain optimum health and well being. This document provides a road map of what we have learned from participants and experts involved in this specialist field to guide the delivery and development of Intellectual Disability nursing in the future.

Intellectual Disability nurses must have the capacity to adapt, modify and accordingly adjust to the changing environment for Disability services. They must plan for the future to adapt and deliver a more holistic model of service that includes both health and social care. Alongside the very significant current and emerging challenges for these nurses, we believe it is very timely we are taking forward this plan to ensure the academic teaching, managerial and operational supports for intellectual disability nursing are the best they can be.

The RNID holds an unparalleled qualification, skills and competencies that support individuals with an intellectual disability. The RNID is required to continuously modify their role, ways of working and practice to support evolving models of service and changes in service structure.

The vision this document sets out, and its ultimate aim is to set a clear direction for intellectual disability nurses, one that is sustainable and has person-centredness, safety and inclusion at its heart. By doing this we can and will achieve even higher levels of excellence in the delivery of intellectual disability nursing. We recommend the operationalisation of its recommendations via a joint implementation group.

This future plan for intellectual disability nursing has been influenced by many and we would like to express our sincere thanks to all involved. Specific appreciation is extended to Professor Mary McCarron and her team in Trinity College Dublin for their partnership working with the project steering group to undertake this work. Thanks also to all participants who provided the information and expertise to inform the report; individuals with an intellectual disability, their families, staff of all levels and grades throughout disability services, representative groups and national and international experts in the field. Thanks are also extended to each individual member of the steering group and to Liz Roche and Anne Marie Ryan for the leadership and coordination they have provided in developing this document.

Mary Wynne
Interim Nursing and Midwifery Services Director
HSE

Pat Healy
National Director; Community, Strategy and Planning,
HSE

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List of Abbreviations

ADoN	Assistant Director of Nursing
CNM	Clinical Nurse Manager
CNS	Clinical Nurse Specialist
CPD	Continuous Professional Development
DoH	Department of Health
DoHC	Department of Health and Children
DoN	Director of Nursing
GoI	Government of Ireland
HEI	Higher Education Institution
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
HSE ONMSD	Health Service Executive, Office of the Nursing and Midwifery Services Director
IASSIDD	International Association for the Scientific Study of Intellectual and Developmental Disabilities
INMO	Irish Nurses and Midwives Organisation
NARI	National Ageing Research Institute
NDA	National Disability Authority
NMBI	Nursing and Midwifery Board of Ireland
NMPDU	Nursing and Midwifery Planning and Development Unit
OT	Occupational Therapy
PHN	Public Health Nurse
PWID	People with Intellectual Disabilities
RANP	Registered Advanced Nurse Practitioner
RNID	Registered Nurse Intellectual Disability
SIPTU	Services Industrial Professional and Technical Union
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

A note on terminology:

Throughout the document, reference is made to "the individual with an intellectual disability and their families". This is included as this report refers to all services for individuals with an intellectual disability including children's services. It is emphasised that the decisions relating to an adult individual's life should in the first instance be taken by the person him/herself on the basis that the person is presumed to have capacity (Assisted Decision-Making (Capacity) Act 2015). Family involvement would be included on a graduated basis which would be determined by the degree to which the individual could exercise capacity in making decisions about his or her life, to ensure that the person with an intellectual disability is supported to make autonomous decisions or where this is not possible to ensure that decision making is shared appropriately between the individual and his or her family.

Reference is also made to "Person-Centred Planning". In the context of this report it refers to a global approach to support individuals with an intellectual disability discover how they wish to live their lives and how to make this possible. Models/Frameworks used to support planning that is person-centred may change over time.

Glossary of Terms

Registered Advanced Nurse Practitioner	Advanced Nursing is carried out by autonomous experienced practitioners who are competent, accountable and responsible for their own practice. They are highly experienced in clinical practice and are educated to Master's Degree level (or higher). (NCNM, 2004)
Clinical Nurse Specialist	Specialist practice encompasses a major clinical focus, which comprises assessment, planning, delivery, and evaluation of care. A nurse 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. (NCNM, 2008)
Risk Management	"The culture, processes and structures that are directed towards realising potential opportunities while managing adverse effects" (AS/NZS 4360: 2004 cited in HSE, 2010, p. 5)
Risk Assessment	"The process of identification, analysis and evaluation of a risk" (Australian Government, 2010, p. 40)
Key performance Indicators (KPI's)	*Rate* based KPIs use information about events that are expected to happen frequently – represented as proportions or ratios *Count* KPIs measure number of events *Sentinel* KPIs identify individual events that are undesirable that usually warrant a detailed analysis to determine why the event occurred. (HIQA, 2013)

Key to participant quote codes used in findings chapter

Focus groups
The participant identification codes comprise a stem which indicates the focus group and individual participant identifications.

Family Focus Groups 1, 2, 3, & 4:	FFG1; FFG2; FFG3; & FFG4
People with Intellectual Disability Focus Groups 1, 2, 3, & 4:	SU1; SU2; SU3; & SU4
RNID Focus Groups 1, 2, & 3:	NFG1; NFG2; & NFG3
Managers' Focus Groups 1 & 2	MFG1; & MFG2
Students' Focus Group	SFG
Interface Focus Groups 1 & 2	IFG1; & IFG2
Educators' Focus Group	EFG

Open text responses in survey
These responses comprise a stem of the relevant question e.g. 21 followed by the identification code of the survey respondent. Examples: 21:45; 21:124

Expert interviews
The responses comprise the stem 'E' followed by the participant identification number. Example: E3

Submissions
These responses comprise the stem 'S' followed by the participant identification number. Example: S2

Vision for Intellectual Disability Nursing

Registered Nurses in Intellectual Disability (RNIDs), are a key profession in the provision of health and social care supports for people with intellectual disabilities. These professionals welcome the prospect of advancing and enabling the highest quality of opportunities and providing health and social care supports to individuals with an intellectual disability in the changing landscape of disability services.

The findings of this national project suggest a clear requirement for the role of the RNID in the future in supporting the implementation of policy thereby enhancing the service delivery model in an interdisciplinary environment.

Changing demographics, renewed movement into community settings and newly emerging health care needs among people with intellectual disability mean that the delivery of person-centred care in all aspects of people's lives is central to the RNIDs role. This will involve new forms of care in the community, high quality health care provision to address complex health needs and long term and progressive conditions as people age and a holistic commitment to realising the fullest community lives possible for people with an intellectual disability.

RNIDs are committed to being at the forefront of implementing service reform for people with an intellectual disability, movement to more community forms of living and service delivery, through modeling and leading person-centred approaches. RNIDs will also serve where needed in liaison roles between primary, secondary and tertiary healthcare services and individuals with an intellectual disability.

As a group whose educational and experiential preparation is solely focused on people with an intellectual disability; RNIDs have the values, knowledge and professionalism to deliver safe, high quality, compassionate, ethical, legal and accountable practice to the individual with an intellectual disability across the lifespan and in the variety of settings where they live.

The art and science of intellectual disability nursing is underpinned by the following six domains of practice:

- Professional values and the conduct of nurse competences
- Nursing practice and clinical decision making competences
- Knowledge and cognitive competences
- Communication and interpersonal competences
- Management and team competences
- Leadership and professional scholarship competencies

(NMBI, 2016)

From this national work undertaken by the HSE, a framework for the future of intellectual disability nursing has emerged that advances an overarching commitment to Person-Centredness and targets key improvements in the areas of Supporting Individuals with an Intellectual Disability with their Health, Well-being and Social Care; Developing Nursing Capacity, Capability and Professional Leadership and Improving the Experience and Outcomes for Individuals with an Intellectual Disability.

Demographic changes among people with an intellectual disability have resulted in the presentation of increasingly complex health needs for many, particularly in the early years. Consequently, this work has overwhelmingly identified clinical nursing skills as an area of key competence for future service delivery with the aim of managing chronic conditions and supporting healthy lives across a lifespan more in keeping with that of the mainstream population.

RNIDs have the knowledge, skills and capabilities to support these individuals and are called upon to focus on the promotion of optimum physical and mental health and the promotion of social inclusion recognising that each person has unique characteristics, capabilities, needs and wishes in relation to each of these. It requires the nurse to undertake a range of health and social assessments thereby developing a comprehensive understanding of the volume and depth of the individual's support requirements and making informed decisions about their nursing care and supports. It will require them to provide and/or supervise interventions that may span from supportive guidance in some instances to intensive physical and/or psychological interventions to some individuals maximising the use of technology in the process.

Emphasis was also placed on the importance of the role of the RNID in the facilitation of integrated care between specialist intellectual disability services and other services such as those provided in acute hospitals, in primary care, and mental health services noting that all should take a whole person approach when dealing with the individual with an intellectual disability. The project highlighted the requirement to identify the potential contribution of specialist and advanced nursing practice to the lives of individuals with an intellectual disability and their families.

The changing landscape of service provision does, and will continue to present new challenges and opportunities. Revised service structures will be needed, curricula updated and new ways of working implemented in order to support community living for the individual with an intellectual disability. This will ensure that the unique skills of the RNID will be continuously enhanced and embraced as central to the realisation of both the personal goals of the individual with an intellectual disability and to the advancement of public policy goals to improve, support and celebrate their lives. In doing so RNIDs will have a visible leading role in the promotion of health; working with individuals to equip them to manage their own health and well-being.

Executive Summary

Introduction

In a comprehensive examination of the contemporary role of the Registered Nurse Intellectual Disability (RNID) in Ireland a broad range of stakeholders' views were sought. Responses were analysed to address the overall aim of the project: *"to determine the future role of the registered nurse intellectual disability (RNID) who provides health and social care services to individuals with an intellectual disability and to their families and carers in this changing landscape".*

An extensive literature review confirmed that there is a changing landscape driven by improved survival rates for children with complex health needs, the shift to community-based care with an increased focus on a social care model, and a growing ageing population with a wide diversity of health and social care needs.

These trends have produced new challenges, changing service provision and a requirement for the expansion of the skills and nursing roles of RNIDs to encompass:

- The needs of school and childcare services
- Primary care, hospital systems, and community integration
- Lifespan approaches spanning perinatal to end of life concerns
- Balancing promotion of opportunity with safety management within community integration
- Working in conjunction with Government systems, for example Justice, Education, and Employment.

Design and Sample

The project employed a mixed-methods design, incorporating a number of phases of data collection and analysis culminating in a number of recommendations for the future development of the profession.
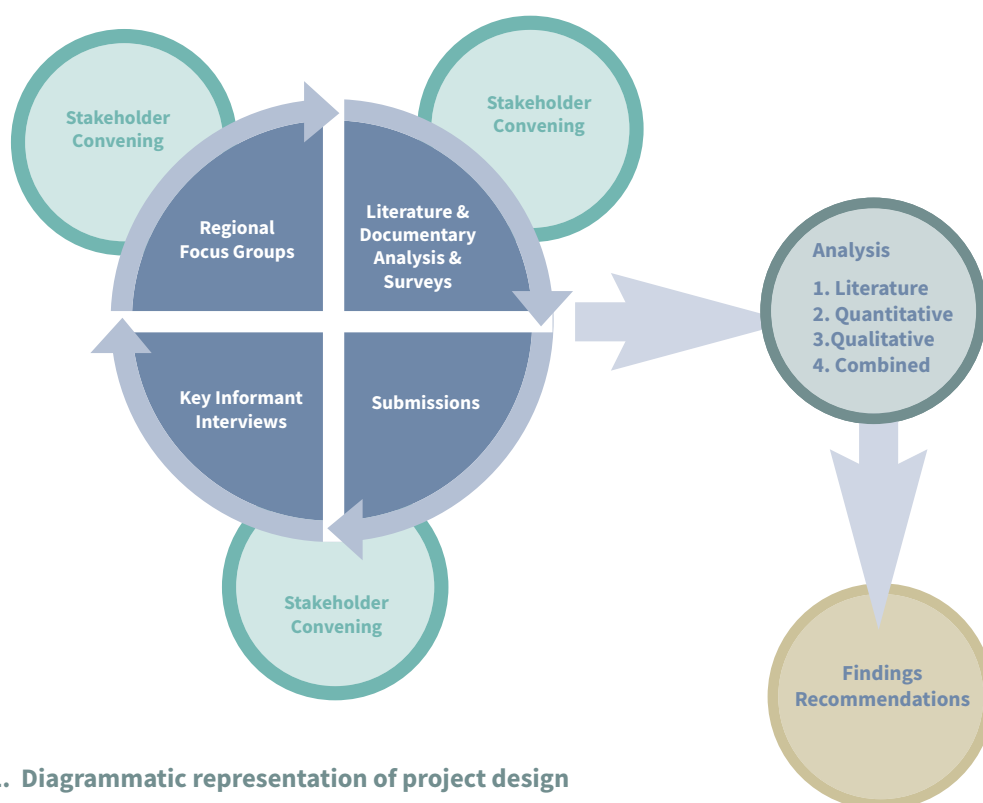
Figure 1. Diagrammatic representation of project design

Data was collected through survey responses, expert interviews, family and service-user focus group interviews, clinical and management staff focus group interviews, convenings, and document reviews. Throughout the data collection process, consideration was given to the values, barriers, facilitators and leadership that would be required to ensure that individuals with an intellectual disability are able to receive person-centred, holistic, expert nursing care regardless of setting. The project methodology also involved a triangulation process of qualitative, quantitative and documentary analysis. The design of the project and the different stages of data collection are presented in Figure 1.

Framing the Report

This report is underpinned by the following recent disability service policy and legislation:

- Time to Move on from Congregated Settings: A Strategy for Community Inclusion (HSE, 2011)
- Progressing Disability Services for Children and Young People (HSE, 2012a)
- New Directions: Review of Day Services and Implementation Plan (HSE, 2012b)
- Assisted Decision-Making (capacity) Act (GoI, 2015)
- Transforming Lives: The programme to implement the recommendations of the Value for Money and Policy Review of Disability Services in Ireland (HSE, 2015b; DoH, 2012b)
- The Programme for Government (2016)

Whilst acknowledging the existing knowledge, skills, expertise and commitment of RNIDs, both the literature and findings recognised that changing demographics and models of service provision mean there is a requirement to plan the future development of the discipline to increase its responsiveness to the needs of people with an intellectual disability based upon a health, well-being and social care model. In addition to the pivotal role which RNIDs play in supporting individuals living in congregated settings to move to homes within their community, nurses working in intellectual disability services will also need to:

- Support the management of complex and enduring health and social care needs of individuals with an intellectual disability, including health promotion
- Build interdisciplinary and cross-sector collaborative roles working in an integrated care delivery model
- Support both family caring and independent living for people with an intellectual disability across the lifespan by providing a range of health, social, educational, psychological and behavioural interventions
- Demonstrate effective professional leadership at all levels in the health, well-being and social care system in Ireland
- Respond to the demands of a changing environment including taking on new roles based on HIQA regulations
- Adapt to a social model of care whilst supporting the individual's health and well-being

Addressing such needs will require senior nurses, planners and managers of services to use a systematic approach to examine the numbers required and the deployment of RNIDs as part of their overall integrated workforce planning activity. A national staffing framework; inclusive of decision support tools to calculate nurse staffing requirements within intellectual disability services will need to be developed based on the best available international evidence. Within intellectual disability services and Community Health Organisations, such a framework will determine the most appropriate nurse staffing levels based on the care and support requirements of individuals with an intellectual disability. In addition, it will assist with the planning of appropriate education provision and will also inform national RNID workforce projections to aid the examination of the supply of and demand for RNIDs at all levels.

As care moves to community settings, some RNIDs may be redeployed from roles where their predominant activity was the direct provision of care, to roles where they are also managing and coordinating health, well-being and social care for the person with an intellectual disability. Evidence from this review also identified critical areas for the further development of specialist and advanced RNID clinical practice roles to meet the growing challenges of supporting people with complex health needs.

The findings of this project are structured into four themes, as outlined in Figure 2, and each theme is discussed in the context of relevant policy, legislation and evidence. Specific recommendations are suggested within each theme to progress these components in practice.
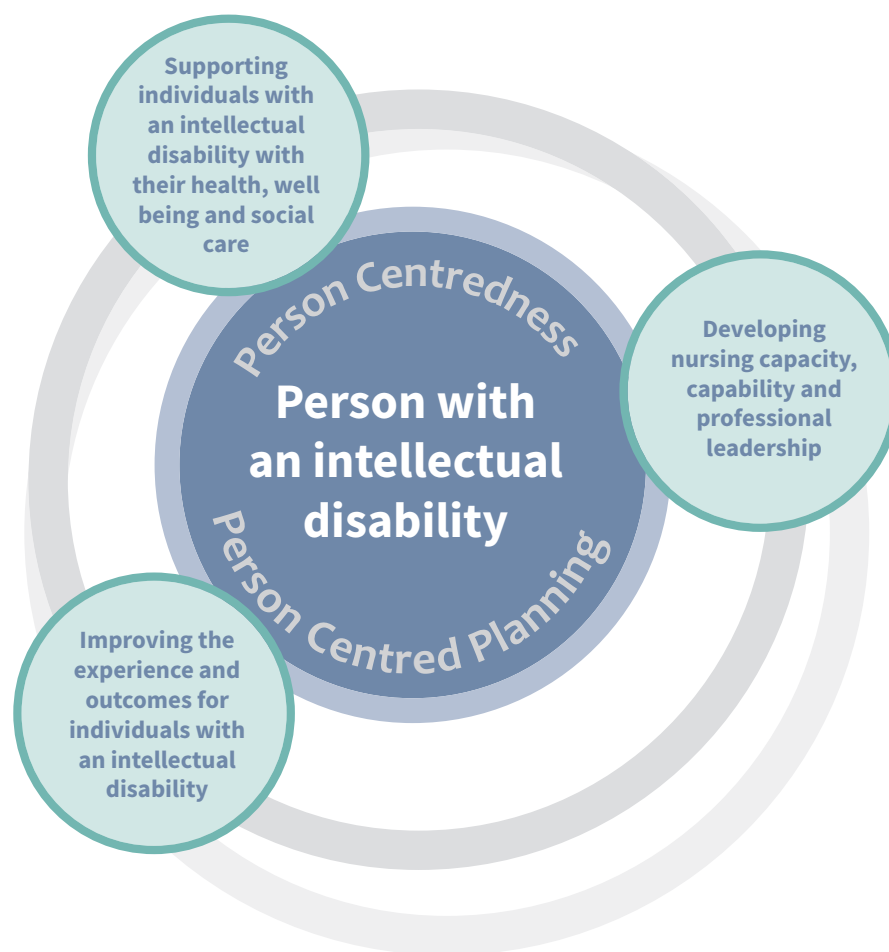
Figure 2: Framework for the development of Intellectual disability nursing

Theme 1: Person-Centredness and Person-Centred Planning

Person-centred approaches to care and support are at the heart of the disability policy and practice agenda in Ireland (DoHC, 2010a; HSE, 2012c; HIQA, 2013a, 2013b).). This approach involves discovering how a person wants to live their life and identifying the supports and resources required to make that possible (NARI, 2006; NDA, 2005a). It also emphasises partnership working and shared decision making between the person with an intellectual disability and those participating in the care and support process (NDA, 2005a, 2005b; Thompson et al., 2008; Sanderson, 2000). Persons are to be treated with dignity, compassion and respect, and care and support provided is to be personalised, co-ordinated and enabling.

This philosophy offers an alternative to a historic bio-medical model of care and calls upon the nurse to develop their professional knowledge, skills and values to support its implementation (Keenan, 2008). Fundamentally, person-centred care calls for a change in the roles and responsibilities of all professionals, service users and significant others to work in partnership to deliver care (NDA, 2005a, 2005b).

Through person-centred approaches to care and support, people with an intellectual disability are facilitated by the RNID to make informed choices about their life and are enabled to manage their own care to the level of their abilities, or to choose when to seek support from others.

In order for the acknowledged right of self-determination for people with an intellectual disability (HSE, 2011) to be realised, personnel skilled in supporting person-centred planning are required. This skill will be vital to RNIDs in aiding their understanding of the key features of the Assisted Decision Making (Capacity) Act (2015). This Act requires legally recognised decision-makers to support a person to maximise their decision-making powers and places a legal requirement on service providers to enable a person to make a decision through the provision of a range of supports and information appropriate to their level of ability.

Recommendation 1
RNIDs will continue to ensure that their practice is informed by the values and principles of person-centredness and person-centred support in the assessment, planning and delivery of health and social care with individuals with an intellectual disability in all settings.

Recommendation 2
RNIDs will receive further professional development in supporting the self-determination of individuals with an intellectual disability through, for example, advanced advocacy training.

Recommendation 3
The HSE will develop specific policy and systems for professional supervision within intellectual disability services in accordance with the HSE's overall HR circular on clinical supervision. RNIDs will be supported to engage with regular and effective professional supervision to ensure that the values of person-centredness are applied consistently in practice.

Recommendation 4
The focus, knowledge, skills and competence of the RNID will be central to the interdisciplinary, community-based model of support for individuals with an intellectual disability.

Recommendation 5
RNIDs and professionals from other disciplines will work collaboratively to support individuals with an intellectual disability live ordinary lives in ordinary places.

Recommendation 6
The RNID will be supported to undertake additional training to understand the components of the Assisted Decision-Making (Capacity) Act (2015). This will include the need for legally recognised decision-makers to support a person to maximise their decision-making powers and for RNIDs to develop an understanding of what this means for staff supporting individuals with an intellectual disability.

Theme 2: Supporting Individuals with an Intellectual Disability with their Health, Well-being and Social Care

Health and Well-being

It is increasingly recognised that the prevalence of chronic health conditions in people with an intellectual disability is higher than in the general population, and that the health care needs of this population are often unrecognised and unmet (Haveman et al., 2011; Emerson, 2011; McCarron et al., 2011a, 2011b; McCarron et al., 2014). There is evidence to suggest that some people with an intellectual disability may not actively pursue positive health, and it will be increasingly important that RNIDs encourage the maintenance of a person's health as a core element in planning activities.

Key ideas that emerged in this theme were a perceived unsuitability of general health service delivery for persons with an intellectual disability, and the need for additional supports to address the complex health needs of both children and an ageing population with multiple morbidities.

Considerable evidence already points to a disparity between the health and healthcare of people with an intellectual disability and that of the general population. Families and service users suggested that their experiences would be greatly enhanced if there was a knowledgeable professional they could access to support their "navigating" generic health, social and community services. RNIDs may be that critical liaison person within the health services at primary, secondary and tertiary level. This was repeatedly highlighted in the findings, with suggestions that the RNID both support people with an intellectual disability and their families and provide specialist knowledge and skills to other professionals within these settings.

RNIDs being prepared with enhanced skills to perform and manage comprehensive health assessments was also identified as key to the improvement of evidence-based healthcare practices for people with an intellectual disability in all locations of service delivery.

It was also suggested that RNIDs should be supported to work with family carers across the lifespan with a particular focus on the management of complex health needs, supporting families and individuals with intellectual disability with planning for and implementing transitions across the lifespan, encouraging health promotion habits and behaviour, supporting management of enduring conditions and offering palliative care when needed. Expert informants suggested that there is a need for clearly managed pathways for health and social care with RNIDs in key roles.

Social Care

A wide range of recent policy documents support a policy imperative for individuals with an intellectual disability to live in the community (GoI, 2004; DoHC, 2006; HSE, 2011). Community living has been shown to provide a variety of improvements to the lives of people with intellectual disability. Smaller, more individualised settings often support a better quality of life, increased opportunities to function more independently, and more frequent access to community activities; and has also been associated with stable physical well-being and increased contact with friends and family (Doody, 2012; Stancliffe et al., 2011; Young, 2006). Survey responses in this study indicated that RNIDs currently support community integration as a significant part of their role. However, transitions to new settings and between healthcare and living situations were identified as particularly difficult for individuals with an intellectual disability and their families. RNIDs will increasingly need to offer a high level of support to ensure coordinated, proactive and effective support.

Indeed, RNIDs are considered by many as key informants to be strategically placed to act as advocates for and liaise with individuals with an intellectual disability and their families. The findings reinforce that RNIDs must be prepared for this role in both specialist intellectual disability and general health and social care services.

RNIDs also have a role as agents of inclusion as they work at the very heart of initiatives to develop services for people with an intellectual disability (Gates, 2006; Sheerin, 2011a, 2011b). As RNIDs promote the service-user's self-advocacy, independence and integration within the wider community, they must be skilled in assessing, planning and delivering jointly with the service-user within an interdisciplinary context that acknowledges and manages safety and risk.

The role of the RNID will therefore need to be evident across a diverse spectrum of care areas including:

- Primary care; working as part of the primary care team providing a population based nursing service, that encompasses child protection, social care, and supporting individuals manage long term conditions.

- Secondary care services; throughout acute hospital services, in liaison roles with maternity services, progressing disability services for children with an intellectual disability, in mental health services, in prison services, and in various specialist services of people with an intellectual disability e.g. autism, rehabilitation. Liaison posts within acute hospital services provide significant support to individuals presenting in emergency departments and should be developed further to provide individuals with ongoing support throughout their acute hospital journey.

- Tertiary services; in high support services, palliative care, dementia, dual diagnosis services.

- Strategic governance of services; in policy development, academia, child and vulnerable person's protection, regulation and inspection.

Professional Role of the RNID

RNIDs, through their undergraduate preparation, have the knowledge and skills to assess, plan, prioritise, deliver and evaluate health and social care based on a comprehensive and systematic assessment of health, social and nursing care needs in partnership with the person with an intellectual disability, their family/advocate and the wider team (NMBI, 2016).

The focus of the RNID should be on the promotion of optimum physical and mental health and the support of social care and inclusion, recognising that each person has unique characteristics, capabilities, needs and wishes. The professional RNID role is to assist individuals with an intellectual disability and their families towards healthy lifestyles and self-care at a variety of levels:

- As a registered nurse, within their scope of practice, by undertaking assessments, planning care, providing interventions and evaluating the impact of care for individuals with an intellectual disability and their families.
- As a clinical nurse specialist providing focussed assessment and specialist intervention to the individual and their family within agreed protocols and guidelines under the supervision of others such as a RANP, doctor or psychologist.
- As a registered advanced nurse practitioner, making autonomous decisions, undertaking advanced assessment of the individual's strengths and needs, selecting and providing and/or coordinating complex interventions for the individual and his/her family, and assessing the intervention impact.

In some circumstances assessments undertaken by the RNID will also support referral to specialist assessment and/or intervention.

The Registered Nurse Intellectual Disabilities: Support Across the Life-Span

It is increasingly recognised that people with an intellectual disability have a variety of individually-determined support needs and that these vary significantly across the life-span. Some of these relate to the challenges in accessing health and social services and the need for link persons to bridge these gaps. Other support needs may relate to difficulties in engaging with primary, secondary and tertiary health services. In such instances, it may be necessary to modify such services or to provide pathways through them, facilitated by knowledgeable professionals. Finally, while acknowledging the the fact that people with an intellectual disability are not inherently ill, there is growing evidence that they may, for a number of reasons, have poorer health outcomes than those in other parts of society. There is a clear requirement for the provision of accessible and inclusive approaches to health assessment, promotion and treatment, mediated through suitable specialists. Considering the knowledge and expertise the Registered Nurse in Intellectual Disabilities, it is envisaged that they will be central in addressing such issues.

The RNID will work at a number of levels. Having completed an undergraduate degree in intellectual disability nursing, the RNID will be skilled to provide generalist support to people with an intellectual disability in respect of health screening, assessment and promotion across their life-span. They will also be able to support families in liaising with services and other members of the multi-disciplinary team. Experienced RNIDs, who have completed post-graduate studies may be employed as Clinical Nurse Specialists or Registered Advanced Nurse Practitioners in defined areas (for example, augmented communication, autism, behaviour support, dementia etc.) which will allow them to meet the specific support needs of individual people at various points throughout the life-span. Some of the ways that RNIDs will support people with an intellectual disability, through their lives, are set out in the figure on the following page. The exemplars provided are not exhaustive, as the role of the RNID will continually develop to meet people's changing needs.

Shaping the Future of Intellectual Disability Nursing in Ireland

Figure 3: The roles of the RNID through the life-span

Pregnancy
- RNID Generalist offering support and advice in Primary Care
- RNID Specialist Liaison in Maternity Services

Infancy
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Specialist (Early Interventions) in Primary Care liaising with health, social care, disability services and multi-disciplinary team

Childhood
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison in Childrens Secondary and Tertiary Health Care and Schools
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, augmented communication)

Adolescence
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison in Childrens Secondary and Tertiary Health Care and Schools
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, relationships & sexuality)

Young Adult
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists/RANPs in Adult Secondary and Tertiary Health Care
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, relationships & sexuality, work support)

Adult
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists/RANPs in Adult Secondary and Tertiary Health Care
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, relationships & sexuality, work support)

Middle Age
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists (dementia etc.)/RANPs in Adult Secondary and Tertiary Health Care
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, relationships & sexuality, mental health)

Older Adult
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists (dementia etc.)/RANPs in Adult Secondary and Tertiary Health Care
- RNID Specialist/RANP (e.g. epilepsy, ageing, behaviour support, relationships & sexuality, bone health)

End of Life
- RNID Generalist providing health screening and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists/RANPs (end of life) in Palliative Care
- RNID Specialist/RANP (e.g. bereavement, counselling)

Recommendation 7
Individuals with an intellectual disability will have access to the specialist knowledge and skills of the RNID across primary, secondary and tertiary care settings.

Recommendation 8
Consideration will be given to the development of liaison roles within acute hospital services based on service need, to support the individual with an intellectual disability throughout their entire acute hospital journey.

Recommendation 9
RNIDs will be prepared to undertake, as required leadership and governance roles within health and social care services for individuals with an intellectual disability and will be clearly identified as key members of multidisciplinary teams.

Recommendation 10
Specialist RNID roles in a range of locations will support individuals with an intellectual disability with regard to their health needs; for example in community agencies, acute hospitals, day services, schools and other educational facilities, workplaces, legal and business services and the criminal justice system. Such roles will be based on identified service need.

Recommendation 11
RNID's as well as other team members, will undertake a care management and liaison role ensuring timely and appropriate access to health services for individuals with an intellectual disability.

Theme 3: Developing Nursing Capacity, Capability and Professional Leadership

The RNID undertakes a diverse range of roles to support the individual with an intellectual disability and their family; from providing holistic nursing including intensive physical care with individuals with profound and complex disabilities to providing guidance and support in the management of children, adolescents and adults for the purpose of optimising the life, health and social care of the individual (INMO, 2015).

The literature reviewed highlighted RNID specialist skills, including:
- Knowledge and awareness of how cognitive and communicative impairments distort clinical presentations
- Knowledge and awareness of specific intellectual disability syndromes and causes of intellectual disability
- Ability to establish an individual's complex needs based on observable, behavioural signs, often in the absence of subjective accounts
- Knowledge and awareness of how impoverished or otherwise adverse life experiences influence the presentation of signs and symptoms of ill health
- Ability to recognise the anxiety associated with accessing services and the experience of ill health
- Ability to undertake comprehensive assessments of both health (physical and psychological) and social care needs
- Ability to work in multidisciplinary settings and with different agencies to develop and implement care plans
- Ability to provide nursing care interventions that address health needs, support healthy lifestyles and and prevent ill health.
- Ability to educate and advise persons with an intellectual disability and carers
- Ability to safeguard and protect the rights of people with an intellectual disability especially when they are vulnerable and in need of support.

(RCN, 2011a, 2011b; RCN, 2013a, 2013b, 2013c, 2013d; Atkinson et al., 2010)

The contribution of the RNID may, however, need to be clearly articulated so that the health and social care needs of persons with an intellectual disability can be met.

Specialist and advanced practice roles
Specialist and advanced nursing clinical roles provide higher levels of clinical decision making. Such roles are built around the development of core competencies and increased expertise in an area of clinical practice, underpinned by evidence of education at a higher level.

A Clinical Nurse Specialist (CNS) is required to apply additional knowledge and skills gained specifically focussed in a defined area of practice, and requires skill and competency in:
- Clinical focus
- Client advocate
- Education and training
- Audit and research
- Consultancy

Advanced nursing practice requires the individual RNID to be educated to Master's level to inform advanced, autonomous practice, leadership and quality improvement. It requires significant post registration experience and a defined level of experience in the specialist area of practice.

Evidence from this project noted that specialist and advanced practice posts need to be developed to address persons with early onset dementia, autism, early detection of deterioration in an individual's physical or mental health status, complex needs, and support in different locations (acute hospitals, primary care) and across the lifespan (children's services, older persons' care). Other examples of specialist roles included in end-of-life and palliative care, mental health, acute liaison, maternity liaison, children with life limiting conditions and health promotion.

Undergraduate preparation and continuing professional development

Given the growing evidence of the increasing and ageing population of individuals with intellectual disabilities, and many of all ages presenting with a range of complex multiple health needs, greater knowledge, education and skills will be needed to protect and promote health, well-being and social care; provide care management, leadership and supervision; undertake evidence-based inquiry and deliver evidence-based education and training (Parrot et al., 2008; Maulix et al., 2011).

Undergraduate preparation

During the course of the project, recommended improvement in undergraduate curricula and education included extending the array of clinical practice placements to include primary care and experiences in generic health services, including maternity services. Managers in particular also identified the need for education in autism, dementia, ageing, behavioural care and community care. It was suggested that increased collaboration between universities and associated intellectual disability services was needed to ensure that programmes better meet the needs of individuals with an intellectual disability by building the skills and knowledge required for the changing profile of intellectual disability services.

Postgraduate education

The Nurses and Midwives Act (2011) emphasises the duty of registered nurses to maintain professional competence to support their practice. It also identifies that he/she will need to demonstrate evidence of this competence to the satisfaction of a Nursing and Midwifery Board of Ireland scheme for competence assurance.

The need was highlighted for a broader range of postgraduate education programmes and courses that present RNIDs with opportunities for professional development and specialisation.

Examples of areas highlighted during the project included:
(1) Autism; dementia; ageing; epilepsy; bone health; behavioural support; advanced and augmented communication; and community care support and
(2) General and specialist health assessments, providing health and social care, supporting families, and liaising with other professionals in working with individuals with an intellectual disability across the lifespan.

Similarly, demand was apparent for the development of Clinical Nurse Specialist and Registered Advanced Nurse Practitioner posts in disability services. Associated education programmes at level 8 and 9 of the Irish National Framework of Qualifications (NFQ) will need to be developed and available so that staff have the necessary knowledge and skills for these autonomous posts.

Having a supportive leader and organisational learning culture were also identified as important components in the transfer of learning to nursing practice. This is consistent with the HSE's corporate plan emphasising learning as one of the core values of the organisation, and the plan's noting of the importance of encouraging staff to achieve their full potential and supporting learning, innovation and creativity.

Ensuring practice is evidence based

The use of reliable evidence to support and underpin nursing decision making and practice is increasingly important in all health and social care services, but nurses' ability to source and evaluate the evidence available varies (Doody & Doody, 2011). RNIDs and their managers and nurse leaders need to ensure that practice is underpinned and supported by policies, procedures, protocols and guidelines (PPPG's) that are informed by evidence.

Supports should be provided for RNIDs to develop their capacity and capability to access and assess the evidence available, and to facilitate the change required to implement evidence-based approaches and initiatives. This means staff in academia must work with individuals with an intellectual disability, nurses in practice and other relevant stakeholders to build the evidence base, identify areas that require further evidence and research, and continually seek to develop new interventions based on evidence and demonstrated nursing outcomes.

Submissions highlighted a number of key recommended initiatives:

- The appointment of registered advanced nurse practitioners within disability services
- The development of joint practice/academic posts
- Availability of appropriate technology in practice areas to access evidence
- Support by commissioners and managers of services for RNIDs to engage with and undertake service based research
- The provision of specific education programmes around evidence based practice including skills in searching for and critiquing evidence, undertaking audit and research methodologies
- Support and encouragement by managers to develop professional networks to increase the sharing of practice within services, across services regionally, nationally and internationally
- Support by academic staff to RNIDs in clinical practice to write and publish papers pertaining to their practice
- Support by nurse leaders to develop mechanisms for sharing and discussing research.

Professional leadership

The national implementation framework 'Transforming Lives' (2015), the programme to implement the recommendations of the 'Value for Money and Policy Review of Disability Services in Ireland (DoH, 2012b), the subsequent Programme for Government (GoI, 2016) and other Disability policies, notes that greater accountability and transparency are needed in services and in service provision. There was a view among respondents that the advancement of such governance and accountability required grounding in transformational leadership and the implementation of best practices.

Effective leaders supporting ongoing development and sustainability of person-centred cultures of care will need to engage with individuals with an intellectual disability, their families and colleagues to develop a collaborative and consultative leadership approach. This will help define priorities, provide feedback and lead to a more open, transparent and engaged organisational culture (DoH UK, 2015). All staff, then, both individually and collectively, will work as a combined unit for the good of the person with an intellectual disability.

Through the generation of new measurement approaches and research, evidence of the nursing contribution and value to the lives of people with an intellectual disability will be become more evident and support the required ongoing development of the profession. Such visible, high profile intellectual disability nursing leadership at all levels of disability and health and social care services will help progress policy development that supports individuals with an intellectual disability, and will promote, develop and support nursing practice and the contribution of the profession overall.

Leaders within disability services are encouraged to network with RNIDs nationally and internationally to learn from and share their experience regarding service and professional development. Specifically, nurse leaders within disability services are encouraged to network with members of the 5 nation membership of the "Strengthening the Commitment" group. This group is supported in its functions by the Governments of each of the nations through the offices of the Chief Nursing Officers of each country including Northern Ireland, Scotland, Wales, England and Ireland.

Recommendation 12

Pre- and post-registration educational curricula will be strengthened to better prepare RNIDs to respond effectively to the increased complexity of health, well-being and social care needs of people with an intellectual disability across the lifespan.

Recommendation 13

A broader range of intellectual disability placement opportunities will be developed for undergraduate nursing students and new supervision guidelines developed so that RNID supervision requirements do not preclude the utilisation of some important placement opportunities.

Recommendation 14

Continuing professional development and postgraduate education programmes for RNIDs will be developed in response to the changing care and support requirements of individuals with an intellectual disability across the lifespan. These will be delivered using a blended learning approach as appropriate.

Recommendation 15

Higher Education Institutions will further develop collaborative partnerships with intellectual disability services to enhance the skills and competencies of nurses and to ensure positive health outcomes for individuals with an intellectual disability.

Recommendation 16

Individuals with an intellectual disability will increasingly be involved in the design and delivery of education programmes.

Recommendation 17

RNIDs will ensure their practice is evidence based by strengthening their involvement with practice development initiatives, availing of continuing professional development, engaging with research activity and participating in professional supervision.

Recommendation 18

RNIDs will be actively involved in the development of policies, procedures, protocols and guidelines to support intellectual disability nursing practice.

Recommendation 19

In the context of integrated workforce planning, a national staffing framework; inclusive of decision support tools to calculate nurse staffing requirements within intellectual disability services will be developed based on the best available international evidence.

Recommendation 20

Clinical Nurse Specialist and Advanced Nurse Practitioner roles will be developed in accordance with Nursing and Midwifery Board of Ireland criteria and in response to identified service need. These roles will be designed to specifically address disparities in health policy implementation, health service delivery and health outcomes for individuals with an intellectual disability.

Recommendation 21

Consideration will be given to the appointment of joint posts between intellectual disability services and higher education institutions to further progress the development of evidence based intellectual disability nursing practice.

Recommendation 22
Leadership development programmes will be provided for nurses working at all levels within intellectual disability services.

Recommendation 23
RNIDs throughout the health sector will explore mechanisms to network and share practice and research including the use of journal clubs, networks, conferences and seminars and social media. RNIDs are also encouraged to build networks with colleagues at Community Health Organisation level to be informed about local developments and training opportunities. RNIDs are also encouraged to further develop professional networks with the international "Strengthening the Commitment" steering group which spans membership from Northern Ireland, Scotland, Wales, England and Ireland.

Recommendation 24
RNIDs will respond to contemporary health, well-being and social care policy recommendations and will provide leadership to ensure its timely implementation.

Recommendation 25
Opportunities will be created for RNIDs to contribute to national policy; in particular addressing health disparities for individuals with an intellectual disability.

Theme 4: Improving the Experience & Outcomes for individuals with an Intellectual Disability

Quality care in Irish intellectual disability residential services is regulated by the Health Act 2007 (amended) (GoI, 2007) and National Standards for Residential Services for Children and Adults with Disabilities (HIQA, 2013). These regulations and standards provide for the monitoring of human rights and quality care for individuals with intellectual disabilities receiving respite/residential health and social care services other than mental health services, which come under The Mental Health Act (GoI, 2001) and The Quality Framework for Mental Health Services in Ireland (MHC, 2007).

An understanding and implementation of these quality frameworks and the Nurses Code of Professional Conduct and Ethics (NMBI 2014) are fundamental to the improvement of the intellectual disability nursing service.

Similarly, Transforming Lives (2015): the programme to implement the recommendations of the 'Value for Money and Policy: Review of Disability Services in Ireland' (2012) recommended that a governance framework be established for disability services that would include systems for information to support service design, delivery and evaluation, and systems for quality assurance and processes for performance management by services. The intent is to ensure accountability within the system and support evidence-based decision making. RNIDs at all levels will need to be clear as to their role and responsibilities within this governance framework. Evidence from the focus groups held with individuals with an intellectual disability, their families and responses by RNIDs in the survey, all highlighted that quality and safety of persons with an intellectual disability were of great and increasing importance. RNIDs must position themselves to play a central role in improving quality in services.

Governance for Quality and Safety
The HSE "Framework for Improving Quality in our Health Service" (2016) (Figure 3) seeks to develop a culture that places the individual with an intellectual disability at the centre of health and social care, reliably delivers safe, effective, equitable, personalised care and continuously seeks improvement. It notes that it is the combined force of drivers working together that creates this culture and the acceleration for improvement.

The individual changes and achievements for people with an intellectual disability that are the hallmark of successful person-centred planning require well-managed planning activities, determined support of implementation plans and the creation of person-centred environments and staffing in health and social care services. Many respondents agreed that the success of person-centred approaches will always be best measured in terms of the quality of life and health outcomes for individuals with intellectual disabilities and requires a culture of continuously improving personalised quality care. There is an important opportunity for the intellectual disability nurse in their work with the person with an intellectual disability and their family to define, provide and evaluate their care supports, and focus on enhancing and expanding the environment of individuals with an intellectual disability to assist them to develop and realise their own talents, abilities, preferences, lifestyles and goals in the wider community.

Achieving this will also require RNIDs to enhance their partnership working with the persons' formal supports, for example multi-disciplinary and multi-agency team members within disability and mainstream health and social services, as well as informal supports, such as family and friends. Both these strategies can contribute greatly to advancing the service user's quality of life. (Keith & Schalock, 2000; Keith, 2001; Cummins, 2002; Schalock et al., 2007; Brown et al., 2009; NDA, 2010a, 2010b).

Quality improvement is also strongly linked to analysing and intelligently using information about the service (HSE, 2015a). Having access to accurate, valid, reliable, timely, relevant, legible and complete information is critical (HIQA, 2013). In addition to regulatory and thematic inspections by HIQA, other mechanisms are currently being used in some disability services to identify, collect, collate and analyse data to measure the quality of nursing care, including: Key Performance Indicators (KPIs), Quality Care-Metrics, and Caring Behaviours Assurance System-Ireland (CBAS-I). Such data must be accessed and utilised effectively by RNIDs.

Furthermore, the use of Donabedian's (2003) system of the division of healthcare into structure, process, and outcome (see Table 22), can assist nurses in disability services to define and quantify the components of quality that require examination and measurement. This in turn may further improve the quality of life of the person with an intellectual disability.

Figure 4:
Framework for Improving Quality in our Health Service (HSE 2016)

Leadership for Quality

Governance for Quality

Person and Family Engagement

A Culture of Person Centred Quality Care that continuously improves

Measurement for Quality

Staff Engagement

Use of Improvement Methods

Key Performance Indicators

Using key performance indicators (KPIs) is an effective approach to measuring specific elements of nursing care considered integral to the overall experience of the person with an intellectual disability. Key Performance Indicators (KPIs) are specific and measureable elements of health and social care that can be used to assess quality of care (HIQA, 2013) that measure performance against agreed standards and can demonstrate over time where there is improvement. KPIs are therefore useful in providing accountability and assurance to the person with an intellectual disability, his/her family and the public.

Quality Care Metrics

Quality care metrics are another quantifiable measurement of nursing care against agreed standards (Foulkes, 2011, cited in HSE, 2015b) providing real time data to assist individual nurses and midwives and their managers to:

■ Monitor and assess performance against evidenced based standards.
■ Quantify trends and characteristics
■ Highlight exceptional care and areas of risk which require immediate attention
■ Provide a standardised system to track and benchmark the quality of care
■ Offer direction on educational needs for healthcare staff
■ Promote staff engagement and accountability for the quality of care

The Office of the Nursing and Midwifery Services Director in the HSE established a national project team to improve care and the patient/service experience across all areas of practice. They developed a framework to support the implementation of nursing/midwifery quality care metrics in Ireland and supported the use of the web based 'Test Your Care' system for measuring identified metrics and patient experience (HSEb, 2015). National work is ongoing to develop a suite of metrics for all areas of intellectual disability nursing practice. There is an opportunity for RNIDs at all levels within services to work in partnership with individuals with an intellectual disability and with other stakeholders to identify structure, process and outcome metrics/key performance indicators in relation to the care and services which they provide.

Risk Assessment and Safety Planning

The safety of individuals with an intellectual disability is of paramount concern for intellectual disability nursing as it is a basic human right (HSE, 2014a; HIQA, 2013; HIQA, 2009). Safeguarding Vulnerable Persons at Risk of Abuse, Policy and Procedures (HSE, 2014a) provides the intellectual disability nurse with clear standards to adhere to with regard to their roles and responsibilities in understanding, detecting, managing and responding to abuse, in reporting and investigating abuse, and in supporting the abused individual and perpetrator. While risk is a major part of everyday life for individuals with an intellectual disability because of their potential vulnerability, needs, and the activities they choose (Northway, 2002; HSE, 2014a), traditional approaches to managing risk have often lead to severe restrictions being imposed on people with an intellectual disability and has, at times, increased their dependence on others (Aldridge, 2007).

As intellectual disability nurses promote the self-advocacy, independence and integration of the individual with an intellectual disability within the wider community, they are called on to plan and deliver this jointly with the person within a context that acknowledges and manages safety and assesses risk. RNIDs may see risk as having the potential to empower, if assessed and managed in a systematic and positive way, whereby community access is increased, opportunities are realised, talents are developed and potential harm is minimised (Titterton, 2005; Aldridge, 2007; Bonardi, 2009; HSE, 2009b; RCN, 2013d).

In developing safety management systems, regulations and RNIDs' training, an individual's and their family's own assessment of risk in pursuing their desire to make choices must be included in such considerations. Positive risk-taking with appropriate safeguards including organisational and team support is to be encouraged as an integral component of person-centred plans. Similarly, data systems and approaches used to monitor factors that place people at risk must also be underpinned by a commitment to prepare the work force to facilitate choice and negotiate 'risk dilemmas' in ways that reduce risk of overregulation and limitations on flexibility.

RNID respondents did understand that a balance needed to be achieved between risk and rights, and found this to be an increasingly important issue in their work. Indeed, a large number of respondents expressed the view that additional nursing skills training was needed in person-centeredness, advocacy, risk assessment, safety management and supported decision making.

The importance of learning from past experience, quality measurement and feedback on the current experience of individuals with an intellectual disability is emphasised in the HSE Corporate plan (HSE, 2015a). This requirement is also specifically noted in Theme 5 of the National Standards for Safer Better healthcare (HIQA, 2012). RNIDs need to ensure that structures and processes to measure quality are in place within their services, and, consistent with this guidance, ensure all incidents and complaints are reported and investigated in line with HSE policy.

Recommendation 26
Nurse leaders and others who are designated Persons in Charge within intellectual disability services will be supported to undertake and engage in relevant education and provided with subsequent support to develop a systematic approach to quality measurement and improvement.

Recommendation 27
Nurse leaders and others who are designated Persons in Charge will participate in the wider professional nursing fora at regional, national and international level and engage in quality related development activities.

Recommendation 28
The capacity and capability of nurses within intellectual disability services will be developed to implement and evaluate evidence-based quality improvement methodologies through the provision of relevant education programmes and subsequent support.

Recommendation 29
Nurses at all levels working in intellectual disability services will access, use and evaluate the resources and tools developed by the HSE's Quality Improvement Division to achieve a culture of person centred quality care which is continuously improving.

Recommendation 30
RNIDs will be supported to undertake training in the HSE national risk assessment and safety management guidance for intellectual disability services. The RNID should be key in its application to practice; specifically in areas of incident reporting, investigation and using findings to inform learning and change.

Recommendation 31
RNID practice will demonstrate an acknowledgement of the dynamic nature of risk, ensuring that there is ongoing multidisciplinary and collaborative review of the type and level of risk and associated updating of safety plans for individuals with an intellectual disability.

Conclusion

The findings confirmed that the changing landscape of service provision does, and will continue to present new challenges for stakeholders and service providers alike. It will also offer new opportunities for a reconfiguration of services provision offering a new context within which the unique skills of the RNID will be embraced and enhanced (see Figure 4). This will lead to continuing quality improvement of the health, well-being and quality of life of people with an intellectual disability and of their families.

Figure 5: Expansion areas of person-centred service provision

- The report itself comprises seven chapters. Following the introductory chapter, Chapter 2 presents a critical review of relevant national and international evidence-based and policy literature pertaining to the future direction of intellectual disability services and the roles of nurses and frontline carers in those services. This also includes examination of an extensive number of reports, position papers and other grey literature to supplement information from published articles, governmental policy documents and white papers. Materials were gathered through systematic searches of leading global healthcare and related databases.

- Chapter 3 describes the methodology and rationale for the design, sampling, data collection and analytic approaches.

- Chapter 4 provides the demographics of the survey sample.

- Chapter 5 presents the key findings, structured according to the themes which emerged during triangulation and analyses of the different datasets.

Findings are further contextualised and additional meaning was derived through an in-depth discussion in Chapter 6. It is from this discussion that the framework for the development of the profession and the recommendations emerged.

The report concludes in Chapter 7 by recommending a process to progress the implementation of the recommendations.

Recommendation 32

Services for Persons with a disability, in partnership with the Office of the Nursing and Midwifery Services Director will establish the appropriate structures and processes to lead, drive and monitor the implementation of recommendations 1-31 of this report.

In doing so, a Joint Implementation Group comprising Service User representatives, RNIDs, HSE, Staff representative organisations, Educators, NMBI and other relevant stakeholders will be established to undertake this work.

Their role in respect to each of the recommendations will be to:
a)   Develop a detailed action plan
b)   Identify who has lead responsibility
c)   Identify the resources required (human and financial)
d)   Outline the time frames for the implementation of the recommendations
e)   Drive and monitor the implementation plan.

A formal evaluation of the implementation of the recommendations will be undertaken in 5 years from publication.

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Chapter One

Introduction

Chapter 1

1.1 Prologue

In 2013, the Heath Service Executive commissioned Trinity College Dublin to work in collaboration on a national project to shape the future role of the Registered Nurse in Intellectual Disability (RNID) in Ireland. The aims and objectives of the project are detailed below.

1.2 Project Aim

- To determine the future role of the Registered Nurse in Intellectual Disability (RNID) who provides health and social care services to individuals with an intellectual disability and their families/carers in a changing landscape.

1.3 Project Objectives

- To review relevant national and international peer-reviewed evidence and policy literature (including "grey literature") in relation to intellectual disability services and intellectual disability nursing therein.
- To describe the profile of nurses working in HSE and HSE funded intellectual disability services in Ireland.
- To describe the current roles of nursing and support staff in health and social care intellectual disability services in Ireland identifying the variety of settings where RNIDs work and where roles have changed/expanded to meet evolving service.
- To identify the future role of RNIDs to support people with an intellectual disability in primary, secondary and tertiary care services, and across the age continuum, and to ensure application by the profession of national policy.
- To identify where and how this future role may interface with the roles of other health care professionals and volunteers in supporting people with an intellectual disability in all locations of care.
- To identify the core and specialist/advanced clinical skills and competencies that RNIDs require to ensure standardised application of policy in every location of care and support.
- To identify and analyse the gap between the current and future roles of the RNID.
- To make recommendations to the HSE Project Steering Group for the professional development of intellectual disability nurses to meet future service need (undergraduate and post-graduate).
- To make recommendations to the HSE Project Steering Group for the professional, educational and organisational requirements to support role development of nurses working in intellectual disability services.

1.4 Background

This project was undertaken in a changing landscape of service provision to people with an intellectual disability in Ireland. Renewed movement into community settings, changing demographics and culture, provision for newly emerging health and social care needs among people with intellectual disability as well as the advent of personalised supports and proposed changes to the funding mechanisms mean that the role of the RNID will develop and transform over the next decade. These changes represent both opportunities and challenges for RNIDs.

Within this context, consideration of the future role of the RNID is not only timely but a necessary factor in the development of that role and more importantly in the advent of services that will support people with intellectual disability in Ireland in the years to come. It is anticipated that this report will inform the development of the intellectual disability nursing profession so that RNIDs can change the ways in which they provide care and support to people with intellectual disability. The aim being that the transformed profession will be able to facilitate people with intellectual disability to maximise their health, well-being and quality of life.

Chapter 1 introduces the project, its purpose and the Steering Group.

Chapter 2 sets the context for the report by presenting a targeted review of relevant peer-reviewed research and grey literature. A brief history of intellectual disability nursing is followed by a review of national policy and service frameworks that will largely influence the context in which RNIDs will work in the future. The background to the provision of care from national and international viewpoints is examined as are the needs and supports required by people with intellectual disability in the second decade of the 21st century and beyond. In short, Chapter 2 sets the context for the report.

Chapter 3, the methodology chapter, explains how the work was done. This was a mixed methods study that as well as surveying potentially one-third of all intellectual disability nurses who were on the register also undertook in-depth interviews with experts in the field, examined submissions from interested parties across Ireland and, through focus groups, listened to the views of a multiplicity of people who have a stake in the outcome of this research, most notably individuals with an intellectual disability and their families.

Chapter 4 details the demographics of the nurses who responded to the survey and Chapter 5 explains the synthesised findings that emerged from the totality of the data sources and outlines the respondents to other data collection methodologies. Chapter 6 examines the findings in the context of the literature and makes recommendations based on those findings. Finally, Chapter 7 concludes the report of the project.

1.5 Project Steering Group

In meeting the aims and objectives of the project the research team was supported by a project steering group established by the Office of the Nursing and Midwifery Services Director in the Health Services Executive (HSE ONMSD), and an expert group convened by the Trinity College team. In addition to governmental departments and the HSE the following were represented on the steering group:

- Association of Nurse Managers – Intellectual Disability Services
- Directors of Nursing - Intellectual Disability Services
- HSE Human Resources
- HSE National Disability Services Office – Social Care Division
- HSE Office of the Nursing and Midwifery Services Director (ONMSD)
- Inclusion Ireland
- Irish Nurses and Midwives Organisation
- National Advocacy Service
- National Disability Authority
- National Federation of Voluntary Bodies
- Nursing and Midwifery Practice Development Director
- Nursing and Midwifery Board of Ireland
- Psychiatric Nurses Association
- Quality Improvement Division, HSE
- Services, Industrial, Professional and Technical Union (SIPTU)
- Third-level Education: representatives from the Universities and the Institutes of Technology

Appendix 1 outlines membership of:
- Project Steering Group
- The Project Team and
- Expert Group (the convening group) members

Chapter Two
Literature

"The expert RNID supporting the delivery of assessment and care, improves diagnosis and outcomes for people with intellectual disability"

Chapter 2

2.1 Introduction

This literature review begins with a short history of the RNID role to date, a consideration of the changing policy, service delivery and health environment for individuals with an intellectual disability and highlights the challenges that RNIDs and other staff groups must address. In particular the literature review is designed to:

- Highlight the historical contributions of RNIDs
- Outline definitions and the classification of Intellectual Disability
- Consider the changing policy and practice context
- Describe the current intellectual disability service system
- Illustrate the demographic trends that are producing new challenges and changing service provision
- Place RNID contributions within a changing and multidisciplinary workforce
- Reinforce the values of person-centredness and person-centred planning
- Balance promotion of opportunity with management of risk and maintenance of quality
- Offer insights on the support of family carers
- Discuss health-related, education, residential, employment, and day programming needs requiring new approaches, specifically address needs for increased health promotion
- Take a lifespan approach including addressing end of life concerns
- Review responses to the increased occurrence of dementia

2.2 History of Intellectual Disability Nursing

The need for specialised care for people with intellectual disability has been recognised since the 1940s (Scanlan, 1991; Sweeney, 2011), but it was not until 1959 that intellectual disability nurse education commenced in Ireland (Sheerin, 2000). The initial nursing approach was largely custodial, in congregated traditional institutional settings. Changes occurred over time moving philosophically from a medical model to a more social care model and from custodial congregated settings to more independent and community based settings (Sheerin, 2000, Doody et al 2012a). In light of changing philosophies, intellectual disability nurse education moved to a three-year diploma programme in 1994 and a four-year degree programme in 2002. More recent innovation has been the development of Clinical Nurse Specialists (CNS) and Advanced Nurse Practitioners (ANP) with CNS numbers increasing from 100 in 2001 to 133 in 2010 (Doody et al., 2012b) and the first two ANP positions established (Carney, 2014).

More latterly, the implementation of the 2011 Nurses and Midwives Act enhances the protection of the public in its dealings with nurses, provides for their registration and regulation, and enhances the high standards of professional education, training and competence of nurses. Revised standards and requirements for the preparation of undergraduate nurses caring for individuals with an intellectual disability were published by the Nursing and Midwifery Board of Ireland in February 2016.

2.3 Definitions and Classification of Intellectual Disability

The Disability Act 2005 sets out the following definition: *"disability", in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment"*

Intellectual disability is *"a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. The disability originates before the age of 18."* (American Association of Intellectual and Developmental Disabilities, 2014). Intellectual Disability is now the preferred term for a condition which is sometimes referred to as Mental Retardation in the United States, Developmental Disabilities in Canada, and Learning Disability in the United Kingdom (POMONA II, 2008).

The severity of Intellectual Disability (ID) is correlated with intelligence quotient (IQ) scores of mild (55-70), moderate (40-55), severe (25-40), and profound (below 25). There are also various aetiologies of intellectual disability, including genetic (X-linked, other chromosomal), metabolic, teratogenic (congenital infections, chemical agents), central nervous system defects, other birth defects, neonatal, perinatal, causes that are multifactorial, and causes of no known aetiology (Morgan et al., 2008; Ellison et al., 2013).

Disorder Characteristics

Intellectual disability consists of impairments in general mental abilities in an individual that impact on adaptive functions in three areas, or domains (American Psychiatric Association, 2013a, 2013b). These domains determine how well a person is able to cope with everyday activities.

- The *conceptual domain* includes skills in language, writing, reading, maths, reasoning, memory and knowledge.
- The *social domain* refers to empathy, interpersonal communication skills, ability to make and retain friendships, interpersonal communication skills, and similar capacities.
- The *practical domain* consists of self-management in areas including personal care, money management, job responsibilities, recreation and organisation of work and school tasks.

Intellectual disability begins during the developmental period. The disorder is considered to be chronic, and it often co-occurs with other mental conditions such as depression, autism spectrum disorder, and attention-deficit/hyperactivity disorder (American Psychiatric Association, 2013b).

Changes in Definition of Intellectual Disability

Changes in the definition of intellectual disability reflect the transition from a medical oriented approach to disability, where disability is regarded as a person-centred trait or "deficit", to a more ecological approach, where the disability is defined in the context of the nature of interaction between the person and his/her environment, and the supports needed by an individual to enhance or maximise this interaction (Schalock et al, 2007; POMONA II, 2008; Greenspan and Woods, 2014).

Prevalence of Intellectual Disability

In Ireland the National Intellectual Disability Database (NIDD) collects information on people with all levels of ID, eligible for, or receiving services in a full range of residential circumstances (Doyle et al 2017).

- At the end of December 2016, there were 28,275 people registered on the NIDD, representing a prevalence of 6.16 per 1,000 population.
- There are more males than females registered with an ID, 58.8%:41.2%.
- Prevalence of mild ID was 2 per 1,000, and the prevalence rate for moderate, severe or profound ID was established as 3.59 per 1,000.

As those with mild ID are less likely to require specialized services, the number of people on the NIDD with a mild intellectual disability may be underestimated.

2.4 Changing National Policy and Service Delivery Context

Ongoing developments in disability service provision have been reflected in the changing roles and education of nurses to date. However better connectivity between Irish disability policy, intellectual disability service and health and social care service delivery (DoH, 2012a; HSE, 2012a) needs continuous attention. The Report of Disability Policy Review (DoHC, 2010a) highlighted nearly ninety percent of people with intellectual disability receive services from a sole intellectual disability service provider in segregated group settings away from their local community. Work continues on moving from residential and day-care provision primarily in congregated and campus-based settings to person-centred and community-based approaches encouraging social integration and inclusiveness (Sheerin, 2012a, 2012b; HSE, 2011 Sheerin et al. (2015). However, some people with intellectual disability remain in other services including psychiatric institutions (DoHC, 2006; Doyle et al 2017) and the care these clients receive can be improved (DoHC, 2006).

Key policy documents guiding change include The Disability Strategy (GoI, 2004), the Disability Act 2005 (GoI, 2005), Vision for Change (DoHC, 2006), Time to Move on from Congregated Settings (HSE, 2011), Value for Money (DoH, 2012c), Progressing Disability Services for Children and Young People (HSE, 2012a) and New Directions (HSE, 2012b).

These documents raise the need for change in assessment of need (GoI, 2005). In addition, there is need for greater integration with general population health and community services as well as interventions to address specific health and social care issues of people with intellectual disability. All of these have implications for the development of professional skills to meet the care and support needs of people with intellectual disability and of their families whilst facilitating them to pursue their desire to live ordinary lives in ordinary places. Two policy driven areas are of particular note, firstly, the implementation of person-centred care and, secondly, managing quality, safety and risk management.

2.4.1 Health Delivery Change

Policy documents driving change go beyond those specifically targeting disability issues. Relevant health-related policy documents include *Healthy Ireland – A Framework for Improved Health and Wellbeing 2013 – 2025* (DoHb, 2013); *Future Health (A Strategic Framework for Reform of the Health Service 2012- 2015)* (DoH, 2012a); *National Carers' Strategy* (DoH, 2012); *National Positive Ageing Strategy* (DoHa, 2013); *Irish National Dementia Strategy* (HSE, 2014b); *Palliative Care For Children With Life-Limiting Conditions In Ireland- A National Policy* (DoHC, 2009); and *Tackling Chronic Disease – A Policy Framework for the Management of Chronic Diseases* (DoH, 2008a). These documents are encouraging the support of screenings, health promotion practices, in-home care, quality care for all patients and the development and implementation of evidence-based assessment and clinical pathway approaches to the management of long term and progressive conditions including dementia.

2.4.2 Service Delivery Changes

Description of service provision and locations of care
The provision of services to people with ID in Ireland, and elsewhere has moved from a medical care model towards a social care model that focuses on choice, social inclusion, and rights of people with ID.

- There were 27,863 people with ID in receipt of Services as of December 2016; of these 27.3% (7,612) were in receipt of full time residential services (including full time residential care or community group homes).
- Of those registered on the NIDD in December 2016, 68.7% (19,416) lived at home with parents, siblings or relatives.
- As of December 2016, 99.8% of people in receipt of services availed of at least one day programme.
- Multidisciplinary support services are being increasingly accessed by those receiving services (85.5% in 2016) (Doyle et al 2017).

Within this history of policy related change there has also been considerable realignment of staff (ERHA, 2003). The older institutional service delivery models were traditionally physician, psychiatrist and/or religious order-led, with significant numbers of RNIDs. More recently, there is a range of provider systems with varying levels of reliance on institutional beds, campus settings, community based group homes, specialist health clinics, special schools, day programmes, sheltered workshops and work programmes, independent apartments, and supports for family carers. These changes have been accompanied by less reliance on medical professionals in leadership roles (ERHA, 2003).

An expansion of other staff groupings includes speech and language therapists; physiotherapists; occupational therapists; psychologists; vocational and day programming support staff; social workers; and special educators with a recognition of the person with intellectual disability and their family members as part of the care team. A significant change in staffing, particularly in out-of-home residential programming of all kinds, was the development of a cadre of social care workers, the increasing rigour of their training and the emergence of those with social care training in leadership positions within services. Currently, there are service providers who rely almost exclusively on this group, others who maintain a mix of social care workers and RNIDs and some who continue to rely primarily on RNIDs to address all aspects of daily care (HSE, 2011). Finally, there are newer positions of health care assistants and trends by some providers to utilise general nurses to manage specific health care needs.

With a commitment to address the holistic needs of people with intellectual disability, the RNID in the past played multiple roles. However, as has been noted, the service arena has changed and the way in which the needs of service users are met has also changed (ERHA, 2003). Therefore, in an increasingly multidisciplinary service there is a need to consider the unique roles of RNIDs, how they most effectively work with other disciplines and how, in their roles, they ensure continued attention to holistic care.

2.4.3 Person-Centredness and Person-Centred Planning

Social Role Valorization was developed from its predecessor the principle of normalisation by Wolf Wolfersberger in the 1980s. Both approaches attempt to address the devaluing of people with intellectual disability that was evident in 1960s by revaluing how they are seen by society both as people and as social beings. These ideas ushered in a new paradigm of support for people with intellectual disability which aimed to replace the care based model that had previously existed. Social role valorisation may be considered an important forerunner of approaches to support that are based on person-centredness as it focuses on the positive roles that people with an intellectual disability can play in society and is grounded in their strengths and capacities, rather than in their weaknesses and inabilities (Osburn 2006).

Person-centredness, which is an overarching commitment for RNIDs and their practice, is a way of interacting with another that acknowledges the other, and recognizes that such acknowledgement is best fulfilled through an implicit acceptance of and respect for all that the other is (McCarron et al., 2013a). Person-centred planning (PCP), in turn, is an approach to the development of a service that is informed by person-centredness and is a "way of discovering how a person wants to live their life and what is required to make that possible" (NDA, 2005a, p.12). Such a planning approach puts the person with ID at centre stage as of right and places an onus on the service, the family and the person themselves to discover and implement what is needed to make what the person wishes to do and how the person wishes to do it a possibility. A serious commitment to envisaging a new future for the person and a genuine commitment to make it happen are both required (NDA, 2005a). Relationships between paid staff and the user of the service also become reciprocal in this approach and previous power imbalances are overcome when knowledge of professionals becomes subordinate to personal knowledge of the individual with ID (O'Brien & Lovett, 1992). Fundamentally, person-centred care calls for a change in the roles and responsibilities of professionals. It requires people with intellectual disability and significant others to work in partnership to deliver care (NDA, 2005a, 2005b) and turn aspirations into reality (Health Foundation 2015). For RNIDs, their commitment to a person-centred approach must go beyond simple participation. It must include advocacy, training of others, and the roles of assuring that plans are implemented and voices are heard even when the people with intellectual disability have difficulty communicating.

2.4.4 Quality, Safety and Risk Management

Quality of care in Irish intellectual disability residential services is regulated by the *Health Act 2007* (amended) (GoI, 2007) and *National Standards for Residential Services for Children and Adults with Disabilities* (HIQA, 2013a). This framework provides for the monitoring of human rights and quality service standards for people with intellectual disabilities receiving residential health and social care services other than via mainstream mental health services. These come under the *Mental Health Acts 2001* and *2008* (GoI, 2001) and the *Quality Framework for Mental Health Services in Ireland* (MHC, 2007; 2009).

In these policies, there is a focus upon quality, safety and risk, and a need is to increase awareness among main stream services professionals of barriers to care that reinforce health inequalities and the opportunities to reduce or remove such barriers. As people with intellectual disability increasingly live community-based lives they face the same exposures as others to the potential for financial, physical and sexual exploitation. Yet, efforts to avoid or manage such risks may have the unintended consequence of restrictions being imposed on the lives of people with intellectual disability (Aldridge, 2007). Instead, risk management should be focused upon increasing self-advocacy and independence and on harm reduction strategies implemented by staff with the skills to interview effectively those who may have been abused and to apply supportive interventions to address the physical and psychosocial toll of abuse (McCallion, et al., 2004). The development of such skills will be an important challenge to be addressed in undergraduate and post-graduate RNID education.

In Ireland, quality is defined by the four quality domains set out in the Safer Better Healthcare Standards (HIQA, 2012):
1. Person centred - care that is respectful and responsive to individuals needs and values and partners with them in designing and delivering that care
2. Effective - care that is delivered according to the best evidence as to what is clinically effective in improving an individual's health outcomes
3. Safe - care that avoids, prevents and minimises harm to patients and learns from when things go wrong
4. Better health and wellbeing - care that seeks to identify and take opportunities to support patients in improving their own health and wellbeing

Quality improvement (QI) is the combined and unceasing efforts of everyone - healthcare professionals, patients and their families, researchers, commissioners, providers and educators - to make the changes that will lead to
■ better patient outcomes
■ better experience of care
■ continued development and supporting of staff in delivering quality care
<div align="center">(HSE 2016)</div>

2.4.4.1 Quality Measurement Frameworks

Quality improvement is also strongly linked to analysing and intelligently using information about the service (HSE 2015a). Having access to accurate, valid, reliable, timely, relevant, legible and complete information is important to this process (HIQA 2013). In addition to regulatory and thematic inspections by HIQA, a number of other mechanisms to identify, collect, collate and analyse quality data are currently being developed or are in use within services in Ireland.

■ Key performance indicators
■ Quality Care-Metrics - including service user experience
■ Caring Behaviours Assurance System-Ireland (CBAS-I)
■ Outcomes for Disability Services
■ Staff engagement
■ Other quality measurement frameworks

Key performance indicators
Using key performance indicators (KPIs) is an effective approach to measuring specific elements of nursing care considered integral to the overall experience of the individual with an intellectual disability. They measure performance against agreed standards and can show trends to demonstrate improvements being made over time and provide accountability and assurance to the person with an intellectual disability, his/her family and the public.

Key performance indicators within disability services currently measure a mix of structure, process and outcome indicators. At a national level rate based, count and sentinel KPIs such as activity relating to the personal assistant or home support service, indicators relating to implementation plans for children's services, number of children receiving a residential service, access to services etc., are measured, reported and used by the Community Healthcare Offices (CHO's) and Community Strategy and Planning in the HSE to further improve the service provided.

Quality care metrics
Quality care metrics are quantifiable measurements of nursing care measured against agreed standards (Foulkes, 2011; as cited in HSE, 2015b) providing a "real time" measuring system for individual nurses and their managers that:
■ monitors and assesses performance against evidenced based standards
■ quantifies trends and characteristics
■ highlights exceptional care and areas of risk which require immediate attention
■ provides a standardised system to track and benchmark the quality of care
■ offers direction on educational needs for healthcare staff
■ promotes staff engagement and accountability for the quality of care.

Feedback from service users on their experience is a "central pillar" of quality in healthcare and is positively associated with outcomes such as safety and engagement in health promotion activities (Doyle et al., 2013, p1).

The Office of the Nursing and Midwifery Services Director in the HSE established a national project to improve care and the "patient" experience across all areas of practice using a framework (Figure 6), supported by the use of the web based "Test Your Care" system of measurement of identified metrics and patient experience (HSE, 2015b).

Figure 6: Framework for quality care metrics
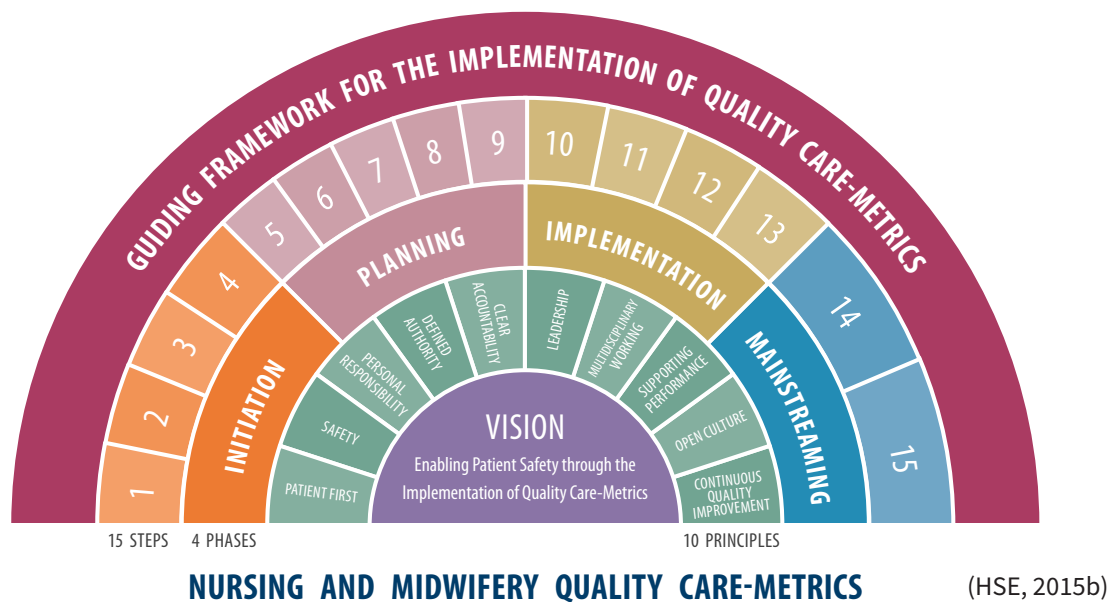
NURSING AND MIDWIFERY QUALITY CARE-METRICS   (HSE, 2015b)

RNIDs at all levels within services will need to work in partnership with individuals with an intellectual disability and with other stakeholders to identify structure, process and outcome metrics/key performance indicators in relation to the care/service they provide.

Caring Behaviours Assurance System-Ireland (CBAS-I)
Caring Behaviours Assurance System-Ireland (CBAS-I) has been adapted from the original CBAS evidenced based framework, to fit the framework of the eight themes arising from the National Standards (HIQA, 2012). It is an evidence based system that offers a mechanism for health care employees to provide assurance that care is delivered in a safe, quality, compassionate, person-centred care way, from 'Bed to Board' enabling healthcare teams to understand, question and co-develop strategies to become more effective in the provision of safe, quality, compassionate, person-centred care.

Outcomes for Disability Services
As part of the implementation of the Transforming Lives policy, the National Disability Authority of Ireland are working with the Department of Health and the Health Services Executive to develop outcomes and associated measurements for disability services. These outcomes will relate to community living, choice and control, social participation, personal relationships, education and personal development, employment and valued social roles, quality of life, health and well-being and safety.

Staff engagement
The active engagement of staff with their work and their organisation has an impact on both service user and staff outcomes (West and Dawson 2012). The HSE commenced national staff surveys in 2014 and subsequently developed structures and processes to progress this concept nationally. RNIDs are encouraged to participate; to improve their experience of work and to support ongoing improvements in care.

Other quality measurement frameworks
A "Health Equalities Framework" (HEF) outcome measurement system for learning disability services has been developed and tested in the UK and has demonstrated some early positive results in relation to outcome measurement for persons with an intellectual disability. It measures the contribution of nurses and others in reducing the exposure to known determinants of health inequality for persons with an intellectual disability. Focussing on these five determinants (Emerson et al 2010), Social, Genetic and Biological, Communication, Behaviour and Lifestyle and Service Quality, health inequality indicators have been developed for each of these and the person with an intellectual disability can be rated against a five point impact scale. Indicator and descriptor statements support the staff with the rating to be selected.

2.4.4.2 Quality Improvement in Services

Demonstration of a sustained focus on safety, welfare and quality improvement, to make real and tangible changes in the lives of individuals with an intellectual disability is a key priority in the HSE. In doing so they have established a cross sectoral National Implementation Taskforce to drive the change programme system wide, providing additional structures and processes at national and local level to support compliance with national standards and engender a culture of continuous quality improvement within services. Examples of initiatives are:

■ Appointment of post holders at both national and local level e.g., quality and safety personnel, heads of social care
■ Policy development and implementation e.g., Safeguarding of Vulnerable Adults from Abuse, Safety Management
■ In partnership with the Quality Improvement Division, providing enablement programmes to support care improvement for adults in residential services e.g., Six Step Programme
■ Forums to support sharing of learning and listening e.g., Summits

A key challenge for the National Implementation Task Force on the Safety of Vulnerable People in Residential Disability Services is to identify how we can build capacity together so that our organisations can respond to what each individual person wants and needs to live the life of his/her choosing. The challenge for services is to support individuals with an intellectual disability to choose where they live; who they live with, and ensure that they have choices around what they do every day, with tailored supports for each person. RNIDs will be required to actively participate in these quality improvement initiatives in order to meet these goals.

The report of the Aras Attracta Swinford Review Group (2016) states that there is a compelling case for change in the way disability services are delivered. Change is required at a national level and across the disability sector, particularly in light of national policy on the move to non – congregated settings. It is paramount that service funders and providers have a clear understanding of what daily life is like for people living with a disability. The Review Group elucidated a suite of recommendations for further improvement in service provision to ensure any learning from this review is reflected and promoted throughout the wider intellectual disability sector.

Three overarching recommendations of the Review Group relate directly to service delivery in Aras Attracta:
■ A move to a rights- based social model of service delivery,
■ The voice of residents need to be facilitated, listened to, and promoted,
■ Strengthening and enhancing leadership and management.

2.5 The Demographics of Intellectual Disability in Ireland

The true total population of people with an intellectual disability in Ireland is undetermined (Ryan & Rice, 2012). In December 2016 there were 28,275 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 et al 2017). This represents a prevalence rate of 6.16 per 1000 of the population in the Irish Republic, whereas international prevalence rates are usually estimated at 2% of the population (DOH, 2001; Janicki et al, 2012). This likely reflects an under-representation of people with a mild intellectual disability (DoHC, 2006) and there is growing concern that increasing ethnic diversity of the Irish population may mean variations in rates of intellectual disabilities (DoH, 2001).

2.5.1 The Demographics of Children and Young People

The population of children and young people with intellectual disability is expanding and currently nearly 36% of those registered on the NIDD are under the age of 20 (Doyle et al 2017). In addition, the rate of new-borns with intellectual disability, children with intellectual disability who have life-limiting conditions and the survival rates of children and young people with intellectual disability who have complex physical health care needs, have also increased significantly. This growth is due to their increased life expectancy, and improvements in medical care and services (McCarron et al., 2011a; Nakken and Vlaskamp, 2007; McConkey et al 2007; HSE, 2009a; Simkiss, 2011). Many have life-limiting conditions, rare syndromes, multiple and complex needs, and require high levels of assistance and support (Mafuba and Gates 2014a; Eddy, 2013). They are particularly vulnerable and their care is challenging due to

their wide range of health and social care needs (Phelvin, 2012). Health issues can include respiratory, gastrointestinal conditions and epilepsy, with an increasing number regarded as "technology dependent" due to their need for oxygen, suction equipment, tubes for feeding and intensive medication (Mencap, 2012; HSE, 2009a; Simkiss, 2011).

While the vast majority of children and young people live at home supported by family or relatives, approximately 2% live in community group homes or residential services. The most commonly utilised services are nursing, speech and language therapy, occupational therapy, psychology, early intervention, home intervention, preschool, schools, in home and residential respite and palliative care. In this service landscape there is a requirement for RNIDs to understand policy, legislation and systems relevant to health and social service provision. This also means that RNIDs should recognise the complex nature of their contribution and that of other health and social care professionals within service provision (Kelly & O'Donohoe, 2014; Mafuba and Gates, 2014a; DoH, 2014; HSE, 2009a; DoHC, 2010a). In particular there is a need for the RNID to develop community care skills for working with the child and family in the home.

2.5.2 The Demographics of Ageing

The numbers of individuals with intellectual disability over the age of 35 has steadily risen (Kelly & O'Donoghue, 2014) highlighting that adults with intellectual disability are experiencing increased longevity. For the first time we have sizeable groups of individuals with intellectual disability ageing and needing related services. Ageing persons also represent a greater number of those either using, or in need of out-of-home care, more directly impacting staff service delivery in provider agencies.

People with intellectual disability also have low rates of employment which means a heavy reliance on government income support schemes that are close to, or below poverty lines. They are less likely to have married or have had children and do not have robust networks of close friends (McCarron et al., 2011a). Taken together this means that people with intellectual disability are dependent upon staffed living and programming situations and/or the small number of family members who provide most of their care (Bigby et al., 2014; Duggan & Linehan, 2013; McCallion & McCarron, 2015).

Life expectancy for people with intellectual disability has increased from an average 18.5 years in 1930 to 59.1 years in 1970 to an estimated 66.2 years in 1993 (Braddock, 1999), with projections that by 2020 the number of people with intellectual disability aged over 65 will have doubled (Janicki & Dalton, 2000). There are reports of similar growth in the United Kingdom, other European countries and Australia (Bigby et al., 2014). However, recent data and discussions in *The Lancet* (Heslop et al., 2014; McCallion & McCarron, 2014), and recent symposia at International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) in Europe have highlighted that continued growth in longevity has stalled over the last 10 years, despite there being more older adults with intellectual disability (McCallion et al., 2014; McCarron et al, 2014). Findings that there are higher rates of avoidable deaths from manageable health conditions point to the need for more concerted and skillful health care delivery for people with intellectual disability (Heslop et al., 2014).

Services, particularly residential care and community based group homes, the primary service locations for RNIDs and other professionals in the intellectual disability field, are therefore increasingly about care for an ageing population.

2.6 Transitions

The intellectual disability services' network has devoted considerable resources to developing work and day programme placements and community-based living arrangements for people with intellectual disability. A philosophy of care has emerged which is prevalent in most developed countries (Schalock et al., 2002) with optimum living plans for people with intellectual disability assuming that the individual shall live in the community; control to the extent possible one's life; have a vital and supportive network of friends and relationships; and experience more independence this year as compared to last (McCallion & McCarron, 2007).

There has been much attention to the transition from home to school and the issues of early intervention programming particularly for people with autism, the management of mainstreamed education rather than reliance upon special schools, and the transition from school to adult services including potential movement to independent

and/or out-of-home supervised living arrangements (Cobb & Alwell, 2009; Floyd et al., 2009; McIntyre et al., 2006). Such approaches to the support of people with intellectual disability who are transitioning happen both within intellectual disability services and in mainstreamed education outside of the traditional system. Support services for children also include a range of professionals such as teachers (traditional and special education); special needs assistants; physiotherapists; occupational therapists; psychologists; speech therapists and, to a limited extent, nursing and physician services. The transfer to adult services is often less supportive particularly if the individual with intellectual disability was not previously linked to an intellectual disability service. They may only receive day services, and due to high staff turnover the comprehensiveness and continuity of these services are often compromised. Those who transition to out-of-home care may receive many of the same interventions but it is likely that there will be again different staff and differences in intervention intensity.

Adulthood and old age may also be a time of losses. When people with intellectual disability did not live to old age it was possible for parents to outlive their offspring (McCallion & Tobin, 1995). Today, it is more likely that, for people with intellectual disability, there will be multiple losses in their lifetime. These include loss of parents, other valued friends and neighbours, and many transitions in key staff in day, residential and community group home programmes (from transfer and promotion of staff more than death) with whom people with intellectual disability have contact (Lightfoot & McCallion, 2015). Additionally, such losses may also presage other important life transitions, for example movement from the family home to an out-of-home placement and related separation from well-established and valued social networks and neighbourhoods (Bigby et al., 2014).

Attention to transition issues has not always been a central role for RNIDs. However, the trends outlined suggest that just as there is a need for attention to the transitions at earlier ages such as to school, from school to work and from home to out of home placement, RNIDs will be needed to play roles in supporting people with intellectual disability in their late life transitions (McCallion & McCarron, 2015). A key question in all of these transitions is who will be the advocate for the person with intellectual disability and what principles will drive decision-making and support. Given the life transitions and potential for ageing-related health concerns experienced, the needs of both families and of people with intellectual disability are likely to change. Given new or increased impairments associated with ageing there is a need for retirement planning; ageing-focused day programming; support of health needs; and adaptations of homes and programme sites to maintain personal independence, (Lightfoot & McCallion, 2015; McCarron & Griffiths, 2003). Planning for transitions in living situations will be more prominent, whether moves to live with other family members, to out-of-home care or to more community-based out of home care (Janicki et al, 2005). RNIDs will be called upon to help plan such moves, to ensure that the individual is part of the decision and to help support the post-move adjustment of the individual involved.

Advocacy has the potential to reduce individuals' feelings of disempowerment by enabling them to gain a sense of control. Advocacy may be direct in that staff utilise their relationship with the person, access to resources and decision-making, and their knowledge of healthcare and service systems to act on behalf of the person (Teasdale, 1998). Indirect advocacy, by assisting the person with intellectual disability and their family to advocate for themselves, in order to reduce or eliminate barriers encountered, ensures that their views are heard and acted upon (Jenkins & Northway, 2002). There are both general and specialist advocacy concerns. For RNIDs in particular there is a need for a skill set in supporting self-advocacy and providing direct advocacy themselves for inclusion of people with intellectual disability in mainstream health services and for the receipt of quality healthcare when they are included.

2.7 Illnesses and Conditions that Compromise Independent Living

The experience of chronic illness among people with intellectual disability and the similarities and dissimilarities with experiences of the general population have been the subject of a number of investigations. These have pointed out realities of a high prevalence of disorders, many of which go unrecognised and untreated, with significant implications for the lives of the individual, their family and services (Scheepers et al, 2005; Krahn et al., 2006, Gibbs et al., 2008; Van Schrojenstein Lantman-de Valk *et al*, 2008; Emerson et al., 2011a, 2011b; Emerson, 2011; McCarron et al., 2011a; NSW Health, 2012).

In addition, a recent clinical review on the management of care for adults with Down syndrome, (Jensen, & Bulova, 2014), highlighted that ageing in this population is a relatively new territory with little evidence to guide care. The need is highlighted for all practitioners to be vigilant for increased rates of hypothyroidism, obstructive sleep apnoea, osteoporosis, dementia and respiratory problems.

This need for increased vigilance is particularly true for all people with intellectual disability as they live longer. Compared with older adults in the general population, ageing people with intellectual disability also show:

- Higher rates of chronic conditions such as dementia (Jokinen et al, 2013; McCarron et al., 2014b)
- Higher rates of osteopenia and osteoporosis (Burke et al., 2015)
- Different patterns of co-occurring conditions such as mental health concerns (McCarron et al., 2013b)
- Higher rates of unhealthy lifestyles (Haveman et al, 2010; McCarron et al., 2013b)
- Higher levels of medication use (O'Dwyer et al, 2016; Raghavan & Pater, 2010)

In the findings for Wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), rates of diagnosed osteoporosis at 16.4% were a little higher than TILDA reports (14.3%) for the general population. More importantly, when measured objectively as part of the IDS-TILDA study, high levels of osteopenia (37% compared to 14% in the general population) and osteoporosis (35% compared to 28%) were discovered. This suggests that at least seven out of ten people with intellectual disability over age 40 have poor bone health, most are undiagnosed, and primary care and other health practitioners may be unprepared for the rates of poor bone health and may not be considering such morbidity in their treatment of other conditions and identification of pain concerns (Burke et al., 2014). As RNIDs work to manage these complex health conditions and respond to the challenges of ageing, they must be prepared to assume a specialist and leadership role in the identification and management of osteopenia and osteoporosis.

Concern also goes beyond older adults. With the advances in diagnosis and follow-up, increased ageing and improved health care, there is a new and growing population of children, adults and ageing people with intellectual disability presenting a range of complex needs and multiple disabilities unlike those previously addressed by services (Parrott et al., 2008; Torr & Davis, 2007). For example, individuals with profound intellectual and multiple disabilities are unable to communicate verbally, walk or feed independently and require high levels of assistance in daily living (Sullivan, 2008). Also common is the presence of sensory or physical disabilities, mental health problems and complex health needs (Mencap, 2012). Many have had neonatal intensive care due to severe levels of neurological damage (Hewitt-Taylor, 2009; Sullivan, 2008) and may be "technology dependent" due to their need for oxygen, suction equipment and tubes for feeding (Mencap, 2012). Incidence of rare syndromes is also increasing given pre-term neonatal survival rates and rates of foetal alcohol spectrum disorder (FASD), attention deficit hyperactive disorder (ADHD) and autism spectrum disorder (ASD) are also increasing, compounded by wider issues such as social disadvantage and poverty (Simkiss, 2011; Nicholl et al., 2013).

These physical health challenges increase demands on caregivers, particularly when they may be dealing with their own increasing health concerns. Higher and different co-morbidity, poorer management of health conditions and minimal emphasis on prevention mean that significant physical health-related burdens fall upon caregivers (Bigby et al., 2014; Lightfoot & McCallion, 2015; McCarron et al., 2013b). However at present the training of health professionals does not adequately address working with older adults with intellectual disability, with many health professionals being unfamiliar with typical health and functioning issues (Haveman et al., 2011). As a result poorly prepared health professionals may miss health problems in people with intellectual disability (McCarron et al., 2013b).

2.7.1 Psychosocial Health

Health difficulties include psychosocial health concerns. A recent summary of available studies suggests that total rates of psychosocial concerns range from 20 to 40% of assessed older people with intellectual disability. The occurrence of most mental health concerns appears to decline with age, except for dementia, which increases with age (Jacobson, 2003). Six factors are posited to place people with intellectual disability at particular risk:

(1) Their life experiences
(2) Behavioural phenotypes (particularly for dementia)
(3) Side effects of medications which they may metabolise differently from others
(4) Higher rates of sensory impairments which increase communication difficulties
(5) Ageing specific disorders such as Alzheimer's; cardiovascular disease and cancer which may predispose to depression and anxiety

(6)   Life events such as bereavements and abuse (Tyrrell & Dodd, 2003). Recent findings from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing confirm such findings although cardiovascular and cancer illnesses appear to be lower than than reported elsewhere and epilepsy, mental health concerns, unaddressed pain, comorbidity, and the consequences of polypharmacy appear to be of more importance (McCarron, et al 2014)

Individuals with intellectual disability are particularly vulnerable for developing behaviours that challenge (Dosen, 2007) with a prevalence rate of between 10% and 15% (Broadhurst & Mansell, 2007). These behaviours that challenge place the individual and his/her family at risk and can prevent them from having ordinary experiences in the community (Cooper et al., 2009; Heyvaert et al., 2012). These findings that as many as 50% of older adults with intellectual disability and mental health problems present with behaviours that challenge is another reason why attention to psychosocial health is of concern for RNIDs (Jacobson, 2003).

2.7.2 Autism

Autism is a particular and growing concern among younger people with intellectual disability. LaMalfa and colleagues (2004) concluded that 40% of people with intellectual disability have autism, whilst 70% of people with autism have intellectual disability. The combination of intellectual disability and autism presents many challenges and deficits across a range of behaviours and skills that are not seen in intellectual disability or autism alone (Boucher et al., 2008). People with severe and profound intellectual disability and autism spectrum disorders (ASD) have greater deficits in social and adaptive behaviour and more behaviourally-based feeding problems, particularly food selectivity and refusal, compared to people with intellectual disability alone (Fodstad & Matson, 2008, Matson et al., 2003). Children with intellectual disability and autism tend not to grow out of these behaviours that challenge which persist over the individual's life (Murphy et al., 2005). The severity of intellectual disability has been related to higher rates of behaviours that challenge, with self-injury, aggression and stereotypies evident (Goldmon et al, 2009; Murphy et al., 2009). There are new studies emerging of the continued presence and challenges of autism as people with intellectual disability age (Seltzer et al., 2004).

2.7.3 Dementia

Alzheimer's dementia in people with Down syndrome exceeds that of the general population. One study reported a prevalence of 2% in people aged 30-39 years, 9.4% in people aged 40-49 years, 36.1% in people aged 50-59 years, and 54.5% in people aged 60-69 years (Prasher, 1995). These rates are considerably higher than prevalence rates reported for the general population of between 4.3% to 10% in people aged 65 years and over (see for example Hoffman et al., 1991). Reports of the prevalence of Alzheimer's dementia for other people with intellectual disability (who do not have Down syndrome) are more equivocal, with some finding that rates are similar to the general population (Janicki & Dalton, 2000) and others that it is higher (Cooper, 1997). People with Down syndrome and dementia experience an early and precipitous but then extended decline in cognitive functions and skills (McCarron et al., 2014b). They pose behaviours that challenge and care concerns such as wandering, sleep disturbance; and incontinence; and may present with auditory and visual hallucinations (Holland, et al, 2000; Tyrrell et al, 2001). In addition, symptoms of depression and other mental health concerns may be mistaken for symptoms of dementia and may also co-occur with dementia, further impairing functioning and compromising behaviour (McCarron & Griffiths, 2003). IDS-TILDA reported that the prevalence of dementia in people with Down syndrome doubled over a three-year period from 15.5 % to 29.5% (McCarron et al., 2014b). In addition, a recent longitudinal follow-up of a group of women with Down syndrome confirmed earlier reports of increased incidence of other health conditions when dementia symptoms were present. These included hearing, vision and mobility impairments and increased incidence of depression, epilepsy and lung disease (McCarron et al., 2014b).

There are, however, examples of nurse-led interventions that offer specialised support including regional dementia clinics, specialised dementia-ready units, collaborative intellectual disability service/hospice support of end of life, and dementia supportive day programmes with health components in Ireland (Fahey-McCarthy et al., 2009; McCallion & Janicki, 2002; McCarron et al., 2014c). Equally, equipping staff to be members of the care teams for such interventions is another challenge for RNID educational and training programmes.

2.7.4 Epilepsy

The prevalence of epilepsy in people with intellectual disability at 14% to 44% (Bowely & Kerr, 2000, Beavis et al., 2011) greatly exceeds the 0.4-1% reported for the general population (Picot et al, 2008). Epilepsy also appears to be associated with severity of intellectual disability, increasing from 6% of those categorised as having a mild intellectual disability, 24% of those categorised as having a moderate intellectual disability and rising to 50% of those with profound intellectual disability (Lhatoo & Sander, 2001). Associated morbidities and global skills deficits make epilepsy care in people with intellectual disability highly complex (Espie et al., 2003). The prevalence of epilepsy is low (1.4%) in children with Down syndrome but increases in the fourth and fifth decades of life for people with Down syndrome, coincident with the onset of Alzheimer's disease with prevalence rates ranging from 78% -98% (Evenhuis, 1990, Visser et al., 1997, Tyrell et al., 2001, McCarron et al., 2005). Increased prevalence of mental health problems have been reported to be associated with epilepsy and there are concerns about the risk of both diagnostic over-shadowing and under-shadowing of epilepsy diagnosis in people with intellectual disability. This arises from communication difficulties, inadequate history, staff turnover, cognitive and behaviour challenges, poor tolerance of tests such as EEG and brain imaging, and motor problems (Chapman et al., 2011). In addition, polypharmacy is high in people with an intellectual disability (McCarron et al., 2011a). In other words, there is often long term exposure to drug treatments for mental health and behaviours that challenge. Adverse medication effects including involuntary movements and twitching, gait disturbance, and tardive dyskinesia can be easily misinterpreted as seizure activity. Epilepsy care, therefore, is complex (Kerr et al., 2009) and is increasingly a critical concern as age advances for people with intellectual disability, particularly those with Down syndrome. The training of those making epilepsy diagnoses and supporting care appears to be of concern with findings of expert RNID intervention improving diagnosis (John, 2008). This suggests that such care be identified and supported as part of the RNID role. This may also be an important area for advanced training.

2.7.5 Healthcare Utilisation

The additional consequence of these health needs for people with intellectual disabilities is that they are high and people with intellectual disability are frequent users of all healthcare services and require access to primary care, paediatric, general hospital and specialist intellectual disability services (Slevin et al., 2007; DoH 2008b; Gibbs et al., 2008; Perera et al., 2009). Attention has also been drawn to increasing demands on both general population and specialist healthcare systems as the population of children, adults and older people with complex care needs increase and make greater use of community-based, general population resources (Backer, Chapman & Mitchell, 2009; Webber et al, 2010; NSW Health, 2012). There are also concerns that, as people with intellectual disability make greater use of community-based healthcare resources, the staff and facilities involved are often unprepared (McCarron & Lawlor, 2003). For example, recent findings on different patterns and combinations of morbidities, lack of access to and use of preventive interventions and inattention to population health among people with intellectual disability raise serious concerns about the preparedness in general population health delivery (McCallion et al., 2013; McCarron et al., 2013b). It is well documented that many healthcare practitioners have limited knowledge and experience of working with people with intellectual disability. Further, there is a limited focus in education programmes of their distinct needs (An Bord Altranais, 2005a, 2005b; Lewis & Stenfert-Kroese, 2010). This is another area for new roles and new initiatives.

RNIDs already have and must further develop a unique skill set in addressing complex communication and health needs of people with intellectual disability across the life span. As individuals with an intellectual disability live more and more in community-based and community settings there is a need to develop multidisciplinary mechanisms. RNIDs need to assume the role of working across primary health care and hospital-based settings. There are already examples of RNIDs serving in primary care teams in the UK (RCGP, 2010) and active steps in response to the United Kingdom's own scoping exercise on learning disability nursing are being taken to develop more specialised training (Public Health Nursing Division, Department of Health, 2014). In Ireland, there will be a similar need to consider the development of Clinical Nurse Specialist and Advanced Nurse Practitioner roles.

The Community Health Organisation Report launched by the HSE in October 2013, recommended the establishment of nine Community Healthcare Organisations (CHO) and identified the associated governance and management arrangements. These CHOs have been established. The report highlights the transitional arrangements that are required to maintain the safety and integrity of the service delivery system for all service users.

This CHO approach will position primary care at the centre of delivering services through around 90 local Primary Care Networks with average populations of 50,000 with better, more integrated access to specialised services in social care (incorporating disability service and older persons), primary care, mental health and health and wellbeing.

Arising from the entire process there is a clear consensus that in the future Community Healthcare Organisations must enable and support integrated care within community services and between the community and hospital services. RNIDs working in the community are best placed to have a central role informing and supporting primary care regarding the need to deliver rapid access to secondary care and specialised services for people with an intellectual disability. Due to both the complexity and scale of how these parts of the system fit together, disability champions in the form of the RNIDs will be required to promote integration and support individuals with an intellectual disability and their families navigate the system.

2.8 Health Management and Health Promotion across the Lifespan

Key elements of health management and health promotion are access to appropriate foods, participation in physical activity, accessing of health screening and follow-up preventive care. The availability of resources, financial and personal and support from social networks are also noted as important (McCallion et al., 2013; Taggart et al., 2013).

People with intellectual disability have higher levels of obesity (Swinburne, 2014; Lennox et al., 2007), are more likely to lead sedentary lifestyles (McGuire et al., 2007), participate less than the general population in physical activity (McCarron et al., 2014a), are more likely to consume high fat diets (Ewing et al., 2004), tend to have nutritionally poor diets with limited access to fruits and vegetables and excessive access to fats, candy/sweets, desserts and junk food (Humpries et al., 2009) and are less likely to have benefitted from preventative health screening or other health promotion measures (Bigby et al., 2014; Emerson, 2011; Emerson et al., 2001; Haveman et al., 2010; McCarron et al., 2011a) further increasing the chances of later life diseases such as diabetes, hypertension, heart disease and arthritis (Bigby, et al., 2014; Evenhuis et al., 2001; McCallion et al., 2013; Haveman et al., 2011).

There is a particular concern about attendance at screening and related follow-up. In the United Kingdom, for example, Samele et al., (2006) estimated that national uptake of cervical cancer screening was 84% – 89% overall, but only 13% – 47% per cent in the intellectual disability population. Similarly, the Disability Rights Commission (DRC 2006) analysed data from general practitioner practices on uptake of breast screening in Wales and found there was attendance by only 26% of women with intellectual disability as compared to 71% of woman without intellectual disability. There are similar findings for vision and hearing impairment and for dental care (MacGiolla-Phadraig et al., 2014; Emerson & Baines, 2011). Findings from IDS-TILDA also indicated low rates of screening (McCarron et al., 2011a) and shared the concern expressed by Emerson & Baines (2011) about lack of attention to limited health literacy including on sexual health among people with intellectual disability. There is a need then for advocacy for the inclusion of screening and other health checks in care of people with intellectual disability, attention to developing health promotion materials at appropriate literacy levels and an upskilling of staff to provide education, and conduct and respond to screenings.

Poor levels of care for women with intellectual disability are of particular concern with issues around menstrual disorders, cervical and breast cancer screening, contraception, and osteoporosis (Wilkinson & Cerreto, 2008). Looking specifically at availability of pap smear testing for women with intellectual disability, Lin and colleagues, (2010) concluded there is a requirement for knowledgeable, confident and widely available primary care-based screening services. RNIDs must be prepared to step up and address this growing challenge.

2.8.1 Assessing and Managing Illness Issues

The attention to dementia issues for ageing people with intellectual disability serves to highlight co-morbidity (McCarron et al., 2013b; Swinburne et al., 2014). A multi-disciplinary focus is clearly needed to assess and manage health concerns. A useful framework on key issues in quality of life for people with intellectual disability drawn from work by McCallion and McCarron (2007) identifies three principles:

- Absence of pain
- Maintenance of health
- Psychosocial well-being

2.8.1.1 Absence of Pain

Many diseases of old age such as arthritis are accompanied by pain, yet people with intellectual disability are often unable or unaware of the need to complain about that pain in order for it to be treated (McCallion & McCarron, 2007; McCallion 2003). RNIDs in their investigations of the causes of behaviour problems and other symptoms should be sensitive to identifying pain issues and when identified, to encourage appropriate responses. Medications may be appropriate and may be prescribed by the attending physician or registered nurse prescriber. Multidisciplinary input should be encouraged to identify other strategies including positioning, complementary therapies, and proactive addressing of comfort needs. It is acknowledged that identifying pain in people with intellectual disability, particularly those with multiple and profound disabilities is complex (Bromley et al., 1998).

2.8.1.2 Maintenance of Health

As multidisciplinary team members, RNIDs should be aware of recommended ageing and intellectual disability-related routine health screenings and should advocate for their completion. Modification of diet and exercise patterns have been shown to be effective for improved health for people with intellectual disability, similar to the general population but are not yet part of routine programming (Rimmer et al., 2010). A key concern in the maintenance of health is the use of medications. Data emerging from IDS-TILDA has identified high rates of polypharmacy (5 or more medications) and excessive polypharmacy (10 or more medications), use of combinations of medications that aggravate constipation and other side effects and concerning use of medication without demonstrated efficacy in people with intellectual disability (O'Dwyer et al., 2016). Clearly there are challenges here for physicians, psychiatrists, pharmacists and nurses. The role of the RNID in monitoring the use and associated side effects of medication and in educating the person with an intellectual disability, families and other staff.

2.8.1.3 Psychosocial Well-being

RNIDs have a role in supporting the psychosocial well-being of older adults with intellectual disability. This is not only about treating psychosocial concerns but also preventing their occurrence (McCallion & McCarron, 2007). Proactive, appropriate and sensitive programmes and services, early identification of symptoms and their causes and effectively delivered responses will all contribute to such well-being. For all psychosocial concerns including dementia symptoms, their identification requires the capture of sometimes subtle changes from previous functioning. As well as the use of appropriate instruments, timely diagnosis and treatment will be aided by routine reassessment and by the completion of documentation in ways that permit comparison with previous reports of functioning. It is being suggested that annual assessments of physical and psychosocial functioning with a recommended battery of instruments be initiated for people with Down syndrome over 35 and other people with intellectual disability over age 50 (see Burt & Alyward, 2000; Jokinen et al., 2013).

2.8.2 End of Life and Palliative Care

Heslop and colleagues (2014) reported the results of an inquiry into premature deaths of people with intellectual disability in the UK, in which avoidable deaths from causes amenable to change by good quality health care were more than twice as common in people with intellectual disability (37%) compared to the general population of England and Wales (13%). It was found that quality health care would have reduced this elevated mortality, with problems in advanced care planning, living in inappropriate accommodation, adjusting care as needs changed and carers not feeling listened to all contributing to poor outcomes. In their response, McCallion and McCarron (2014) highlighted similar concerns across multiple countries. Death and the management of late stage chronic conditions such as dementia are as likely to be part of the last days of people with intellectual disability as they are for the general population meaning that palliative care interventions are relevant.

RNIDs with appropriate training, in line with their clinical expertise, are well positioned to both deliver related training and support evidence-based approaches to providing care and support for those with intellectual disability ageing and dying in community and in intellectual disability service contexts. Fauri and Grimes (1994) argued that where possible, preparing for death is preferable rather than reacting to death. Finally, families and staff must develop an

openness to continuing to deal with grief and bereavement issues after a time when they and society has decided grief should be over (Fahey-McCarthy et al., 2009). There is an opportunity for RNIDs to be prepared to support people with intellectual disability, their family caregivers and their peers when end of life approaches. As part of multidisciplinary teams, RNIDs may advocate for, and provide grief and bereavement education and supports. A recent study of collaboration and training needs among intellectual disability services and a specialist palliative care provider highlighted a number of critical steps in successful delivery of palliative care for people with intellectual disability (Fahey-McCarthy et al., 2009). The steps include the following:

- Raising awareness among staff in both systems of the philosophies underpinning care and the expertise inherent in both intellectual disability and specialist palliative care services
- Recognising staff in intellectual disability services as highly dedicated and committed to providing optimal care but sometimes lacking knowledge and skills in managing pain, constipation, dyspnoea and fevers and care experience in siting sub-cutaneous lines and managing nutrition and hydration
- Recognising that staff in specialist palliative care offer skills around symptom management and external sources of support to help navigate final days
- Developing procedures and protocols within intellectual disability services to address understanding the wishes of the individual for their last days, the suitability of extraordinary measures such as enteral feeds and ventilators given disease trajectory and the management of last days and death including the post-death grieving period. RNIDs must play their role within multidisciplinary care teams, increasing collaboration, communication and building of bridges with acute care settings and community-based physicians working in intellectual disability, dementia and palliative care settings, and working with other intellectual disability services staff to develop the ability to care for dying persons on site (Fahey-McCarthy et al., 2009).

2.9 Working with Families Caring at Home

The greatest focus for service providers had traditionally been upon children and young adults with intellectual disability. In school and in care there have been mandates, legal or implied, for a basic level of services, for example for special education services (McCallion, 2003). For adults with intellectual disability, mandates are less defined and attention is paid mostly to those in out-of-home placements. Those living at home who are attending work or day programmes may also receive some additional services. However, adults living at home are less likely to receive professional services and may, indeed, need few such services while they are in their young and middle adult years (Lightfoot & McCallion, 2015; McCallion & Kolomer, 2003). It is often a surprise to intellectual disability staff and administrators to realise the number of people with intellectual disability and their families who have minimal or no contact with services until their older years. It is not until then that they make their first contact which then needs to be sustained on a more or less permanent basis.

For all the attention paid to out-of-home care, the majority of people with intellectual disability are cared for at home. There is every expectation that the large number of people with intellectual disability living at home and currently being cared for by individuals in their 40s and 50s will, by 2030, still be cared for by these individuals, who will then be in their 60s and 70s. There is also a likelihood that greater and rapidly growing demands will be placed on limited out-of-home services when caregivers are having increased difficulties or are no longer able or available to provide care (Lightfoot & McCallion, 2015). There is a need therefore to consider better current and future planning for these families and thoughtful provision of respite and other supportive services, early encouragement of health promotion recommendations for both caregiver and care recipient, and the designation of staff to become specialists in such support.

For RNIDs called upon to assist in the planning for future care of people with intellectual disability, out-of-home care may seem the easier and, in the case of community group home placement, even the preferable approach. However, this approach assumes that "a bed" is available and that this transition is the desire of the person with an intellectual disability and the family. This may not be the case in many instances. Future care planning really needs to begin with an assessment of the desires of the individual with intellectual disability and the family; an understanding of the available social network and past patterns of care; consideration of possible improvements in informal care supports; and then the addition of formal services (Bigby et al, 2014; McCarron & McCallion, 2006). RNID training will need to ensure that there is appropriate preparation of skilled staff to meet this need. There are strategies such as permanency planning that help value the role of families and people with intellectual disability themselves.

Permanency Planning

The increased longevity of people with intellectual disability has raised the issue of permanency, futures or long-term planning for people with intellectual disability who outlive parents and siblings. The planning role for RNIDs, once they have engaged families in future planning, is to ensure that adequate and up-to-date information is available and that planning for transitions is not missed. Families who successfully utilise respite and other services have been found to be more likely to consider residential placement (Caldwell & Heller, 2003). It must be emphasised that the decisions relating to an individual's life should in the first instance be taken by the person him/herself on the basis that the person is presumed to have capacity (Assisted Decision-Making (Capacity) Act 2015). Family involvement would be included on a graduated basis which would be determined by the degree to which the individual could exercise capacity in making decisions about his or her life. Therefore, the role for RNIDs may be to encourage and facilitate such related service use and to ensure that the person with intellectual disability is supported to make autonomous decisions or where this is not possible to ensure that decision making is shared appropriately between the individual and his or her family. Key services with regard to which decisions might be made include: in-home respite, out-of-home respite or holiday programmes, home-help services, transportation assistance, and day and recreation or leisure programmes.

2.10 Role in Training

The effective delivery of services to people with intellectual disability and their family caregivers across the lifespan requires a comprehensive reorientation of services and a multidisciplinary approach. RNIDs must be willing to be the recipients of training in these approaches as well as to play a role in their delivery. Approaches include:

■ Helping all staff understand the general ageing processes of people with intellectual disability and their family caregivers and how to assess the unique experiences of those who present for assistance
■ Implementing systematic and sensitive approaches to helping individuals and their families engage in long-term planning
■ Developing and delivering training and developing mechanisms to support self-advocacy and decision-making for people with intellectual disability
■ Developing and teaching holistic approaches to the presentation of behaviours that challenge and facilitate understanding of the causes of those behaviours, how they may be avoided, and the delivery of appropriate, effective responses
■ Supporting the expression of grief and bereavement by people with intellectual disability
■ Designing and implementing documentation, screening and routine assessment processes to monitor change in functioning of people with intellectual disability and offering critical information to inform differential diagnosis
■ Demonstrating where RNID unique skills and experiences fit within multidisciplinary service delivery.
Delivery of such training will involve daily modelling of these values and skills as much as in formal teaching and in-service (McCarron & McCallion, 2006).

2.11 Increasing Specialisation amid Changing Needs: Yet Offering Holistic Care

There has been a growing consensus on the key skill areas needed by RNIDs to meet the changing needs of people with intellectual disability. Mansell and Harris (1998) identified the top five skill areas for RNIDs in community intellectual disability teams as client-based interventions, co-ordination and planning of care, training, care management and health promotion. Boarder (2002) emphasised the importance of interdisciplinary teamwork and an increasing health focus supporting health maintenance, responding to specific physical and mental health difficulties, and assessment. Skills in advocacy, maintaining place in the community, behaviours that challenge, skills development and personal relationships were also emphasised. More specifically addressing an Irish and UK context, Barr (2006) identified the top role areas for RNIDs as consultancy, assessment, treatment, training and promoting access to services, care planning and health promotion with particular concerns around epilepsy, medication and updates on new procedures. It is clear from the review of the literature on changing needs that there is an emerging consensus on the role of the RNID. There are already shared understandings of the specialist skills

■ Knowledge and awareness of how cognitive and communicative impairments, impoverishment and adverse life experiences distort clinical presentations and the ability to undertake effective assessment in partnership with people with intellectual disability, in spite of these factors

■ Knowledge and awareness of the strong association of specific intellectual disability syndromes with heightened health risk

■ Being able to establish a person's complex needs based on observable, behavioural signs and absent verbal report

■ Working to recognise and reduce anxiety associated with accessing services and the experiences of ill-health using effective communication

■ Working in multidisciplinary settings and with different agencies to develop and implement care plans

■ Providing nursing care interventions that address health needs, support healthy lifestyles and promote public health and safety

■ Safeguarding and protecting the rights of all people with intellectual disability, especially when they are vulnerable and in need of support (RCN, 2011A, 2011B; Atkinson et al., 2010).

In addition, this literature review indicates that there is a need to understand the additional educational requirements for RNIDs if they are to play key roles in support of children with intellectual disability and complex health needs, adults who are self-managing their care in increasingly independent living situations and older adults with intellectual disability needing support with chronic conditions including dementia and their end of life care. There are also challenges to be met in understanding and preparing RNIDs for roles in facilitating life transitions, including early education and educational programming, and providing support for family carers when they too may be experiencing stress and health concerns. Further, RNIDs must collaborate with mainstream health services whether general practitioner, clinic or hospital-based to ensure they are accessible and suitable for people with intellectual disability.

2.12 Conclusion

Among the constants in this literature review have been the needs for care, support and advocacy for people with intellectual disability and the availability of committed RNIDs to lead such efforts. The literature review has addressed changing healthcare needs across the lifespan, including significant challenges posed by the success of both improved medical care at birth and the early years and in older adulthood in terms of more complex care needs and the need for both lifespan health promotion and management of chronic conditions (Mafuba & Gates 2014b). New roles for RNIDs and others have been considered in providing such supports. The implementation of early intervention, educational programming, person-centred care plans and both movement to the community and genuine integration once there have encouraged the engagement of a wide range of professions. There is a need for both interdisciplinary working and genuine collaboration with specialists, community care workers, and staff in general population health, education and social care providers. There is also a need for more sustained and extensive support for family carers. Newly established structures for quality monitoring and risk management also require consideration. All of these issues need to be addressed in any reconsideration of the role of RNIDs.
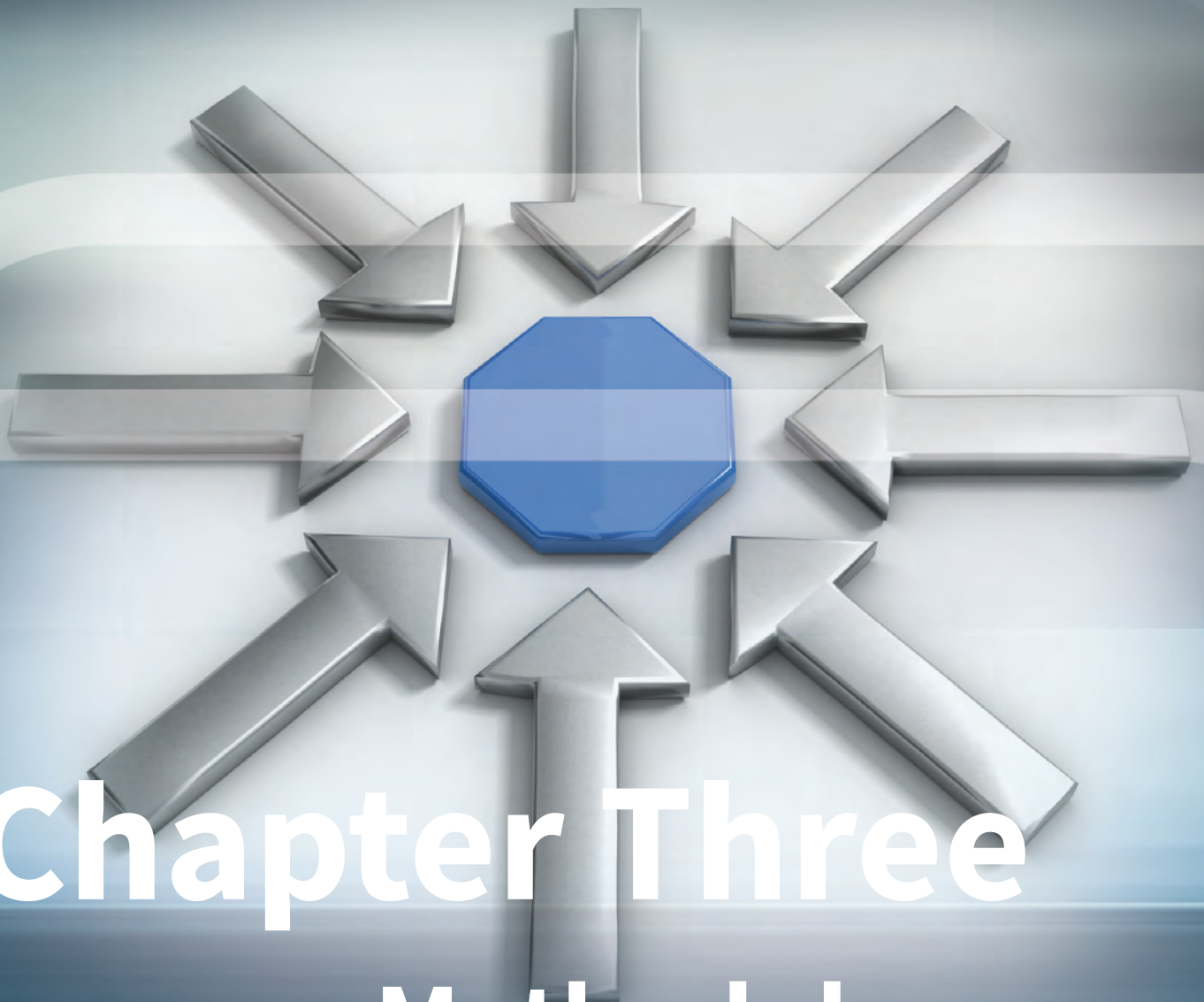
Chapter Three
Methodology

"The promotion of continuity in care coordination and advancement of person-centred care for people with an intellectual disability"

Chapter 3

3.1 Project Aim

The aim of this project was to determine the future role of the Registered Intellectual Disability Nurse (RNID), who provides health and social care services to individuals with an intellectual disability and their families/carers, in a changing landscape. To achieve this aim, consideration was given to the values, capabilities, barriers, facilitators and leadership that would be required to ensure that individuals with an intellectual disability are able to receive person-centred and expert nursing care that is responsive to their individual needs and strengths, and offers equitable access, quality of life and health outcomes regardless of level of disability.

3.2 Project Design

The study employed a mixed-methods design, incorporating a number of phases of data collection over its fourteen-month period. Data was collected using surveys, focus groups, interviews, submissions and expert interviews as well as three national stakeholder convenings and a review of the literature.

3.3 Data Collection Approaches

3.3.1 Survey

Inclusion Criteria
The inclusion criteria for the survey were that the name of prospective respondents must be maintained on the intellectual disability division of the Register of Nurses maintained by the Nursing and Midwifery Board of Ireland.

Sample
A random sample of 1500 RNIDs was selected by the Nursing and Midwifery Board of Ireland (NMBI). Survey questionnaires and an information sheet were posted via a third party, thereby ensuring that no one associated with the study was aware of the identity of the selected nurses. Return was facilitated through the provision of stamped, addressed envelopes. Although the nature of the sampling process was such that it was not possible to send individual reminders, distribution of the survey was preceded by widespread advertising within professional and service arenas. This was repeated following distribution to help maximise response rates. After extending the period for the survey return, 394 completed surveys were returned, representing a response rate of 26.3%.

Data Collection Method: Survey
A 21-item survey tool derived from Sheerin (2006) and Alaszewski et al (2001) (see Appendix 2), was developed to elicit quantitative and qualitative data from a randomly selected national sample (n=1500) of RNIDs. It consisted of Likert-type scale statements and questions, lists for rating and open questions which allowed respondents to elaborate on particular issues. The survey, which was designed in association with the Project Steering Group and piloted among a sample of 10 RNIDs, sought to develop a profile of RNIDs and the scope of RNID service delivery. It included questions on:

Areas of current practice
Key nursing skills
UItilisation of skills and knowledge
Perspectives on future service provision
Future education and training requirements
The perceived need for development of clinical nurse specialist and advanced nursing practice

During piloting, the time estimated for completion of the tool was found to be approximately 40 minutes. The survey was sent in hard copy with self-addressed stamped envelopes.

3.3.2 Focus Groups

Inclusion Criteria

The generic inclusion criteria for the focus groups were that all prospective participants would be: self-advocating and able to consent to participate; and 18 years of age or older. More specifically, prospective participants had to be able to satisfy one of the following criteria:

RNID

Family member of a person with an intellectual disability

Person with an intellectual disability

Member of intellectual disability staff who interfaces with RNIDs

Service manager

Educator in an institute of technology or university approved to provide nursing   education which allows graduates to register as RNIDs

Intellectual disability nursing student

A further focus group was conducted with international experts.

Sampling

Recruitment for the focus groups was premised on the need to garner participation from a wide range of stakeholders over a wide geographic spread. In the interest of homogeneity (Krueger, 2008, Morgan, 1998), focus groups were set up around 7 groupings. RNIDs were to group from a self-selecting sample of nurses who had indicated an interest in participating following completion of the survey, together with a convenience sample drawn from the extensive contacts maintained by the participating schools, services and the HSE. The latter were invited to participate through the distribution of advertisements by the relevant data holders. The Nurse Managers' Group also assisted in this process.

The services of Inclusion Ireland and the National Federation of Voluntary Bodies were utilised in obtaining a convenience sample of self-advocating adults with an intellectual disability and family members of people with an intellectual disability. This was facilitated through the distribution of advertisements inviting participation. Focus groups with family members were further selected based on the geographical and specific care requirement of the family member with a disability. Other staff groups who work in association with, or interface with, RNIDs were drawn from the extensive contacts maintained by the participating schools, services and the HSE and invited to participate through the distribution of advertisements by the relevant data holders.

Service managers were self-selected using a snow-ball sampling strategy. In order to ensure participation of all higher education institutions providing programmes of education and training leading to registration as an intellectual disability nurse, Letterkenny, Waterford and Dundalk Institutes of Technology, as well as St. Angela's College, Sligo, were invited to nominate a member of academic staff to participate in a focus group. In addition, all higher education institutions providing programmes of education and training leading to registration as an intellectual disability nurse were invited to nominate a final year intellectual disability nursing student to participate in a focus group. Finally, international experts were conveniently sampled for an extra focus group which took place on the margins of an IASSIDD Conference in Vienna in July 2014.

Sampling for some of the focus groups was challenging as it was difficult to get information directly to particular staff groupings. The project team attempted to address this through widespread advertising within professional and service arenas. The breakdown and locations of the focus groups are presented in Table 1.

Table 1: Breakdown of focus groups

Stakeholder group	Location of focus groups	Number of focus groups	Number of participants
Family members	Galway, Cork, Letterkenny, Dublin	4	36
RNIDs	Cork, Galway, Dublin	3	14
RNID nurse educators	Dublin	1	4
Students	Dublin	1	4
People with intellectual disability	Dublin (x2), Roscommon, Cork	4	27
Service Managers	Dublin, Cork	2	11
Interface staff	Dublin, Cork	2	7

Data Collection Method: Focus Group

Ultimately, 17 regional and 1 international expert focus groups were conducted with the aim of gathering additional information on future and changing roles of RNIDs, training needs, opportunities for greater collaboration with social care staff and multidisciplinary team members and support for person-centred and community based care. The focus groups were framed by group-specific topic guides developed in collaboration with the Project Steering Group (Appendices 3-9).

3.3.3 Key Informant Interviews

Inclusion Criteria

The inclusion criteria for the key informant interviews included the generic criteria set out for focus group participants, but also required that prospective interviewees be identified by the Project Steering Group as individuals whose perspective was of significant importance to the outcomes of the project and who had not previously contributed to the other phases of data collection.

Sampling

A purposeful sampling approach was used. Ten individuals were invited to take part in such interviews and six experts from Ireland and the United Kingdom agreed, two males and four females. Of the six interviewees, one had expertise in social care, one in mental health care, one in acute hospital care, one in primary care, one in nursing policy, and there was one nursing academic. In keeping with qualitative research principles, data analysis and data collection occurred simultaneously. As tentative concepts and themes emerged from the ongoing analysis, the interview guide was refined for subsequent interviews.

Data Collection Method: Key Informant Interview

These interviews were framed by an interview guide (Appendix 10) which explored:

Challenges to the role of the RNID
Challenges to people with intellectual disability accessing healthcare; nurses' roles in supporting people with an intellectual disability
The educational preparation of intellectual disability nurses
Effective leadership in intellectual disability services
Leadership in nursing
Clinical nurse specialist and advanced nursing practice developments
The role of intellectual disability nurses in judicial and forensic services

3.3.4 Submissions

Submissions were elicited from a broad range of individuals and organisations which were purposefully sampled based on the recommendations of the project team and Project Steering Committee taking account of the representation of professional groups and organisations in the other data collecting components of the project. The format of the invitation to submit (Appendix 11) was structured by a number of set questions which centred on:

■   Future service developments
■   The changing role of the RNID across health and intellectual disability services
■   Desirable values to underpin services
■   Future nursing skills and competencies
■   Future educational requirements of intellectual disability nurses
■   Supporting health for people with an intellectual disability
■   Effective leadership in intellectual disability services
■   Leadership in nursing
■   Clinical nurse specialist and advanced nursing practice developments

The invitation to make a submission was sent to 95 individuals and organisations and 32 submissions were received electronically (Appendix 12). These represented a broad scope of knowledge and experience.

3.3.5 National Stakeholder Convenings

These convenings brought together a wide range of stakeholders from across professional and service arenas (see Appendix 1 - membership). Three convenings were conducted at strategic times during the study. They considered findings from the various phases of data collection and provided comment on these findings in the context of:

■ The current and future RNID roles
■ Changing policy directions
■ Expectations and actual programme delivery
■ Changing environments
■ Barriers and facilitators to the expansion and embedding of any new roles
■ Changes to RNID preparation
■ Alternate professional perspectives likely to influence the ongoing development of the RNID

Sampling

The convenings' sample was drawn from a broad scope of individuals, including representation from:

> Intellectual Disability Services
> The HSE
> The Department of Health and Children
> Hospital groupings
> Inclusion Ireland
> Trade Unions
> The National Federation of Voluntary Bodies
> Primary, Secondary and Tertiary Care
> The Nursing and Midwifery Board of Ireland

The sample was purposively sampled, following discussions with the Project Steering Group, the HSE Social Care Directorate and the HSE Office of the Nursing and Midwifery Services Director. Of forty invitations sent for the first convening, 27 individuals attended. The second convening was attended by 18 people. The final convening which took place as the report was being finalized was attended by 15 people.

3.3.6 Literature Review

The study team reviewed a wide range of documents and literature pertaining to intellectual disability nursing and service provision, with a broad national and international scope. The Project Steering Group was invited to give feedback on the draft literature review and revisions were made to incorporate and reflect much of this feedback.

3.4 Overall Analysis Approach

As this project adopted a mixed methods design, a number of quantitative and qualitative approaches were employed in analysing the data.

3.4.1 Quantitative Analysis

The quantitative data, obtained through the survey, were entered into SPSS Version 21 (IBM Corporation 2012). The final dataset included 394 respondents. Initially, descriptive statistics were generated to develop a picture of current and expected roles. For open-ended responses, a cross-comparative approach was used to help identify themes that would help further identify and illustrate insights that emerged from the survey data.

3.4.2 Qualitative Analysis

Qualitative data was collected from the focus groups, key informant interviews, convenings and submissions. Digital recordings of focus groups and interviews were transcribed verbatim by a professional company and these were checked for accuracy by moderators and interviewers. The computer software package NVivo (QSR International Pty. Ltd.) was used to assist in the organisation, management and retrieval of this data. The qualitative data were thematically analysed following Thomas' (2006) general inductive approach to qualitative analysis. This systematic approach facilitates the reduction of large amounts of data allowing the team to identify themes and insights from the textual data while establishing logical links between the findings and the objectives of the project. The transcribed qualitative data was read and re-read by members of the research team. The data was then coded into themes using NVivo software. The specific initial themes which emerged from the focus group data included:

> Contextual data
> Family and service user experiences
> Future and changing roles
> Training needs
> Opportunities for greater collaboration with social care staff and multi disciplinary team members
> Support for person-centred and community based care

The initial themes from key informant interview data included:

> The challenges for families and service recipients
> The future role of intellectual disability nursing in meeting these needs
> Future service models
> Education preparation of nurses
> Leadership and specialist and advanced practice intellectual disability nursing roles

The initial themes from the submissions data included:

> Competencies   Leadership
> Core Role   Specialist and advanced roles
> Future service model   Structures
> Education changes   Values
> Future role of the RNID

The discussions of the convenings were written-up and these reports were reviewed to identify both key themes and potential questions for follow-up in interviews and focus groups. Combined analysis of the literature, and the quantitative and qualitative data was undertaken to create a matrix of the three datasets that (1) allowed for cross-checking and comparison of data from those datasets and (2) supported a comprehensive triangulation process across the various sources of data to yield an in-depth understanding of the knowledge, skills and competencies that RNIDs may require to support people with various levels of intellectual disability in a changing health care landscape and to respond to key disability reports including *The Disability Strategy* (GoI, 2004); *Disability Act* 2005 (GoI, 2005); *Vision for Change* (DoHC 2006); *Time to Move on from Congregated Settings* (HSE, 2011); *Value for Money* (DoH, 2012b); *New Directions* (HSE 2012b); *Future Health – A Strategic Framework for Reform of the Health Service 2012- 2015.* (DoH, 2010a); and *National Dementia Strategy* (HSE, 2014b).

3.5 Ethics

Ethical approval was granted from the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin. All involved with the study were bound by national and international codes of good practice in research, and by professional standards within their disciplines. The rights and dignity of participants were respected throughout by adherence to models of good practice related to recruitment, voluntary inclusion, informed consent, privacy, confidentiality and withdrawal without prejudice. The rights of the participants and their well-being were given precedence over data collection. Consent was viewed as an ongoing process, which requires negotiation throughout all aspects of the study. The voluntary nature of participation was emphasised throughout the data collection process and participants were free to withdraw from the study at any time without fear of penalty.

Return of the survey was taken as evidence of implied consent. Both written and verbal consent was obtained before the focus groups and individual interviews; appropriate participant information pages and consent forms were developed for the service user participants. In order to protect confidentiality, audio recordings, transcripts and surveys were given code numbers. Participants were also advised not to write their name on the survey instrument. All data files were password protected and stored in accordance with the Data Protection (Amendment) Act 2003.

3.6 Conclusion

This chapter details the methods that were used to obtain the data that has informed a comprehensive analysis of the current and future role of the RNID in the context of the very dynamic service provision landscape that exists at present. The findings that emerged from the survey and the qualitative findings are presented in Chapter 5. In the following Chapter 4, the basic demographic data of those who responded to the survey is presented.
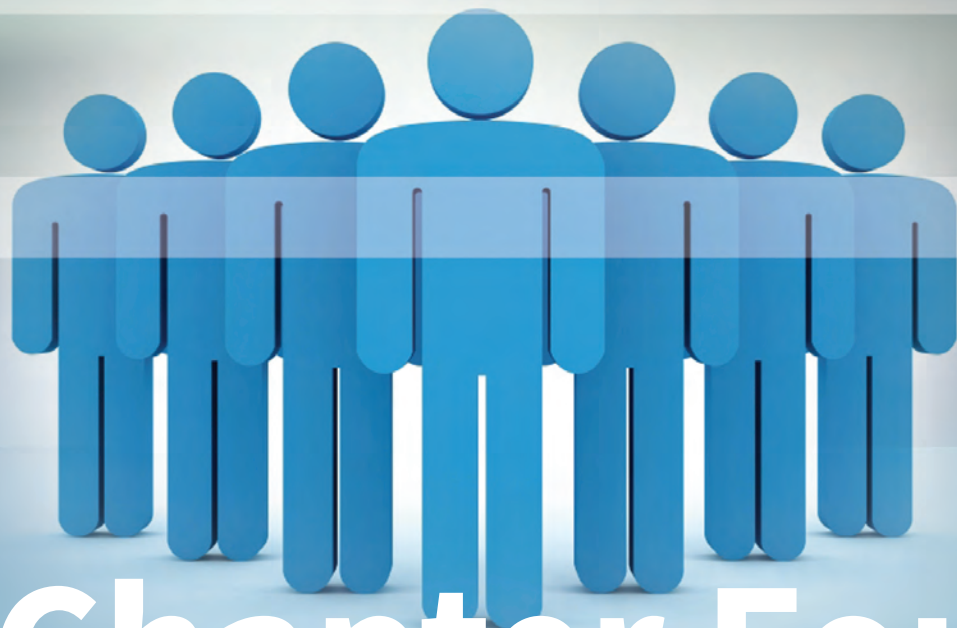
Chapter Four

Demographics

"The vast majority of people with an intellectual disability live at home"
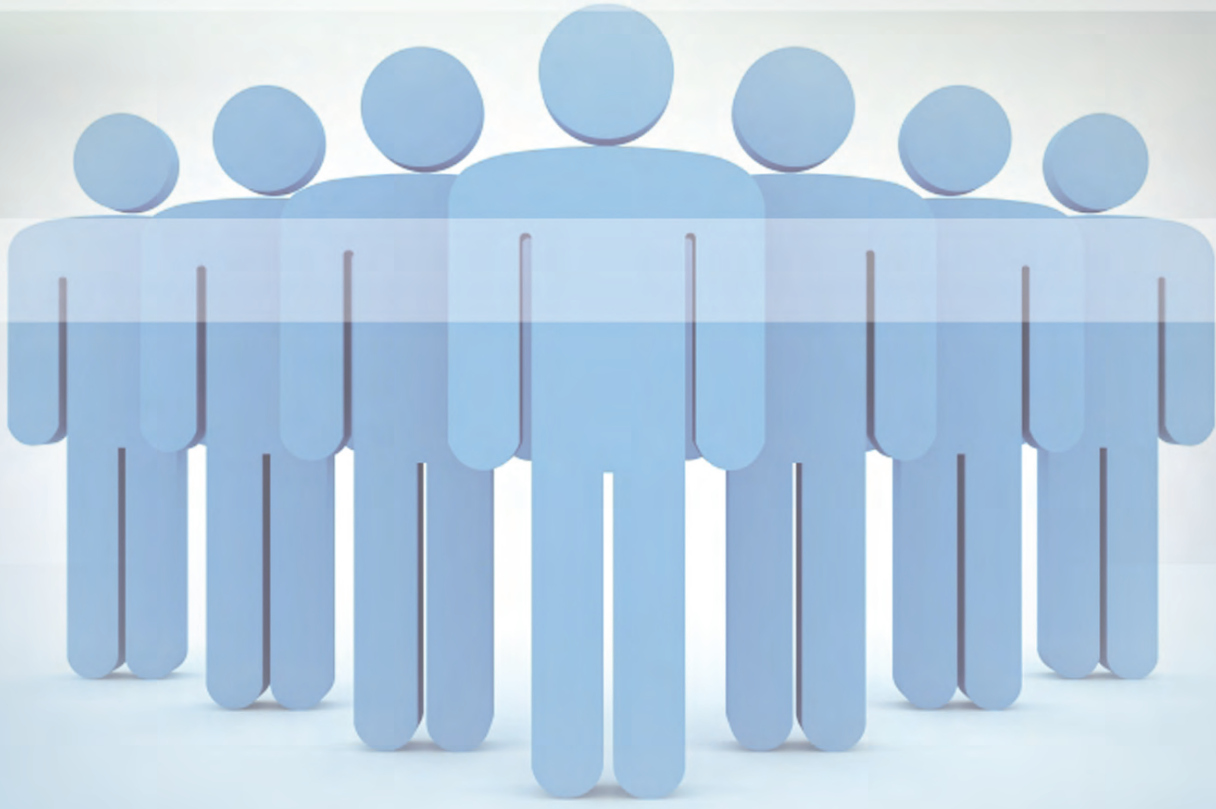
Chapter 4

4.1 Participant Profiles

This chapter provides an overview of the profile of the respondents who participated in the project. In total, 394 survey responses were included for an analysis. A total of 103 people participated in the regional focus groups, 6 in expert interviews, 6 in an international expert meeting and 33 submissions were received.

4.2 Survey sample

The survey findings from this study are based on a random sample of RNIDs, drawn from the Register of Nurses maintained by the Nursing and Midwifery Board of Ireland. Participants responded by returning completed survey documents through the postal system. A total of 406 survey responses were returned but 3% of the surveys completed (n=12) were excluded from the final dataset as they were incomplete to the extent that they did not provide any information on the areas being addressed. Questionnaires that had some data missing were included in the analysis. Where this occurred, percentages were calculated out of the total number of responses to the question.

4.2.1 Gender

The respondents who returned the questionnaire were predominantly female (90.3%) with males comprising slightly less than 10% (9.7%) of the sample.

4.2.2 Age

The age profile of the respondents was clustered in the middle of the working age group as can be seen in Table 2 below:

Table 2: Age profile of the survey participants.

Age group	Percent	Number
21-35 years	22.7	89
36–50 years	50.8	199
51–65 years	26.5	104
Missing	0.5	2

4.2.3 Nursing Divisions

Respondents were asked to indicate under what divisions of The Nursing and Midwifery Board of Ireland Register they were registered. They had the opportunity to indicate multiple arrears of registration. Evidently, as it was an inclusion criterion, all respondents were registered as intellectual disability nurses (n=393; 1 missing response). In addition 28% of respondents were also registered on other nursing divisions and these are charted in Table 3 below.

Table 3: Divisions of the Nursing & Midwifery Board in which participants were registered (n=394).

Division	% registered	Number (n=393)	Missing
Intellectual disability nurse	100	393	1 (.3%)
Psychiatric nurse	8.6	34	1 (.3%)
General nurse	13.7	54	1 (.3%)
Children's nurse	4.6	18	-
Midwife	1.0	4	1 (.3%)

4.2.4 Education

Respondents were asked to indicate the highest level of education which they had completed and the breakdown of the responses can be seen in Table 4 below. The participants were highly educated; almost two-thirds of the sample (62.1%) were educated to degree level or above and almost one-third (32.8%) had a post-graduate qualification.

Table 4: Highest level of education completed by survey participants.

Level	Percent	Number
Certificate	19.8	76
Diploma	18.2	70
Undergraduate degree	31.3	120
Higher/post-graduate diploma	17.7	68
Master's degree	12.8	49
Clinical doctorate	0	0
PhD	0.3	1
Missing	2.5	10

4.2.5 Current Job Title

Almost 60% of the respondents were staff nurses and Clinical Nurse Managers (1, 2 & 3) comprised another 21.9% of the sample. The full breakdown of the participants' job titles can be seen in Table 5 below. Just over ten percent (10.4%) chose the "other" option and those responses included those involved in education, coordinators and directors of services and five respondents indicated that they had social care job titles.

Table 5: Current job title of survey participant.

Title	Percent	Number
Staff Nurse	58.5	230
CNM 1	6.6	26
CNM 2	12.0	47
CNM 3	3.3	13
Clinical Nurse Specialist	3.6	14
Advanced Nurse Practitioner	0.3	1
Assistant Director of Nursing	2.8	11
Director of Nursing	2.0	8
Other	10.0	41

4.2.6 HSE region

As outlined in Table 6 there was very good representation across all HSE areas with the largest number from the HSE West (27.5%). There were five (1.3%) "other" responses in Table 6.

Table 6: HSE region in which participants worked.

HSE Region	Total = 99.7%	Number
HSE Dublin North East	25.9	97
HSE Dublin Mid Leinster	21.3	80
HSE West	27.5	103
HSE South	23.7	89
Other	1.3	5

Other: Scotland; NHS Scotland; not working X 2; retired from HSE NE; all HSE areas

4.2.7 Service Type

Table 7 presents the type of service within which the respondents worked. More than half (55.3%) worked in voluntary agencies and a further one-third (33.9%) worked within a HSE service. Eight percent (n=31) of participants indicated "other" service types and examples of these include: private nursing homes; agency; education; private sector; child and family agency; behaviours that challenge unit in Scotland; self-employed; training of staff who work in intellectual disability services; HSE service and Voluntary agency; HIQA.

Table 7: Type of service in which survey participants worked.

Service type	Percent	Number
HSE service	33.9	132
Voluntary agency	55.3	214
Not for profit	2.6	10
Other	8.0	31
N/A	0.3	1

4.2.8 Current Area of Professional Practice

Respondents were asked to indicate their main area of professional practice. As outlined in Table 8 the most common area where respondents worked was in "residential service/group home in a campus setting" (30.9%). When this response is combined with the response of "community group home" (15.3%) it demonstrates that almost half the participants work in residential settings. Adding in the nursing homes (4.1%) brought the level of participants working in residential settings to one half. The "other" response was frequently used in response to this question (16.8%); many of these (17) were combinations of the given options for instance "Care coordination of people living independently" and "Day service". Further responses included the psychiatric/mental health services; education or training; acute paediatric hospital, and community services.

Table 8: Current area of professional practice.

Practice	Percent	Number
Care coordination of people living independently	2.0	8
Family support (including respite)	4.6	18
Community group home	15.3	60
Residential service/group home in a campus setting	30.9	121
Intensive/specialist service	6.4	25
Sheltered work/employment setting	1.0	4
Early intervention team	4.1	16
Day service	10.5	41
Education setting	2.8	11
Nursing home	4.1	16
Specialist clinic in an intellectual disability service, primary, secondary or tertiary service (specify)	0.3	1
School-age team 16-18 (assessment)	0.3	1
Other (please specify)	16.8	66
N/A	0.5	2

4.2.9 Length of Time in Current Area of Professional Practice

Participants were asked how long they had been working in their current area of professional practice. As can be seen in Table 9 this is a very stable workforce with 45% having worked in their current area for ten years or more and fewer than 10% (9.2%) having worked for one year or less.

Table 9: Length of time survey participants are in current area of professional practice.

Number of years	Percent	Number
Less than 1 year	9.2	36
2–5 years	20.6	81
6–10 years	23.9	94
11-15 years	16.3	64
16–20 years	9.9	39
More than 20 years	18.8	74
N/A	1.3	5
Missing	0.3	1

4.2.10 Level of Intellectual Disability RNIDs Supported

Participants were asked about the level of intellectual disability of the people they supported. As it was perceived that respondents were likely to support services' users across disability levels they had the opportunity to indicate this. Consequently, the percentages amount to more than 100%. As outlined in Table 10, most respondents supported people with intellectual disability who have a moderate or severe/profound level of disability and fewer supported those with a mild level of intellectual disability. They also provided service to people with intellectual disability who were predominantly in the middle to older age groups (Table 11).

Table 10: Level of disability of people with whom survey participants work.

Level of intellectual disability	Percent	Number
Mild	19.0	126
Moderate	33.5	222
Severe/profound	39.1	259
Do not care for/Support	8.4	56

Table 11: Age groups of the people with intellectual disability that RNIDs provide care for and support.

Age Group	Percent	Number
0 – 5 years	8.8	68
6 – 18 years	10.3	79
19 – 49 years	32.2	248
50 – 65 years	29.8	229
Greater than 65 years	18.9	145

4.3 Profiles of the qualitative data source participants

4.3.1. Focus groups

Table 1 details the stakeholder groups and the location of the focus group attendees. As noted in Table 1, the preponderance of attendees at the focus groups were either family members or people with intellectual disability; these two constituencies comprised 66% of the participants in the focus groups. Nurses, nurse managers, nurse educators and students and interface staff attending focus groups were usually female and family member focus groups were more evenly gender balanced, as were focus groups of people with an intellectual disability.
Note: This section dovetails with section 3.3.1 which includes table 1.

The international focus group meeting was held on 14th July in The University of Vienna and it was attended by six nurses (3 males and 3 females) from the following countries: Australia [1], New Zealand [1], Scotland [1], England [1]. Ireland [2].

4.3.2. The Convenings

The convenings were attended by service managers, representatives from trades unions, from national intellectual disability organisations, nurse specialists, nurses in practice, nurse academics and nurse managers as well as members of the HSE. Attendees were predominantly female (3:1 female : male) and they were more likely to be older with much experience in their respective fields.

4.3.3. The Expert [Key Informant] interviews

As noted in section 3.3.2, interviewees were chosen because they all had specific knowledge of service provision in Ireland and in one case of nurse education in another state. All interviewees were regarded as having a wide ranging and deep comprehension of the issues relating to service provision as they currently apply and as they may emerge in the future years and a knowledge base to enable insights into future trends in service delivery and how future educational provision could be matched to such trends.

4.3.4. The Submissions

32 submissions were received from a wide variety of contributors. Approximately half were received from various parts of the HSE as well as HIQA, some services and two trades unions. The remaining submissions were contributed by private individuals working in services or in nurse education. Submissions varied in length with some consisting of multiple pages, others quite brief, and most were 2 to 3 pages. (For a complete list of the submissions see Appendix 12).

4.4 Summary

This chapter has provided an overview of the participant profiles of all the data collection methods and outlines the demographic description of survey respondents.

The qualitative data offered a multi-faceted view of the current and future needs of people with intellectual disability and their families and the view of a wide variety of stakeholders on the strengths and weaknesses of intellectual disability nursing and the future capability of intellectual disability nurses to meet those needs. This sets the context for interpreting the more in depth triangulated findings from the various qualitative data sources. It also provides a foundation to assist in informing the recommendations from this report.

Chapter Five
Findings

"Risk is an issue that must be appropriately managed; the duty of care must be balanced against the rights of the individual to autonomy and choice"

Chapter 5

5.1 Introduction

This in-depth consultation process across various stakeholder groups using quantitative, qualitative and document analysis strategies explored individuals' understanding and vision of the structures that will be required for RNIDs to work in the changing landscape outlined in a number of repeats, for example, *The Disability Strategy* (GoI, 2004), *Disability Act 2005* (GoI, 2005), *Vision for Change* (DoHC, 2006), *Time to Move on from Congregated Settings* (HSE, 2011, *Value for Money* (DoH, 2012b) and *New Directions* (HSE, 2012b). The comprehensive triangulation process utilised survey responses; expert interviews; family and service users' focus group interviews; convenings; and document reviews. It considered the values, capabilities, barriers, facilitators and leadership that would be required to ensure that individuals with an intellectual disability are able to receive person-centred and expert nursing care regardless of setting responsive to their individual needs and strengths, and offering equitable access, quality of life and health outcomes regardless of level of disability.

The resulting findings are presented in terms of:

1) Person-Centredness and Person-Centred Planning
2) Supporting individuals with an Intellectual Disability with their health, well being and social care
3) Developing Nursing Capacity, Capability and Professional Leadership
4) Improving the Experience and Outcomes for individuals with an Intellectual Disability

5.2 Person-Centredness and Person- Centred Planning

Many of the submissions emphasised that the RNID needed to be equipped to respond to changing needs of people with intellectual disabilities, to emerging service developments and to the changing community based health and social care environment. These submissions recommended that responses be grounded in transformational leadership, draw on research into developmental trends and best practice updates on developments in the provision of intellectual disability services and above all, advance person-centredness and person-centred planning, which was seen as a touchstone of excellence in RNID practice as evident in the following quote:

'Transformational leadership is the only style that supports a person-centred culture. Leaders need to enable staff to transform the way they plan and provide care so that it is based on need and not on custom and tradition unsupported by evidence'. (S28)

Expert informants suggested that there is a need for clearly managed pathways for health care and that RNIDs will have a key role to play in their coordination. The focus will, however, be oriented towards the needs of the user and will be person-centred:

"Care will be the ownership of the patient and everybody else is trying to facilitate that". (E4)

How person-centredness will be both maintained and advanced in changing services systems and embedded perhaps for the first time in community-based health and social care provision was identified as the major challenge for RNIDs in the coming years and would require that they and others be strong voices for disability in the strategic planning of health services. This included a need to come together with others to advance this agenda:

"…we should have some sort of a national disability council that's providing strong leadership and advocacy into the health service". (E6)

Ultimately though, many respondents felt the success of such an approach will always be best measured in terms of the health outcomes for people with intellectual disabilities:

"…people have to be able to demonstrate what they're achieving for individuals with learning disability". (E3)

Individual changes and achievements for people with an intellectual disability are the hallmark of successful person-centred planning. This can be achieved if activities are properly planned and then implemented through the creation of person-centred environments in every area where people with an intellectual disability live, work and interact. The centrality of person-centredness and person-centred planning for RNIDs and the RNID role now and in the future strongly emerged.

Family members in the focus groups noted that current trends in capacity legislation and in the standards applied by HIQA might place too much emphasis on promoting autonomy which could reduce the role that family members might play in their relative's life and also might reduce the level of care provided.

RNID respondents did appear to understand the balance which needs to be achieved between risk and rights, and found this to be an increasingly prominent issue in their day to day work. They were concerned that a risk averse culture would impede the independence and quality of life for service users. A large number of respondents expressed the view that additional nursing skills needed to be developed in person-centredness, advocacy, risk assessment and supported decision making as depicted in Table 12. These they perceived as necessary to support better nurse decisions around therapeutic risk taking.

Table 12: Areas of additional education and training for RNIDs

Area	Percent	Rank
Person-centred planning	70.1	3
Clinical risk assessment	64.6	6
Advocacy	60.9	9
Assessment of capacity	56.3	11
Supporting decision making	54.9	17
Measuring nursing and services' quality	51.3	22

All stakeholders – professional, service users and families – identified issues around quality and service user safety as being of great and increasing importance.

There were requests that regulations and policies and the rights and wishes of people with intellectual disabilities and their families all be considered to ensure they may support consistency in practice and offer clear direction for RNIDs and other staff. There was recognition of the need for additional training to better support therapeutic risk taking.

5.3 Supporting individuals with an intellectual disability with their health, well-being and social care

During the focus groups that were held with the families, they noted that generic services tend to have a poor understanding of the issues that confront people with intellectual disability, they also were concerned that the provision of services during the transition process from child to adult was fractured and generally not the seamless process they would like. Along with these views, evidence from the submissions concluded that the health needs of people with intellectual disability are in general not being addressed adequately. This supports the empirical evidence outlined in Chapter 2 which can be summarized in terms of a cascade of disparities experienced by people with ID, including a higher prevalence of adverse conditions and different patterns of multi-morbidity, inadequate attention to care needs, inadequate focus on health promotion, and inadequate access to quality health care services. RNIDs who responded to the survey confirmed that they view the provision of appropriate psychosocial support along with good physical and mental healthcare as being critical aspects of their role.

Table 13: Important areas of practice identified by RNIDs

Area of practice	Ranked 1	Ranked 2
	% (n)	% (n)
Health-related care	28.0 (105)	26.5 (99)
Promotion of optimal physical health	35.5 (133)	19.3 (72)
Psychosocial support	8.5 (32)	16.3 (61)
Promotion of optimal mental health	3.5 (13)	8.6 (32)

When asked about their most frequent activities in relation to more general health issues (Table 14), RNIDs chose physical health supports first, followed by psychosocial support and health-related care activities.

Table 14: Frequency of RNID professional activities

Area of practice	Daily	Weekly	Monthly	Less than monthly	Never	N/A	Missing
	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)
Promotion of optimal physical health	82.7 (315)	7.1 (27)	3.1 (12)	1.8 (7)	1.8 (7)	3.4 (13)	3.3 (13)
Psychosocial support	68.7 (257)	14.7 (55)	5.9 (22)	5.9 (22)	1.3 (5)	3.5 (13)	5.1 (20)
Health-related care	64.6 (244)	16.4 (62)	10.6 (40)	3.4 (13)	1.6 (6)	3.4 (13)	4.1 (16)
Promotion of optimal mental health	31.6 (118)	23.5 (88)	25.1 (94)	11 (41)	5.3 (20)	3.5 (3)	5.1 (20)

The survey data also confirmed that RNIDs believe they will continue to address the health needs of people with intellectual disabilities (Table 15). It is particularly interesting to note that, given 21 prioritised areas of practice (Alaszewski et al, 2001; Sheerin, 2006), see Appendix 1, seven of the ten most highly ranked areas were focused on physical and mental health care, particularly with older people, children and those with complex needs.

Table 15: Priority areas of provision over the next five years identified by RNIDs

Area of practice	Percent	Rank
Services for older people including retirement	75.6	1
Services to manage complex medical needs	69.8	2
Communication skills	75.9	3
Services to support children with complex disability	66.9	4
Specialist services to support people with dementia including specialist memory clinics	63.8	5
Services to support people with autism	58.0	6
Services to support people with mental health concerns	54.6	8
Health education & health promotion services	43.0	11
Services within primary care	41.2	13
Acute hospital liaison services	34.6	14
Specialist health visiting services	34.1	15
Sexual health & parenting services	16.5	21

Respondents also prioritised a need for greater RNID involvement in primary care and acute care liaison with the skills needed to underpin such work also highly ranked (see Table 16).

Table 16: Top key skills required to work in RNIDs' area of practice

Key nursing skill	Percent	Rank
Clinical assessment & observational skills	82.4	1
Nursing care intervention skills	72.7	4
Skills relating to behaviours that challenge	65.1	5
Clinical decision making skills	64.8	6
Feeding, eating, drinking & swallowing disorders skills	54.9	8
Health promotion & education skills	52.5	10
End of life & palliative care skills	27.3	18
Dementia care skills	25.5	19
Sexual health & relationship skills	11.3	21

In the qualitative findings, families, in particular, considered that there was a lack of awareness among mainstream health care services regarding intellectual disabilities and that this adversely affected their ability to have health needs adequately addressed.

5.3.1. Quality and Service User Safety

Under this theme respondents described the complexity in implementing regulations and standards which have been designed to reduce risk. These are often in contrast to the more rights-based, person-centred approach espoused in many key disability policy documents and core to the philosophy underpinned in nursing curricula for RNID undergraduate education.

Respondents with an intellectual disability also raised similar concerns with a desire to have more control over their own lives and their right to establish and maintain personal relationships as evidenced in the following quote:

"Yeah inappropriate behaviour, they don't want you to do that…it's ridiculous when we're somebody with a disability and we're not allowed a relationship". (SU1P4)

Some submissions pointed up the challenge of balancing risk and autonomy and the need to recognize that some adults are, in reality, vulnerable and needing appropriate supports.

5.3.2. Governance and Accountability

Under this theme respondents described issues of accountability which are at the heart of the concept of governance. Activities associated with accountability were reported by RNID respondents to be undertaken on a regular basis. RNID respondents were mindful that not only must they strive to improve the quality of care and support they offer to service users, but that they must also be able to show that they are doing so. Respondents ranked communication, organisational skills and preparation for meeting regulatory standards in support of their practice highly. Over 50% rated "ensuring compliance with standards & regulations" an important future priority for RNIDs. As can be seen in Table 17, 70% of respondents engaged in related activities on a daily to weekly basis.

Table 17: Frequency of RNID activities associated with governance and accountability

Area of practice	Daily	Weekly	Monthly	Less than monthly	Never	N/A	Missing
	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)
Management & administration	53.3 (201)	25.5 (96)	9 (34)	6.4 (24)	2.1 (8)	3.7 (14)	4.3 (17)
Preparation for meeting standards and regulations	43.0 (164)	23.4 (89)	15.2 (58)	12.1 (46)	2.9 (11)	3.4 (13)	3.3 (13)

Respondents worked in different areas of intellectual disability services and with populations of different ages so it was not surprising that not all RNIDs were familiar with all of the documents cited in the survey. What was of note was that over 90% have a relatively good understanding of the HIQA standards. Only half of respondents indicated understanding of the *Value for Money* review, less than might have been expected, but this may reflect people's roles in organisations (see Table 18).

Table 18: RNIDs' understanding of strategies and policy documents

Document	No understanding	Little understanding	Unsure	Some understanding	Fully understand
	% (n)	% (n)	% (n)	% (n)	% (n)
HIQA Standards for Children	6.2 (23)	12.5 (46)	4.1 (15)	49.6 (183)	26.8 (99)
HIQA Standards for Adults	2.9 (11)	4.4 (17)	1.6 (6)	35.4 (136)	55.7 (214)
HSE National Review of Autism Services	12.2 (48)	22.8 (90)	15.5 (61)	36.5 (144)	8.6 (34)
New Directions Review of HSE Day Services	15.7 (60)	23.8 (91)	12.3 (47)	29.8 (114)	18.5 (71)
Respite/Residential Care with Host Families	17.7 (67)	30.3 (115)	9.8 (37)	31.9 (121)	10.3 (39)
Time to Move on from Congregated Settings	10.2 (39)	15.1 (58)	8.9 (34)	32.4 (124)	33.2 (127)
Value for Money & Policy Review	16.7 (64)	20.4 (78)	10.7 (41)	35.2 (135)	17.0 (65)
Implementation Framework, Value for Money & Policy Review	17.7 (68)	21.1 (81)	11.5 (44)	35.2 (135)	14.6 (56)
Progressing Disability	17.6 (67)	24.5 (93)	13.9 (53)	33.4 (127)	10.0 (38)
National Disability Strategy	14.4 (55)	18.5 (71)	12.0 (46)	39.9 (153)	14.9 (57)

Attention was particularly drawn in the focus groups to the increased emphasis on documentation and administration.

"And there are such huge demands on developing policies, reviewing, updating of policies, of standards and requirements from various bodies". (NFG1PF)

The focus groups, interviews and submissions, as well as narrative data from the survey, provided more insight into this concern as it became clear that many nurses were becoming increasingly distant from care provision due to the need to meet the regulatory demands, so distant that many families were unaware that there were nurses working with their loved one, never mind specialist intellectual disability nurses. Time spent with documentation and administration needs was seen by several participants as increasing, but a key value was placed on time spent with service users. A number of families were very positive about their experience when RNIDs successfully balanced these responsibilities as evidenced in this quote:

"So the two people who set the tone for me in relation to going down the whole disability path were both nurses. And it was a hugely positive experience for me on both occasions, yeah, very much so. They would be my, they would be sort of the people that I would measure others against in how they reacted to (name), how they dealt with me, the rest of my family etc., both of them were nurses". (FFG4P5)

Similarly, some respondents with an intellectual disability were also unsure of the nursing title of those of those who provided support to them but some referred to the work which they undertake within intellectual disability service:

"…she's always there for us, she gives us tablets if you're chesty and she gives you medication and that…look after us, take blood pressure and keep our heart healthy and our stomach healthy". (SU3P5)

"Those nurses are really very good to me because they help me a lot more like, especially with my eye and my ulcer". (SU3P3)

Other individuals with intellectual disabilities indicated that these nurses helped service users to attend hospital appointments and managed various health issues such as epilepsy, Alzheimer's disease, diabetes, autism and unstable medical conditions. Whilst they also spoke highly of nurses whom they had encountered in acute hospitals, they stated that there was also a need for intellectual disability nurses there. Some noted that, as they grow older, they would prefer to receive care from RNIDs in older person services for people with intellectual disabilities and not in mainstream services.

Some respondents expressed concern regarding lack of recognition of core nursing-related roles in intellectual disability services. RNID respondents attributed this to the continuing philosophical desire to advance social rather than medical models even as health care needs increase. Respondents recognised that there must be a move away from this "either/or situation" and that RNIDs must be competent in co-ordinating a holistic assessment of the needs of the person with an intellectual disability. Many respondents across groups perceived RNIDs to have a fundamental role in advocating and ensuring equity of access for service users and their carers to get the best health outcomes and supports possible by:

"Helping clients and families navigate the system and gain access to the relevant services/experts". (S10)

It was recognised that strong innovative leadership was required to ensure that RNIDs were positioned to utilise their skills and retain their competencies, ensuring evidence-based approaches to the health and well-being of people with an intellectual disability. It was increasingly recognised that given the complexity of needs of service users, the skills of the nurse were increasingly required as depicted in the following quote:

"Well I'm beginning to wonder should we have nurse stuck on the end of our name because I think that's setting up a massive barrier straight off, to some services". (NFG3P1)

There was also recognition by some that RNIDs are professionals to whom colleagues can turn for advice and expertise:

"And I've noticed through my own experience that staff still look to the nurse if there's a nurse on the team. You know managers of other services might contact another manager who they know is a nurse". (NFG3P1)

Student nurses in particular expressed enthusiasm for, and pride in, their profession, perceiving the distinct holistic approach within intellectual disability nursing as unique. They characterised the RNID as a skilled, committed and very adaptable and responsive professional. On the whole, they were very confident in their skills, abilities and knowledge but considered that they did need to develop greater clinical skill competency.

Acknowledging the potential for RNIDs to take on roles of leadership and governance within health and intellectual disability services, some strategies were proposed as to how this might be progressed. This included a clear professional body of RNIDs who would promote identity and leadership and help more strategically placed RNIDs in the future in decision and policy making.

It was proposed that a support and knowledge sharing network could be useful for RNIDs, particularly those working in settings where they are the only RNID, or those in geographically isolated settings:

"But we need to be…stronger as nurses, as a nurse group. We need to be more vocal. We need to be more supportive of each other …We need to support each other more". (NFG3P2)

Such cohesion was identified as allowing RNIDs to contribute more confidently and knowledgeably to their practice particularly within multidisciplinary teams. As noted by managers in respect to working in primary care, RNIDs should be prepared to assert themselves as leaders within the team.

The ability to be responsive and flexible was also noted in submissions such that RNIDs would need to be grounded in transformational leadership and best practice updates on developments in the provision of intellectual disability services:

"Transformational leadership is the only style that supports a person-centred culture. Leaders need to enable staff to transform the way they plan and provide care so that it is based on need and not on custom and tradition unsupported by evidence". (S28)

and:

"Services for people with intellectual disabilities would benefit from having a dedicated nurse lead in the sector to play a key role as an advisor, educator and facilitator which is central to the team". (S5)

These perspectives on the potential leadership role of RNIDs in services were supported by a number of expert interviewees who linked such leadership with achieving safety, quality and the protection of vulnerable people. It was widely acknowledged that the RNID possessed a broad body of knowledge and was *de facto* a key source of expertise for many members of the multidisciplinary team.

"They will educate and support staff, ensuring that a seamless approach to service provision is in evidence". (S4)

"The RNID should provide education to those in older care provision on how to deal with people with intellectual disabilities". (S24)

On a wider level, it was proposed that RNIDs should also become engaged in the education of others such as generic health professionals. Respondents considered that they had a critical role in advocating for and supporting other health professionals to modify their care delivery models to better respond to the unique needs and circumstances of the person with an intellectual disability.

A primary role for RNIDs, however, was considered to relate to care coordination. It was suggested that they would be employing their wide range of knowledge and skills and would be key to achieving seamless transitioning:

"The service must become more co-ordinated in its approach to service provision for people with intellectual disability and their families. There must be a more seamless transition from early years (0-5) to education (5-18) and progress through adulthood with the same integration and co-ordination". (S5)

Others noted that RNIDs will require a greater level of clinical decision-making skills than was required in congregated intellectual disability environments with well-functioning communication across the various sectors:

"This is where the networking is really important that you do have your therapeutic relationships with the public health nurses, with the GPs and with the consultants in the hospitals in the catchment area". (MFG1PF)

The important role that RNIDs could play in current and future service provision was identified by many stakeholders. As the only profession dedicated and trained specifically to work with people with intellectual disabilities, RNIDs were identified by many stakeholders as having the skills to support such people and their families to interact with specialist and generic health services so as to maximise their health and well-being. They were perceived as possessing a unique repository of expertise which generic health and social care professionals could draw upon in order to support their own work with people with intellectual disabilities in the community. To achieve this, many agreed that RNIDs will be required to be more proactive in supporting each other in settings where they will lack the proximity of colleagues that was a feature of congregated settings.

5.4 Developing Nursing Capacity, Capability and Professional Leadership

5.4.1 Developing Nursing Capacity

Many participants pointed to a need for better support of people with intellectual disabilities during life's main transitions. This was seen as particularly relevant in the realm of healthcare support and provision where the RNID was considered to have a particular relevance, undertaking general and specialist health assessments, providing health care, supporting families, liaising with other professionals, and providing excellent leadership and safe governance.

The survey offered participants twenty-eight areas of practice and asked them to identify the areas to better support the needs of people with intellectual disability. Those most frequently chosen as requiring additional education and training were the management of multiple health conditions (76%) and palliative and end of life care and person-centred planning (70.1%). The areas chosen least often were personal assistance, diabetes care and technological supports of people with intellectual disabilities (see Table 19).

Table 19: Areas of additional education and training

Area	Percent	Number	Rank
Management of multiple health conditions	76.6	294	1
Palliative and end of life	71.9	276	2
Person-centred planning	70.1	269	3
Evidence-based practice methods	68.5	263	4
Dementia assessment and care	66.9	257	5
Clinical risk assessment	64.6	248	6
Educating care staff	63.5	244	7
Care planning and report development	62.8	241	8
Advocacy	60.9	234	9
Evidence-based care programmes	58.1	223	10
Assessment of capacity	56.3	216	11
Community development	56.3	216	11
Supporting family carers	55.7	214	13
Clinical decision making	55.7	214	13
Supporting transitions	55.5	213	15
Health promotion	55.2	212	16
Supporting decision making	54.9	211	17
Psychosocial interventions	56.3	216	18
Counselling with people with intellectual disabilities	53.9	207	19
Medication management	53.1	204	20
Epilepsy care	52.9	203	21
Measuring nursing and services quality	51.3	197	22
Ethical decision making	50.3	193	23
Home and hospital care management and communication	49.5	190	24
Sexuality and parenting	47.9	184	25
Technological supports of people with intellectual disabilities	45.6	175	26
Diabetes care	45.3	174	27
Personal assistance	32.2	127	28

RNIDs themselves saw value in upskilling in clinical areas. A typical quote included:

"I do think however more training on acute medical techniques would be useful to RNIDs as our children are living beyond expectations…definitely need to teach more clinical skills, first aid, palliative…" (161:21)

It was suggested that such upskilling should form the basis for the development of a clear national strategy defining the role of the RNID within the multidisciplinary team and advancing an approach in which the RNID would adopt a key liaison role. This is evidenced in the following quote:

"…key liaison role/specialist resource to facilitate the mainstream health services to meet the needs of people intellectual disabilities. The role would be: defined by expertise and competencies (not employment location, such as, a disability service); focused on meeting the health needs of people with intellectual disabilities; clearly differentiated from social care assistants' and personal assistants' roles". (S27)

One parent had experience of having such support from an RNID in attendance in a general hospital:

"…if our daughter has to go to a hospital…she's accompanied or taken by one of the nurses from that centre. And they are able to act as an interpreter in the hospital for her and to her". (FFG3PM1)

Another parent respondent explained the value of such a role, particularly at the time of her daughter's diagnosis. An example of a typical comment included:

"My first introduction after meeting the social worker there was with the community nurse…she was absolutely brilliant because…she was my go to, my coordinator. Explained to me the various, you know OTs, the psychologists, speech and language therapy, all of that…So it was a very, it was a very sort of low key but a lovely introduction to what could be regarded as a catastrophic event in your life. I thought she did it beautifully". (FFG4P5)

This idea of the RNID as a having a specialist consultant liaison role was also supported by nurses in their focus groups. Such RNIDs would function as reservoirs of expertise and as one-stop supports in the community:

"We need RNIDs out there before they [people with intellectual disabilities] arrive, whether it's going into schools or going into community courses…you know it's pointless having people just arrive and think this is what's going to suit them because it's mainstream. You need education of people and I'd like to see the RNID there before people arrive or smoothening the way for them to arrive". (NFG2PM)

5.4.2 Implications for RNID Undergraduate Education and Training

Some managers considered that students are well prepared by their four years in university and clinical placements and that the undergraduate programme had seen some positive changes in recent years:

"So it's good that we're being listened to and the changes are being reflected in the undergraduate programme as well, I think". (MFG1P1)

Others, however, believed that there was a need for more educational focus on medical/clinical skills.

RNIDs identified a number of key areas in which a modified curriculum would strengthen skills. Communication skills were seen as fundamental, including the ability to present effectively to a range of audiences and the confidence to chair meetings.

5.4.3 Experiential Placements

There was significant interest in greater variety of practice placements in the undergraduate programme, particularly in the community and in the generic health services.

Clinical placements, it was proposed, should be in community-based services responding to the changing needs of people with intellectual disabilities and in a wide range of relevant situations in primary, secondary and tertiary care across the life-span. Requiring registered nurses to be present in all student placement situations was considered to be problematic, particularly in school and community placements and it was noted that this should be raised with the Nursing and Midwifery Board of Ireland. There were additional recommendations that the quality of placements and education be enhanced by developing the teaching roles of nurses, placement coordinators and link lecturers and through greater collaboration between universities, schools of nurse education and nursing and midwifery practice development units.

The need for imaginative placements was echoed in the expert interviews with proposals for placements in family support, as well as within the justice system, to help RNIDs to understand people with intellectual disabilities who might be victims or perpetrators of crime. It was also considered important that nursing students gain "light touch approach" experience and knowledge to learn how to assist people to live their own lives:

"I think in relation to people with intellectual disabilities it's about, there are some of them that do require significant caring but there's a very large number of people that require to be facilitated to be able to live their lives. And I think that's, you know part of the training has to be about what you can assist the person in doing, rather than what you can do for them". (E5)

One submission suggested that there should be a generic stem nursing programme covering 3 years followed by a one-year specialist intellectual disability course. It was also suggested that students on other nursing programmes should be required to complete a mandatory module on intellectual disability. A suggestion for shared learning across professions was also made by one of the expert interviewees who considered that this would enhance nurse training and education.

5.4.4 Post-Graduate Education and Continuing Professional Development

A number of participants identified the need for a greater selection of post-graduate courses for RNIDs. Managers particularly identified the need for education in autism, dementia, ageing, behavioural care and community care. It was suggested that priorities be developed based upon increased collaboration between universities and associated intellectual disability services to ensure that programmes are in tune with the skills and knowledge required for the changing landscape.

RNIDs also identified the importance of continuing professional development (CPD) for the maintenance and upgrading of skills. Some submissions proposed that CPD should be mandatory, and a module on leadership be developed in association with the nursing and midwifery practice development units. RNIDs noted, though, that time and finance are often barriers to staff being able to engage in such programmes.

The increasing expectation for RNIDs to be able to ground their practice in research-derived evidence was noted. Many reported not having developed skills in accessing, appraising and critiquing literature during their education/training. It was, therefore, proposed that short courses might be provided to update registered nurses in these areas.

5.4.5 Clinical Nurse Specialist (CNS) and Advanced Nurse Practitioner (ANP) Roles

Many individuals indicated that they saw the potential for significant developments in specialist and advanced practice roles for RNIDs. A number of areas were identified in particular. Survey respondents identified four areas where the CNS role might be developed: behaviours that challenge (n=62), epilepsy (n=56), dementia (n=46) and end of life/palliative care (n=46). The four most commonly identified areas for ANP development were behaviours that challenge (n=26), dementia (n=23), medication/prescription (n=21) and mental health (n=26).

The other data sets highlighted the importance of such roles in specific areas. It was noted that, with greater longevity, dementia has become more prevalent in the intellectual disability population. There has already been some progression in this regard but further nurse specialists are required:

"Dementia care requires clinical nurses that specialise in memory assessment and subsequent care". (S20)

Another area which was frequently identified was that of epilepsy care. Indeed, it was noted that a consultant neurologist had suggested some RNIDs' knowledge of epilepsy to be superior to that of mainstream nurse specialists. It was predicted that nurse-led epilepsy clinics would be an important part of future service provision but that, due to the number of people with intellectual disabilities who have epilepsy, they would need to be populated by nurse specialists from intellectual disability nursing.

There is significant interest in developing specialists in the area of epilepsy in intellectual disability in local clinics. Palliative and end-of-life care was also identified as needing specialist and advanced practice roles development, both in respect of older and younger people with intellectual disabilities. This was particularly pertinent considering that increasing numbers of children with complex and life-limiting conditions are now surviving child-birth:

"Yeah the population the way it's going that's severe to profound I think you have to look at end of life and palliative care". (MFG1PM)

Increasing longevity also means that age-related issues are now being witnessed frequently among people with intellectual disabilities. This includes the development of cancers that were not commonly seen in past decades:

"…looking at all aspects of the ageing population. And that includes people with intellectual disability so they are going to have all those things, osteoporosis, bowel cancer, they are going to have breast cancer". (MFG1PF)

Specialist skills will need to be developed to facilitate service developments to meet these people's needs, especially as it is clear from participants with intellectual disabilities that they do not want to be moved to mainstream age-related services.

Many participants indicated that they saw nurse specialists and practitioners being loosely linked to disability services but operating in a more fluid way, linking between services and with families and people with intellectual disabilities. Thus, there was a community aspect to it, such that nurses could be located between intellectual disability services and generic health facilities, providing interventions, liaising with others, educating family and professionals and promoting health.

Further proposed areas for development of CNS and ANP roles are outlined in figure 6.

Figure 7: Future Areas for Specialist and Advanced Practice

Despite RNIDs' knowledge and expertise in respect of areas such as these, it was stated that clinical skills "decay" quickly. Many participants believed that RNIDs must be equipped with enhanced clinical skills if they are to provide for the needs of their service users in the changed landscape of service provision. This would include people with increasingly complex health needs at either end of the lifespan and working in environments that are less supportive of the RNID.

5.5 Improving the Experience and Outcomes for Individuals with an Intellectual Disability

5.5.1 Challenges for Families and People with Intellectual Disabilities

A number of parent respondents described difficult and insensitive interactions at the time of their child's birth and diagnosis. Paediatric services were, however, highly praised, with professionals consistently characterised as having better communication skills, understanding, time and patience with people with intellectual disabilities than those who work with adults. Family respondents perceived the adult health services to be unwelcoming places. One typical comment included:

"The difference between here and [paediatric hospital] is unbelievable. I mean just unbelievable in terms of how they even approach people and speak to people and you know they don't call them strange names or call them Downs children or whatever all the time. …. why is the training not nationwide?" (FFG3PF3)

This was supported by comments from expert respondents who further suggested that the current health service is failing people with intellectual disabilities:

"…one of the biggest challenges is that people see them as people and therefore they should be able to access primary care like anybody else". (E5)

Generic adult health services were described as wholly unsuitable to people with intellectual disability, with, what parents described as a lack of coordinated care. It was suggested that this was a significant gap which needed to be filled and a typical comment included:

"…what we are saying is if there's one person who is interested enough to coordinate all of that, it just makes life so much easier". (FFG4P5)

Respondents with an intellectual disability echoed this concern citing lack of communication skills amongst generic healthcare professionals as extremely distressing leaving them perplexed. Typical comments included:

"I find the explaining is not good enough here. You know, people don't explain properly the procedure or the cause of the sickness or prevention of the sickness or aftercare. I find it not very good". (SU2PF2)

Additionally, respondents considered that language used by medical professionals was difficult to understand and easy-to read information was not available. A particular issue highlighted was again around poor communication and health service staff not talking directly to them. A typical comment included:

"It does people with disabilities heads in, is if you ever go to a doctor and you have someone with you, they'll speak over you and your just left there, that drives me up the wall". (SU1P4)

Given that respondents who participated in this study were higher functioning and had better communication skills, those who did not participate are likely to be even more vulnerable and at risk of suboptimal health care. This needs to be urgently addressed and it is critical that RNIDs continue to advocate and act as an ambassador ensuring that health professionals modify their communication styles and care delivery models to reflect the needs and understanding of the person with an intellectual disability.

Furthermore, it was proposed that hospitals were perceived not to be able to address the needs of people with intellectual disability as inpatients, with many families and intellectual disability service users feeling compelled to have someone remain with them at all times during their hospitalisation:

"…you must be with them when they're in hospital. Because nobody else, will take the responsibility that you will and I think that's quite sad". (FFG1PF1)

Many family respondents spoke of the strain placed on both the person with an intellectual disability and their families in the way generic health services, were organised. A typical comment included:

"Taking us all out to the clinic and forty people up to the one clinic at half nine in the morning and you are still sitting there at twelve, and your child [is] having a complete melt down...then parents speak up and you are seen as an aggressive person". (FFG3PF2)

Some family respondents suggested that RNIDs were a valuable resource and had an essential understanding and ability to anticipate the needs of the person with an intellectual disability. As such, there should be RNIDs in every hospital who could address these issues and ensure a coordinated and inclusive approach to health service provision. The following comment portrays this concern:

"Just to have someone there as back up, a few nurses in each department to have them there so to relax the person I mean I was nervous going into hospital. But someone with a severe disability would probably be more nervous". (SU1P4)

RNID respondents further identified areas of unmet health need including:

- Age-related health concerns;
- Complex needs
- Epilepsy
- Mental health
- Behaviours that challenge
- Autism
- Dementia
- Early intervention

It was noted that complexity of health issues has increased and that there is a need for an ever-developing set of skills.

This concern was also raised by expert informants as was an argument for the development of a nurse liaison role: *"..somebody who has any kind of vulnerability going into some of our acute units, you know with all the best intentions there in terms of care provision, sometimes some of those acute services can be fairly high octane you know and I think that in terms of your needs being met in what can be a fairly hectic environment".* (E1)

It was suggested that people with mild intellectual disabilities in particular often have unmet health needs. This is largely due to their frequently being on the edge of, or just outside, intellectual disability service provision. Yet, they face the same issues as other people with intellectual disabilities when trying to access generic health services:

"And I think that's an extremely vulnerable group and I do think that again, you know I know sometimes they come across the mental health services or addiction services, certainly they come across the social worker services. It's an area you know where I think RNIDs need to make a bit of specialisation". (NFG1PM)

A number of families who had experienced "home nursing" considered it to be a very welcome alternative to hospitalisation. This was also echoed in submissions as a potential future role for RNIDs including support of family-provided care interventions within the home, such as percutaneous endoscopic gastrostomy (PEG) feeding.

Given the health inequalities experienced by people with intellectual disabilities, the lack of health promotion was identified as a serious concern. One typical comment included:

"We very rarely if at all see people with intellectual disability involved in health promotion… or see health promotional material that people with intellectual disability can understand or read, they are very rarely mentioned within the strategy. I think the intellectual disability nurse has to fight to be part of policy making". (NFG1PF6)

It was suggested that the skills and knowledge of the RNID had not been employed to their best use in meeting specific health needs of people with intellectual disabilities. Several family respondents expressed a concern that the role of the RNID may become more managerial and less hands-on as evidenced in the following comment:

"Speaking as a family member it seems that many nurses have not moved away from focusing primarily on physical care and this is a mistake". (S28)

It is clear that participants considered that the current health system is not adequately addressing the health needs of people with intellectual disabilities and that the skill set of the RNID is underutilised. An example of a typical comment from an RNID respondent included:

"I then have my degree followed by HDip in Palliative care. I wish to remain in intellectual disability nursing and find there is a limited career pathway and my knowledge/expertise has never been utilised at all. A very frustrating state but despite all this I totally love the work I do!" (65:21)

5.5.2 Health Promotion and Social Inclusion

Respondents felt that the RNID role should have a much stronger focus on health promotion and be proactive in ensuring that people with an intellectual disability are included in mainstream health promotion activities.

"Research will tell us how it [health promotion]…helps prevent diseases, how it helps identify unmet health needs". (NFG1PF6)

One area which was particularly focused on was accessibility of health promotional materials which were deemed to be rarely in formats understandable to people with intellectual disabilities. It was considered that the RNID, working as a community liaison, would play an important part in addressing this issue and would provide educational and support to people with intellectual disabilities and their families.

As a link between various agencies and services, it was also noted that RNIDs could be ideally qualified to encourage social inclusion of people with intellectual disabilities, particularly if they were located in liaison roles. This would allow them to support both families and people with intellectual disabilities in their interactions with mainstream agencies:

"…people who are going to link the person with what's normal activity in the community". (E5)

5.5.3 Looking to the Future

Many submissions identified a need for generic health services to be more equitable and inclusive, and to recognise the individual needs of people with an intellectual disability. An overwhelming majority of respondents highlighted that people with an intellectual disability often require additional and tailored support in accessing general health care services. For many, their experience of accessing generic health care services was overwhelming and fraught with difficulties. The need for easier access with the development of walk-in clinics in primary care centres, accessible information and adequate time and support from RNIDs within these centres was perceived as critical. Expert informants suggested that there is a need for clearly managed pathways for health care and that RNIDs will have a key role to play in their coordination acting as an interface between people with intellectual disability and generic health services.

Typical comments included:

"Fair access to provision of mainstream health care such as GPs/screening/ dental". (S20)

"The ideal would be that the intellectual disability nurse would be floating in the organisation. And could be used as the interface between the hospital and the doctors and everybody else, to interpret and also to then communicate back to the house, or wherever that the person's living in, a very precise instruction". (FFG2PM5)

In light of an expected increasing reliance on generic health services by those living in the community and independent living opportunities, expert informants considered that the RNID would take on a central role in community teams. This would be as part of the restructured community health services, for example in mental health, and the RNID might work jointly with other experts in the community:

"RNIDs need to become the go-to person…they need to become a person that when somebody's saying I need to think about that person with learning difficulties, that somebody else says, oh you need to speak to a nurse, you speak to an intellectual disability nurse about that". (E3)

It was also recognised that the nurse may have to interact in different ways with people with an intellectual disability and their caregivers. A typical comment from expert respondents included:

"…there's going to be a huge role for technology to be a supportive bridge….between our nursing and clinical and medical services". (E4)

A number of submission respondents indicated that it was imperative that the health related role of the RNID should be developed to address these challenges. A typical comment included:

"With the advent of social care workers I think the RNID can now emerge as a nurse first and foremost with skills and training pertinent to the healthcare needs of people with intellectual disability. So RNID would be a nursing specialisation within nursing and not as before, trying to do the impossible, be a nurse, a sociologist, a carer, a social worker, resulting in a jack of all trades, master of none". (S7)

Within primary care, it was considered that the RNID should be an integral and specialist part of the primary health care team. This would involve providing population-based nursing services, advocating and facilitating the needs of individuals and families in the geographical location of the team, leading clinics in intellectual disability-related specialisms such as dementia care and liaising with other health services. The unique holistic focus of the RNID, which has an important part to play in facilitating an overall understanding of health issues in people with intellectual disabilities, was specifically identified. RNIDs were considered by many respondents as positioned to mediate medical and social models, by using a bio-psycho-social approach, and supporting comprehensive health assessment and interventions.

It was evident that if RNIDs are to develop in this regard generic health services must value as patients, people with an intellectual disability, and RNIDs as important staff supports.

The need to forge a more assertive and defined role within the generic health services of the future was clearly identified by RNIDs and a typical comment included:

"I'd like to hope that there'll be more collaborative partnerships with other disciplines out there that you are not working in isolation". (NFG1PF)

A number of respondents envisaged a role for RNIDs that would be akin to that of the community psychiatric nurses. The need for RNIDs to work collaboratively, particularly at the level of specialist practice nurses, was identified as critical by the international expert focus group.

General hospitals were characterised as settings that were not receptive to or understanding of the different needs of people with intellectual disability. This would be one setting where the skills of the RNID would be invaluable. Other respondents suggested that RNIDs in the future will work as part of a multidisciplinary team and have more of a consultancy role. Typical comments included:

"Consultant to the MDT team, consultant to the GP, consultant to management team, consultant to the quality team, consultant to the director". (MFG1PF)

Managers stated that RNIDs must take cognisance of their own skill complement. They should use their expertise, and train in new skills to "take their place at the table" at which strategic and management decisions are made at local, national and European level.

5.5.4 Health Provision in Intellectual Disability Services

There was much discussion of how RNIDs need to develop their health role within intellectual disability services. Concerns were expressed that some see them only as specialists for the medical needs of individual clients. Others raised concerns that they should not align themselves too closely with formal health care delivery given the context of future services being mostly community-based. Despite this, there was agreement that there would likely always be a need for specialist health service provision within more supportive environments and for RNIDs to support people with intellectual disabilities with specific requirements:

"For those with severe intellectual disability I think there is always going to be a need for specialised services in regards to behaviours that challenge, you have dementia, you might have severe medical conditions". (MFG1PM)

The example of the role of psychiatric nurses in the community was cited as a model by some respondents for community-based RNIDs given that RNIDs have a large skill mix and are willing to change and respond to the needs, values and expectations of those they support:

"They (service users) would rely on this liaison person/team to provide professional coordination of care and assistance in accessing the variety of other professionals and support services required through each life stage". (S5)

One aspect of this liaison role highlighted during the second convening of stakeholders, was the development of a hospital liaison role similar to that in the United Kingdom, supporting people with intellectual disabilities with anaesthesia, medications, epilepsy and wound care. It was observed that there already have been developments in relation to paediatrics in some regions of Ireland but there is an opportunity for more to be done to integrate RNIDs in acute generic health settings.

Furthering the role of RNIDs in health and disability services will, it was suggested, require stronger links between the Nursing and Midwifery Board of Ireland and those responsible for developing national health and social policy. Additionally, there would need to be strategic investment by the HSE in providing funding to build the workforce and develop new roles:

"It would require considerable work and planning to design and operationalise a system where intellectual disability nurses are based in or across a number of specialist and mainstream health and social care settings, supporting a range of professionals to achieve better health outcomes for people with intellectual disabilities". (S27)

The role for centres of nursing education was also identified by international experts and this, along with other development aspects will be considered under the theme of "developing clinical capacity.

5.5.5. Supporting Social Inclusion

In the survey, RNIDs reported engagement in advocacy (46.7%) and integration related service (36.3%) activities involvement on a daily to weekly basis (see Table 20).

Table 20: Frequency of RNID involvement in social inclusion activities

Area of practice	Daily	Weekly	Monthly	Less than monthly	Never	N/A	Missing
	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)
Advocacy	46.7 (75)	21.0 (79)	12.8 (48)	12.0 (45)	4.3 (16)	3.5 (13)	4.6 (18)
Services to support community integration	36.3 (136)	26.1 (98)	14.1 (53)	11.7 (44)	8.3 (31)	3.5 (13)	4.8 (19)

Bearing in mind the importance of communication and person-centredness skills that are required for interacting in a meaningful way with families and people with intellectual disabilities, it is noteworthy that both of these skills were highly ranked for working in RNIDs' current area of practice (see Table 21). Looking to the future, most RNIDs recognised that they would be required to develop additional skills and knowledge relating to community support and integration.

Table 21: Top key skills required to work in RNIDs' area of practice

Key nursing skill	Percent
Person-centred planning skills	76.4
Communication skills	75.9
Advocacy skills	53.0
Community integration skills	43.3
Services to support community integration	33.2
Early intervention skills	27.8

The qualitative findings also clearly described roles for RNIDs in the community, working with families and people with intellectual disabilities. In particular, a number of submissions affirmed the importance of the RNID in liaising with various agencies and groups on their behalf. This went beyond interactions with health services, and included liaisons with, for example, schools, housing agencies, employer and community groups. One submission considered that the nurse could be a project manager within the community promoting real inclusion and integration.

5.5.6 Family Support

Family members in the focus groups identified the myriad of challenges that they experienced. Many identified the need for a key, skilled, knowledgeable, supportive and experienced person to guide them:

*" didn't need to be carried, it's just that somebody who would walk through it with me". (*FFG4P2)

A recurring suggestion was that RNIDs would be the ideal professionals to provide this support.

On their part, RNIDs also foresaw roles for the profession in the community that would provide invaluable support to children with intellectual disability and their families. They envisaged, for example, public health nurses referring families to the community RNID at the point of their child's diagnosis. They further suggested that RNIDs could play an important role in supporting pre-school children in their mainstream pre-schools, through education of pre-school staff on intellectual disabilities:

"So I see huge opportunities for the RNID having a very strong lead role in supporting in educational and development of the pre-school staff in the speciality area of intellectual disability". (NFG1PF)

5.5.7 Community Integration

Similarly, some participants envisaged RNIDs becoming central to facilitating the integration of people with intellectual disability. A similar idea was suggested by an expert interviewee who used the term "bridge workers" to describe the role of RNIDs, filling the gaps during times of transition. Typical comments included:

"And I think RNIDs could actually be those kind of bridge workers which would actually help move from education into the adult world…they then would need to have some skills around that whole career guidance piece; that whole bit of kind of work opportunities". (E5)

"…the link worker with the family in terms of a specialist role, about how you help that family from the beginning so that we're not then dealing with, you know a child who later in life has never had an [opportunity]…" (E3)

Many stakeholders were adamant about the distinction between living in the community and being part of the community and expressed concerns that communities were not receptive to people with intellectual disabilities and that they would be isolated. RNIDs were considered to be strategically placed to act as advocates and liaisons for people with intellectual disabilities and their families. Such a strategic placement in the community was also seen as positioning RNIDs to respond in a timely manner to the needs and crises experienced by people with intellectual disabilities and their families. A number of stakeholders suggested that such community RNIDs could be introduced to families at the point at which their child is diagnosed, thereby ensuring that, from this earliest stage, the child and family receive optimal care and support. This echoed the views, noted above, of some RNIDs.

5.6 Summary

This chapter has presented an overview of the major findings across four broad areas:

- ■ Person-Centredness and Person-Centred Planning
- ■ Supporting Individuals with an Intellectual Disability with their Health, Well-Being and Social Care
- ■ Developing Nursing Capacity, Capability and Professional Leadership
- ■ Improving the Experience and Outcomes for Individuals with an Intellectual Disability

They provide insight from the triangulation of survey responses, expert interviews, family and service user focus group interviews, convenings and document reviews to consider the values, capabilities, barriers, facilitators and leadership that would be required to ensure that individuals with an intellectual disability are able to receive person-centred and expert nursing care.

There are issues to be addressed in all thematic areas in terms of the development of both the basic curriculum for RNIDs and advanced training and preparation. This development is required to better prepare RNIDs for a more person-centred, community based and family supportive service delivery environment. A need was also identified for RNIDs to develop new leadership skills and to work with services providers, educational programmess and professional bodies to better define and promote the critical roles RNIDs play in the lives of people with intellectual disability. The implementation of such workforce development strategies would also be consistent with the thrust of general health and disability specific policies including disease specific recommendations such as in The National Dementia Strategy.

The health complexities identified at all stages of the lifespan also encourage new attention to assessment of general health. This will require complex care management skills to enable RNIDs play more critical roles in multidisciplinary responses to such complexity. The respondents across all sectors highlighted that the picture captured in the review of national and international literature of increased ageing, greater health complexities and difficulties in locating appropriate, respectful and disability-understanding healthcare for people with intellectual disability within generic health services is as true for Ireland as elsewhere. In particular, a desire for the development and support of a health liaison role in accessing generic health care was identified and supported by all groups as both critical to ensure the best quality of care and support for people with intellectual disability and as a role for which RNIDs are uniquely qualified and which they are determined to play.

Chapter Six

Discussion and Recommendations

"Many respondents perceive RNIDs to have a fundamental role in advocating and ensuring equity of access for people with intellectual disability"

Chapter 6

6.1 Introduction

This project represents a significant examination of the role of the Registered Nurse Intellectual Disability (RNID) in Ireland. The RNID currently provides health and social care services to individuals with an intellectual disability, and to their families and carers, in a variety of settings from residential/domestic style homes to independent living accommodation. A broad range of stakeholders' views were sought and analysed through a variety of methods to address the overall aim of determining the future role of the RNID.

A comprehensive literature review identified a changing landscape, placing the contribution of RNIDs within demographic trends of:

- Increased survival of children with complex health needs requiring increased supports for families and schools

- Adult years being spent in the community accessing work, leisure and community resources

- A growing ageing population that service providers and the community are planning for, and yet some services are unprepared for, in particular, little readiness by hospitals, primary care and hospice/palliative care to prevent, support and manage long term enduring health conditions.

All of these trends have produced new challenges and require changing service provision and additional training/preparation for RNIDs. In particular, many respondents drew attention to the changing and multidisciplinary intellectual disability workforce and identified the requirement for the expansion of the skills of the RNID and new nursing roles in:

(1)   Schools and children's services, supporting children with intellectual disability and complex needs

(2)   Primary care and hospital systems including maternity services where they would provide specialist knowledge, skills and competencies to specialist and general health services and provide family support. Also, as specialist and advanced practitioners themselves, addressing unique issues for individuals with an intellectual disability by providing specialist or advanced assessment and support, to address dementia, epilepsy, autism, complex health needs and behavioural supports

(3)   Providing lifespan approaches addressing peri-natal and end of life concerns

(4)   Balancing of promotion of opportunity with quality and safety, as person- centred support leads to wider opportunities for community integration for persons with an intellectual disability

(5)   Engagement with the programmes of other Government department systems e.g., Justice, Education and Employment, Housing and Social Welfare.

An in-depth consultation process across various stakeholder groups used quantitative, qualitative and documentary analysis strategies to explore individuals' understanding and vision of the structures that will be required for RNIDs to work in support of priorities outlined in: The Disability Strategy (GoI, 2004); Disability Act 2005 (GoI, 2005); Vision for Change (DoHC, 2006); Time to Move on from Congregated Settings (HSE, 2011); Transforming Lives The programme to implement the recommendations of the Value For Money and Policy Review of Disability Services in Ireland (DoH, 2012/2015b); Progressing Disability Services for Children and Young People (HSE, 2012a); New Directions (HSE, 2012); Healthy Ireland – A Framework for Improved Health and Wellbeing 2013 – 2025 (DoH, 2013); Future Health - A Strategic Framework for Reform of the Health Service 2012- 2015 (DoH, 2012a); National Carers' Strategy (DoH, 2012c); National Positive Ageing Strategy (DoH, 2013a); Irish National Dementia Strategy (HSE, 2014b); Palliative Care For Children With Life-Limiting Conditions In Ireland- A National Policy (DoHC, 2009); and Tackling Chronic Disease – A Policy Framework for the Management of Chronic Diseases(GoI, 2015); Health Information Quality Authority (HIQA) Safeguarding vulnerable adult HSE policy, Children First Act change to (GoI, 2015); Withholding information Act (GoI, 2012), National Standards for Residential Services for Children and Adults with Disabilities (HIQA, 2013); and the Assisted Decision-Making (Capacity) Act (GoI, 2015); Programme for Government (GoI, 2016).

The methodology used involved comprehensive triangulation of survey responses, expert interviews, family and service user focus group interviews, clinical and management staff focus group interviews, convenings and document reviews. Consideration was also given to the values, capabilities, barriers, facilitators and leadership that would be required to ensure that individuals with an intellectual disability are able to receive person-centred, holistic and expert nursing care regardless of setting. Services provided must be responsive to the individual's needs and strengths, and offer equitable access, quality of life and health outcomes regardless of level of disability.

The RNID skill-set and potential for innovative practice across bio-psychosocial concerns will be central to the ongoing provision of person-centred health and social care with people with intellectual disabilities and their families. Service providers wanted the skills of a RNID in their teams but appeared conflicted as to how "nursing" fits with a social care model. However, whilst celebrating the existing knowledge, skills, expertise and commitment of RNIDs, both the literature and findings recognised that, in the same context of changing demographics and models of service provision, there is a requirement to plan the future development of the discipline. The RNID must continue to have a good understanding of national policy. Where radical change is required in service provision, the RNID needs to comprehend what this change means for the discipline moving forward. Historically some services have been staffed by RNIDs where there is little need for professional nurse input based on clients requirements. There are services where the needs are very diverse, for example, some people in a day service may not have any need for professional nurse input, whilst others may have daily health related support needs. The role of the RNID in these and other circumstances is complex. If support structures for people with intellectual disabilities are to move away effectively and efficiently from the medical model (McCoy et al., 2016) to a social support model or a mixed model, consideration must be given to the role and responsibility of the RNID as an essential element for the shaping and delivering of all support services to people with an intellectual disability based on clients' needs. This will include increasing its responsiveness to support requirements in the changing and community-based lives of individuals with intellectual disabilities and realising an inclusive health, wellbeing and social care model.

The specialist nature of the RNID qualification and the central leadership role that the RNID must play in delivering all services/supports to the person with a disability must be acknowledged. The RNID is a very specialised professional with a qualification dedicated to maximising the educational and social capacity as well as the overall health and wellbeing of the individual with a disability. As nurses adapt to a more social care model, their specialist skills can be much broader to embrace more than the traditional nursing role. This skill set will allow the RNID to become more specialised and support the provision of a dynamic service within the lifespan of the service user from birth to end of life.

In addition to the pivotal role that RNIDs have supporting the movement of individuals currently living in congregated settings to homes within their community, it will be necessary for nurses working in intellectual disability services to:

(1)   Continue to provide comprehensive support to manage complex and enduring health needs of individuals with an intellectual disability including related health promotion

(2)   Develop innovative interdisciplinary and cross-sector collaborative roles and ways of working within an integrated care delivery model were the individual with an intellectual disability is the focus regardless of the service type

(3)   Support both family caring and independent living for people with intellectual disability across the lifespan providing health, social, educational, psychological and behavioural interventions to individuals with an intellectual disability as required

(4)   Demonstrate effective professional leadership at all levels and continued support for the individual in a changing social context ensuring the health, well being and social care support requirements are met for all individuals with an intellectual disability

(5)   Respond to the demands of a changing environment including the need to undertake new roles, for example, as Person in Charge (PIC). This is an important part of protecting vulnerable people which involves ensuring that only fit people are involved in owning, managing and working in residential care settings

(6)   Be involved with the design and development of services and policy pertaining to disability care. The RNID has a specialist aptitude within service, therefore their input into service design and delivery is vital.

Central to the realisation of these roles will be the requirement to establish optimum staffing using a systematic approach to determine safe staffing and skill mix requirements linked to ensuring positive outcomes for individuals with an intellectual disability. The development and consistent application of an evidence based staffing framework and associated decision support tools will assist with both local and national workforce planning.

Within intellectual disability services and Community Health Organisations, such a framework will determine the most appropriate nurse staffing levels and structures based on the care and support requirements of individuals with an intellectual disability. In addition, it will assist with the planning of appropriate education provision and will also inform national RNID workforce projections to aid the examination of the supply of and demand for RNIDs at all levels.

Integrated workforce planning will also require senior nurses, planners and managers of services to examine the deployment of RNIDs to ensure that they are assigned to and supported in any emergent new roles. It has become clear from discussions that took place in the expert group convening as the project proceeded that redeployment of RNIDs as set out in HSE policy (HSE, 2011), will be a defining aspect of the changes that should take place over the coming years. As service continues to move from congregated to community settings, some RNIDs may move from roles where their predominant activity is the direct provision of care to roles where they are also managing and coordinating complex health, well being and social care for the individual with an intellectual disability. It is imperative that RNIDs are embedded in primary care services and utilise their expertise in consultative and coordinating activities.

The changes occurring will require an examination of career pathways for RNIDs which will also meet needs of individuals with an intellectual disability. This review has identified the need for new and expanded roles and ways of working, and highlighted critical areas for the development of specialist and advanced RNID clinical practice to meet the growing challenges of supporting people with profound and complex health needs. New and expanded nursing roles guided by a bio-psychosocial model of care delivery, were also called for in areas such as early onset dementia, epilepsy, peri-natal, palliative and end of life care.

Schools of Nursing and Midwifery and professional bodies will therefore need to reorientate the curriculum, and broaden practice placements in the undergraduate programme, increasing opportunities in the community and in the generic health services to ensure new nursing graduates have the knowledge, skills and attitudes to provide holistic nursing care with individuals with an intellectual disability and their families.

Recommendations from a number of stakeholders are best captured in the following quote:

'It would require considerable work and planning to design and operationalise a system where intellectual disability nurses are based in or across a number of specialist and mainstream health and social care settings, supporting a range of professionals to achieve better health outcomes for people with intellectual disabilities'. (S27)

With this in mind, the discussion has been structured into four themes. The findings are discussed in consideration of relevant policy and evidence and specific recommendations are suggested to progress these components in practice.

(1) Person-Centredness and Person-Centred Planning
(2) Supporting Individuals with an Intellectual Disability with their Health, Well-being and Social Care
(3) Developing Nursing Capacity, Capability and Professional Leadership
(4) Improving the Experience and Outcomes for Individuals with an Intellectual Disability.

From these themes, a framework for the development of nursing in disability services has been developed. Within this framework the individual with an intellectual disability is at the centre of practice and person-centredness as a philosophy underpins all aspects of the relationship between the RNID and the individual.

**Figure 2:
Framework for the
development of
Intellectual disability
nursing**
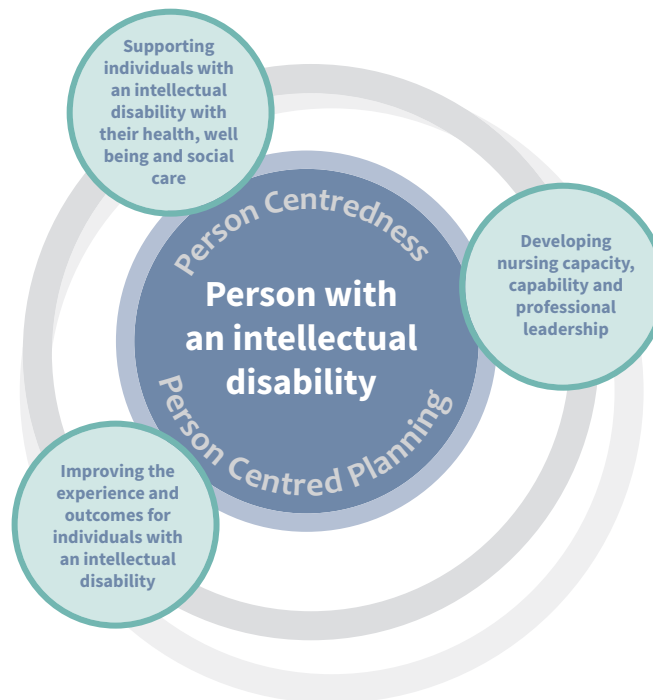
6.2 Person-Centredness and Person-Centred Planning

The literature review, stakeholder interviews, written submissions received and focus group discussions with various stakeholders confirmed the centrality of person-centredness to intellectual disability nursing.

One family member noted that a staff member who is person-centred can transform a situation:

"I think the idea of [the staff member being] a translator and a facilitator, the gateway through, you know whatever situation, you get used to a situation and then when something happens you're in a different world that you don't know. They open the gate." (FFG4PF3)

Other family members who took part in the focus groups articulated similar viewpoints and gave examples of where nurses facilitated such access.

Planning support that is person-centred is at the heart of the disability policy and practice agenda in Ireland (DoHC, 2010a; HSE, 2012c; HIQA, 2013a,b) and involves discovering how a person wants to live their life and what is required to make that possible (NARI, 2006; NDA, 2005a). Person-centredness promotes the centrality of the person with an intellectual disability in all aspects of care delivery and aims to provide effective ways which enable them to gain control in shaping their lives (Keenan, 2008, McCarron et al., 2013). It emphasises partnership working and shared decision making among the person with an intellectual disability and those participating in the care process, rather than doing things to or for them (NDA, 2005a, b; Thompson et al., 2008; Sanderson, 2000). Fundamentally person-centred care calls for a change in the roles and responsibilities of all professionals, service users and significant others to work in partnership to deliver care (NDA, 2005a,b). Evidence suggests that person-centredness improves choice for persons with an intellectual disability, social networks, communication and parental involvement (Claes et al., 2010).

The four underpinning principles of person-centredness are that:
- the person is treated with dignity, compassion and respect
- care is personalised
- care is coordinated and
- care is enabling.

(The Health Foundation, 2014; p.7)

These principles are also emphasised within the Registered Nurses and Midwives Code of Professional Conduct and Ethics (NMBI, 2014) and disability policies (HSE, 2011, 2012; DoH, 2012c). Within this project, there was agreement that if the RNID thinks in a person-centred way, person-centredness becomes the cardinal concept to inform intellectual disability nursing now and in the future.

This philosophy offers a real alternative to a bio-medical model of care and calls upon the nurse to develop their own professional knowledge, skills and values to be actively involved with others in tailoring health and social care supports for individuals with an intellectual disability within the overarching health, wellbeing and social care model (Keenan, 2008; McCarron et al., 2013).

As a philosophy, person-centred care encourages intellectual disability nurses to think in a new and creative way about providing services to people with an intellectual disability, their families and carers. Through person-centred approaches to care, people with an intellectual disability are facilitated by the intellectual disability nurse and others to make informed choices about their life and are enabled to manage their own care to the level of their abilities or to choose when to seek support from others. This is achieved across the lifespan within the context of age-appropriate care (ERHA, 2003) and the individual's capacity to consent (GoI, 2015). Within a person-centred approach intellectual disability nurses also have an important role in the holistic assessment of the individual's support requirements and as part of the planning process recognising and interpreting choice for people with limited verbal communication skills (Martin and Carey, 2009).

The question of how to understand the wishes and choices of someone with severe and profound intellectual and multiple disability is complicated largely because of the apparent difficulty in interpreting the person's non-verbal communications, the primary method of communicating for people with such pervasive disability. It is a key issue for RNIDs because it is only through understanding the person whom he or she supports that the RNID can engage with him or her and provide support in a person-centred way. Understanding the meaning of non-verbal communications of those with severe and profound intellectual and multiple disability (S/PIMD) is achieved by spending time with the person, by attuning to the person (Griffiths and Smith, 2016) and developing a mutual understanding of each other's cognitive and affective states. In general, the assistance of the Speech and Language Therapist will be helpful, but the RNID is uniquely positioned to observe, note, analyse and respond to the person with S/PIMD and develop a deep trust that forms the basis for all true empathic communication and hence an understanding of the other person.

Nurse leaders in disability services need to ensure that the focus of the RNID and care staff is on the facilitation and support of individuals to live the lives they wish to lead. This includes areas of assessment, education, employment/day programme, where they live, their community interactions, and particularly their interactions within primary, secondary and tertiary healthcare.

The acknowledged right of people with intellectual disability to self-determination (HSE, 2011) was recognised as requiring personnel skilled in supporting person-centred planning and in advocacy to ensure that people live the lives of their choosing. These skills will be vital for the RNID in understanding the key features of the Assisted Decision Making (Capacity) Act, as this Act applies to everyone and has relevance for all health and social care services (GoI, 2015). It provides for the individual's right of autonomy and self-determination to be respected through an Enduring Power of Attorney and an Advance Healthcare Directive – made when a person has capacity and to come into effect when they may lack decision-making capacity. It provides for legally recognised decision-makers to support a person to maximise their decision making powers and it places a legal requirement on service providers to comprehensively enable a person to make a decision through the provision of a range of supports and information appropriate to their situation. New models of collaborative working will be required and there was expressed support that RNIDs be equipped to continue to work closely with families and other health and social care professionals to support such positive opportunities for personal choice.

RNIDs will have a pivotal role in communication and understanding of the perspective of the person with an intellectual disability in the context of assessment, care planning, delivery and evaluation. Through opportunities for reflection during professional supervision, the nurse will be equipped to approach partnership working in a positive way and enhance the quality of life of the person with an intellectual disability. By engaging in professional supervision nurses will be assisted to consistently promote the values of person-centredness in their practice by having the opportunity to discuss their practice with an experienced, knowledgeable colleague. Professional supervision will also support RNIDs to grow as professionals thereby improving the quality of care (ONMSD, 2015) provided to persons with an intellectual disability and their families.

There is therefore a need for a collective understanding of the term "person-centredness" within disability services and methodologies developed and implemented to effectively enable the conditions for person-centredness to become a reality in all areas. The implementation of such methodologies will need to be supported, resourced and measured for their effectiveness.

RNIDs, by the nature of their professional preparation for registration as a nurse, have the knowledge, skills and ability to communicate and interact with an individual with an intellectual disability whilst evaluating their holistic support requirements. The RNID also understands the underlying cause of intellectual disability and therefore is well placed to assess and provide appropriate levels of person-centred support to the individual and their family.

It is therefore recommended that:

Recommendation 1
RNIDs will continue to ensure that their practice is informed by the values and principles of person-centredness and person-centred support in the assessment, planning and delivery of health and social care with individuals with an intellectual disability in all settings.

Recommendation 2
RNIDs will receive further professional development in supporting the self-determination of individuals with an intellectual disability through, for example, advanced advocacy training.

Recommendation 3
The HSE will develop specific policy and systems for professional supervision within intellectual disability services in accordance with the HSE's overall HR circular on clinical supervision. RNIDs will be supported to engage with regular and effective professional supervision to ensure that the values of person-centredness are applied consistently in practice.

Recommendation 4
The focus, knowledge, skills and competence of the RNID will be central to the interdisciplinary, community based model of support for individuals with an intellectual disability.

Recommendation 5
RNIDs and professionals from other disciplines will work collaboratively to support individuals with an intellectual disability live ordinary lives in ordinary places.

Recommendation 6
The RNID will be supported to undertake additional training to understand the components of the Assisted Decision-Making (Capacity) Act (2015). This will include the need for legally recognised decision-makers to support a person to maximise their decision-making powers and for RNIDs to develop an understanding of what this means for staff supporting individuals with an intellectual disability.

6.3 Supporting Individuals with an Intellectual Disability with their Health, Wellbeing and Social Care

Health care

Given the wealth of evidence of a greater prevalence of worrying health conditions in the intellectual disability population (Scheepers et al, 2005; Cooper et al., 2007; Haveman et al., 2011, Emerson. 2011; McCarron et al., 2011a, 2011b; McCarron et al., 2014a; NSW Health, 2012; and Scottish Government, 2013) the balance between the promotion of autonomy and the protection of health was highlighted by participants. The barriers to health care reported by participants in the focus groups replicate what has been described in national and international studies including communication difficulties, a reliance on others to access health care, and the increased disparities that result from low income and low literacy.

The aim of mainstreaming policy is to increase social inclusion so that individuals with an intellectual disability are seen as equal within the whole population and in this regard the Health and Wellbeing policy seeks to address this. Although there is evidence to suggest that some people with an intellectual disability may not actively pursue positive health, it will increasingly be important that RNIDs ensure that the maintenance of a person's health is a core element in planning activities. This was very evident in associated primary research such as Wave 2 of the IDS-TILDA study (McCarron et al., 2014a). Risks to health such as access issues, unhealthy lifestyle, self limiting behaviours, poorly managed medication regimes, and/or a poor ability to identify signs and symptoms of illness must be recognised by RNIDs. In turn RNIDs, using strengths based approaches, must promote healthy living opportunities and support individuals and their families to avail of health assessments and early intervention initiatives regardless of setting, including within custodial and justice systems.

Stakeholders were also cognisant of the health inequalities experienced by individuals with intellectual disabilities; many identified areas of need that are currently unmet and most considered that there will be an increase in complex needs among people with intellectual disability in the future. The Congregated Settings Report (HSE, 2011) envisaged people with intellectual disabilities accessing generic health and social services on a par with the general population.

This is further emphasised in the national health and well-being programme, Healthy Ireland: *A Framework for Improved Health and Wellbeing 2013* – 2025 (DoH, 2013) the main aims of which are to:

■ Increase the proportion of people who are healthy at all stages of life
■ Reduce health inequalities
■ Protect the public from threats to health and well-being
■ Create an environment where every individual and sector of society can play their part in achieving a healthy Ireland.

(Department of Health, 2013)

Key themes relating to the health of individuals with an intellectual disability emerged in the data collection, including the perceived unsuitability of general health services delivery, and the changing profile of the population, including additional support needs to address the complex heath concerns of both children who survive complex birth challenges and an ageing population with multi-morbidity.

During the family focus groups it became clear that a lack understanding of intellectual disability, its impact on the individual and their family exists within generic health services. They noted a significant discontinuity between child and adult health services. This was affirmed in submissions which concluded that the health needs of people with intellectual disability are not being addressed within generic services.

These findings concur with the findings of the UK report "Strengthening the Commitment: The Report of the UK Modernising Learning Disabilities Nursing Review" which notes: *"There is evidence showing that many physical, sensory and mental health needs of people with learning disabilities go unrecognised and unmet by services, with consequent negative impacts on their quality of life, life chances, life expectancy" (Scottish Government, 2012 p. 6).*

Parent respondents described difficult and insensitive interactions about diagnosis at the time of their child's birth, generic adult health services being unsuitable for people with intellectual disability, a lack of coordination of care, overly complex language used by medical professionals in hospitals, little easy-to-read information available for themselves or their family members and few health service staff talking directly to their family member who had an intellectual disability.

"It does people with disabilities' heads in, is if you ever go to a doctor and you have someone with you, they'll speak over you and your just left there, that drives me up the wall" (SU55P4).

A typical concern expressed by family members
"...you must be with them when they're in hospital. Because nobody else, will take the responsibility" (FFG1PF1).

Considerable evidence already points to a disparity between the health of people with intellectual disability and that of the general population. Across the focus groups there was agreement that disconnects between health care needs and health delivery must be urgently addressed. Families and service users suggested that their experiences would be greatly enhanced if there was a knowledgeable professional they could access to support them to "navigate" the generic health, social and community services. Respondents also identified a critical concern that RNIDs continue to advocate and act as an ambassador ensuring that health professionals modify their communication styles and care delivery models to reflect the needs and understanding of the individual with an intellectual disability.

One parent had experience of having such support from a RNID in attendance in a general hospital
"...they are able to act as an interpreter nearly in the hospital..." (FFG3PM1)

Repeatedly, family members stressed the value of such a knowledgeable supporter
"...somebody who would walk through it with me" (FFG4P2)

As liaison persons within the health service at primary, secondary and tertiary levels, it was suggested that the specialist knowledge, communication skills and competency of RNIDs positions them to understand the specialist health care and support needed for families and their family member.

This is a role that is already well defined and accepted for Learning Disability nurses in the UK (Scottish Government, 2012). Implementation of this role in Ireland is critical to the successful realisation of the goals of the various health strategies (HSE, 2011; HSE, 2012; DoH, 2010, 2012, 2013) regardless of where people with intellectual disability live. The enablement and support offered to families through the development of such a role will significantly contribute to achieving the goals of National Carers' Strategy (DoH, 2012).

The changing demographics of intellectual disability present new challenges for both families and service providers. The increased longevity of people with an intellectual disability and advances in medical care (McCarron et al, 2011; Nakken and Vlaskamp, 2007; McConkey et al., 2007; IHF & LL, 2013; HSE, 2009a; Simkiss, 2011) has led to a new population of children and older people who require particularly specialised care and support. The survey data indicated that RNIDs currently spend much of their time on health-related care and the promotion of optimal physical health and it is anticipated that these issues will continue to be a priority for the profession. However, the findings go further and propose that through their work RNIDs must be catalysts and drivers of health improvement by facilitating appropriate and timely access to the suitable pathways to care for people with intellectual disability. The RNID must also have the ability to take on board the necessities to adapt to a more social care model and the challenges that this may create.

With these needs and concerns in mind, there was considerable agreement across the stakeholder groups that the clinical skills of RNIDs are underutilised and would also benefit from further development. Skill enhancement and development among RNIDs to perform and manage comprehensive health assessments were identified as key to the improvement of evidence-based healthcare practices for people with an intellectual disability within intellectual disability services and in all locations of service delivery.

It was suggested that RNIDs should be enabled and supported to work with family carers across the lifespan with a particular focus on: (a) management of complex health needs; (b) supporting families and person with intellectual disability with planning for and implementing transitions across the lifespan; (c) encouraging health promotion habits and behaviour; (d) supporting management of enduring conditions; and (e) offering palliative care when needed.

Expert informants suggested that there is a need for clearly managed pathways for health care and that RNIDs should have a key role to play in their coordination. The focus will be oriented towards the needs of the individual with an intellectual disability and will be person-centred:

"Care will be the ownership of the patient and everybody else is trying to facilitate that". (E4)

Social Care

The Disability Strategy (GoI, 2004); Disability Act 2005 (GoI, 2005); Vision for Change (DoHC, 2006), Time to Move from Congregated Settings (HSE,2011), Transforming Lives, the programme to implement the recommendations of the Value For Money and Policy Review of Disability Services in Ireland (HSE, 2015) and the Programme for government (GoI, 2016) all support a policy imperative for people with intellectual disability to live in the community. Community living has been shown to provide a variety of improvements and indicates that smaller more individualised settings ensure a better quality of life, provide increased opportunities to function more independently, access to community activities, stable physical wellbeing and contact with friends and family (Doody, 2012; Stancliffe et al., 2011; Young, 2006). Having the opportunity to self-determine and be autonomous is largely dependent on the willingness of staff, service providers and families to facilitate it (Chou et al., 2011; Mill et al., 2010; Bond and Hurst, 2010).

Being present in the community does not necessarily increase a person's opportunities for social inclusion (Bigby, 2008; McCausland et al., 2016) as it is dependent on having a social network of people who know a person well and is built up over time through participation at home, school, college, clubs and work life (Resch al., 2010). Despite community living offering more opportunities overall, people with intellectual disability still often have low levels of connectedness with family and friends (McCausland et al., 2014). Throughout this project, many stakeholders were adamant about the distinction between living *in* the community and being part *of* the community and expressed concerns that communities were not receptive to people with intellectual disability are often isolated. The IDS-TILDA study confirms these sentiments in noting that whilst social inclusion had reduced slightly from their Wave 1 to Wave 2, feelings of being left out, loneliness or having difficulty making friends continued to exist especially among those living within residential settings and community group homes (McCausland et al., 2014).

The survey responses indicated that RNIDs currently engage in activities to support community integration as a significant part of their role. If, as envisaged, people with intellectual disability are to become fully integrated members of their communities this aspect of the role of the RNID will become increasingly important.

Transitions to new settings and between healthcare and living situations were identified as particularly difficult for people with intellectual disability and their family and such points of transition are increasing with the growing longevity of people with intellectual disability (McCallion & McCarron, 2015). RNIDs will increasingly need to offer a high level of support to ensure coordinated, proactive and effective access to health services in community settings for individuals with an intellectual disability and their families.

RNIDs were considered by many key informants to be strategically placed to act as advocates and liaise for people with intellectual disabilities and their families. The findings reinforce that RNIDs must be prepared for this role and that these roles should be recognised in both specialist intellectual disability and general health and social services. Similarly, participants envisaged RNIDs as having a central role in facilitating the integration of people with intellectual disability; an expert interviewee used the term "bridge workers" to describe these roles for RNIDs, bridging the gap during times of transition:

"…the link worker with the family in terms of a specialist role, about how you help that family from the beginning so that we're not then dealing with, you know a child who later in life has never had an [opportunity]…" (E3)

"And I think RNIDs could actually be those kind of bridge workers which would actually help move from education into the adult world…they then would need to have some skills around that whole career guidance piece; that whole bit of kind of work opportunities". (E5)

Although social integration is a component of the role of RNIDs, in the past, due to the location of some services, nurses had a greater focus upon the delivery of care relating to the person's activities of daily living. However, findings here support recommendations for greater specialisation of the role to reflect often more complex health needs and the need to support person-centred assessment, planning and evaluation of goals and greater participation in the

community for people with intellectual disability and will ensure their families. Service provision for families with young children with intellectual disability in today's environment indicates that they will live independently in the community or with their families, attending mainstream schools and colleges, taking part in leisure activities, leaving home, finding suitable accommodation, vocational training, work and developing relationships (NDA, 2010). The RNID playing an active part in Progressing Disability Services for Children and Young People (Network Teams 0-18yrs) will be important moving forward.

The findings of this project also highlight a particular concern for people with a mild or borderline level of intellectual disability whose needs may be unknown. RNIDs in the future may play a valuable role with this group of people with an intellectual disability and in areas where they have not traditionally been involved such as schools, foster care, workplaces and in the criminal justice system. In particular the latter may involve RNIDs preparing individuals with an intellectual disability for court cases and situations that require a specialist interviewer.

Their role as agents of inclusion are advanced by their contribution to health, well-being and social care reforms and their work is at the very heart of initiatives to develop services for people with intellectual disability (Gates 2006; Sheerin 2011a,b). As intellectual disability nurses promote the service-users' self-advocacy, independence and integration within the wider community, they must assess, plan and deliver this jointly with the service-user within an interdisciplinary context that acknowledges and manages safety and risk.

For persons with an intellectual disability who still reside within a congregated setting and are expected to move (HSE, 2011) the intellectual disability nurse must assume a leading role when considering client mix and client compatibility with co-residents in living situations and be involved in the promotion of individualised service design for individuals (Doody, 2012; Browning and Jones, 2002; Donnelley et al., 1994). This is important as the right client mix promotes household harmony (Borbasi et al., 2008) as even people with severe intellectual disability will have formed attachments to people, aspects of the environment or familiar routines.

Intellectual disability nurses may see risk as having the potential to empower, if assessed and managed in a systematic and positive way, whereby community access is increased, opportunities are realised and potential harm is minimised (Titterton, 2005; Aldridge, 2007; Bonardi, 2009; HSE, 2009b; RCN, 2013d). RNID respondents reported that achieving the balance between risk and rights was an increasing issue in their day-to-day work. They referred to experiences of facilitating individuals to take reasonable risks and of supporting those for whom risk has been inadequately managed. They argued for the promotion and support of self-advocacy and understanding of a person's capacity to make decisions. They also acknowledged the reality that there are many people with intellectual disability who are vulnerable and that there must be appropriate protocols and protections. Appropriate assessment and person-centred planning toolkits and metrics specifically designed to address issues concerning the safety of people with an intellectual disability would support RNIDs in this regard and ensure increased consistency.

In the context of delivering the health and social care policy within the context of a health and wellbeing model of care for persons with an intellectual disability the role of the RNID will need to be evident in:
- Primary care: working as part of the primary care team providing a population based nursing service e.g., in child protection, social work, supporting individuals manage long term conditions
- Secondary care services: in acute hospital services, in liaison roles with maternity services, in early development services for children with an intellectual disability, in mental health services, in prison services, in various specialist services of people with an intellectual disability e.g., autism, rehabilitation
- Tertiary services: in high support services, palliative care, dementia, dual diagnosis services
- Strategic governance of services: in policy development, academia, child protection, regulation and inspection etc.

The specific requirement for such involvement in an integrated health and well being model is evident from needs identified in longitudinal studies of the intellectual disability population in Ireland (McCarron et al., 2013) and from European research that included evidence from Ireland (Haveman et al., 2011).

Professional Role of the RNID

Registered Nurses Intellectual Disability, through their undergraduate preparation, have the knowledge and skills to assess, plan, prioritise, deliver and evaluate health and social care based on a comprehensive and systematic assessment of health, social and nursing care needs in partnership with the person with an intellectual disability, their family/advocate and the wider team (NMBI, 2016). Indeed, they are the only professional to be uniquely focused on achieving such outcomes, in an integrated way, throughout the lifespan of the person with an intellectual disability.

In supporting individuals with an intellectual disability, the focus of the RNID should be on the promotion of optimum physical and mental health and the promotion of social inclusion recognising that each person has unique characteristics, capabilities, needs and wishes in relation to each of these. In the context of an overall integrated health and well being model, it requires the nurse to undertake a range of health and social assessments thereby developing a comprehensive understanding of the volume and depth of the individual's support requirements and making informed decisions about their support requirements to achieve optimal health and well being.

Nursing interventions may span from supportive guidance, for some people to intensive physical and/or psychological interventions for others. This may include:

1) Supporting the individual with their physical health and well-being
2) Addressing co-morbid and complex health needs across the lifespan
3) Providing end of life care and bereavement support
4) Psychosocial interventions
5) Using assistive technology to support communication and social connectedness
6) Providing support associated with the assisted decision-making
7) Working with families
8) Development and implementation of behaviour support plans.

The educational preparation of the RNID provides them with a comprehensive in-depth understanding of the underlying causes/aetiology of disability, such as Prader Willi, William syndrome, Down syndrome, Autism, and the resultant effect of this on their health and well-being. Furthermore, this guides the RNID to provide tailored and person-centred support.

Their professional role is to assist individuals with an intellectual disability and their families towards healthy lifestyles and self care. For example, in caring for individuals with autism the role of the RNID may be at a variety of levels:

■ As a registered nurse, within their scope of practice: undertaking assessments, planning care, providing interventions and evaluating the impact of care with individuals with an intellectual disability and their families. RNIDs on graduation have specific knowledge and skills in relation to communication, social, behavioural and educational needs of individuals with autism – core areas of focus required to support individuals with autism.

■ As a registered nurse supporting clinical nurse specialists or advanced nurse practitioners assess, provide agreed interventions and evaluate the outcome of these interventions.

■ As a clinical nurse specialist providing focussed assessment and intervention to the individual with autism and their family within agreed protocols and guidelines under the supervision of others e.g. an ANP, doctor or clinical psychologist.

■ As a registered advanced nurse practitioner the RNID would make autonomous decisions regarding the assessment, diagnosis and management of the individual with autism; undertaking advanced assessment of the individual's strengths and needs, selecting and providing and/or coordinating complex interventions to the individual and their family and assessing their impact. They would also be knowledgeable and expert in assessing the individual against the goals for intervention: increased independence to an appropriate level for the individual, impact on their health and well being and impact on their quality of life. An advanced nurse practitioner also has the knowledge and skills to undertake audit and research in this area.

In other circumstances, the outcome of assessments undertaken by the RNID will require referral to specialist services for specialist assessment and/or intervention, for example to specialist mental health services or to acute services to provide appropriate support/care to meet physical needs.
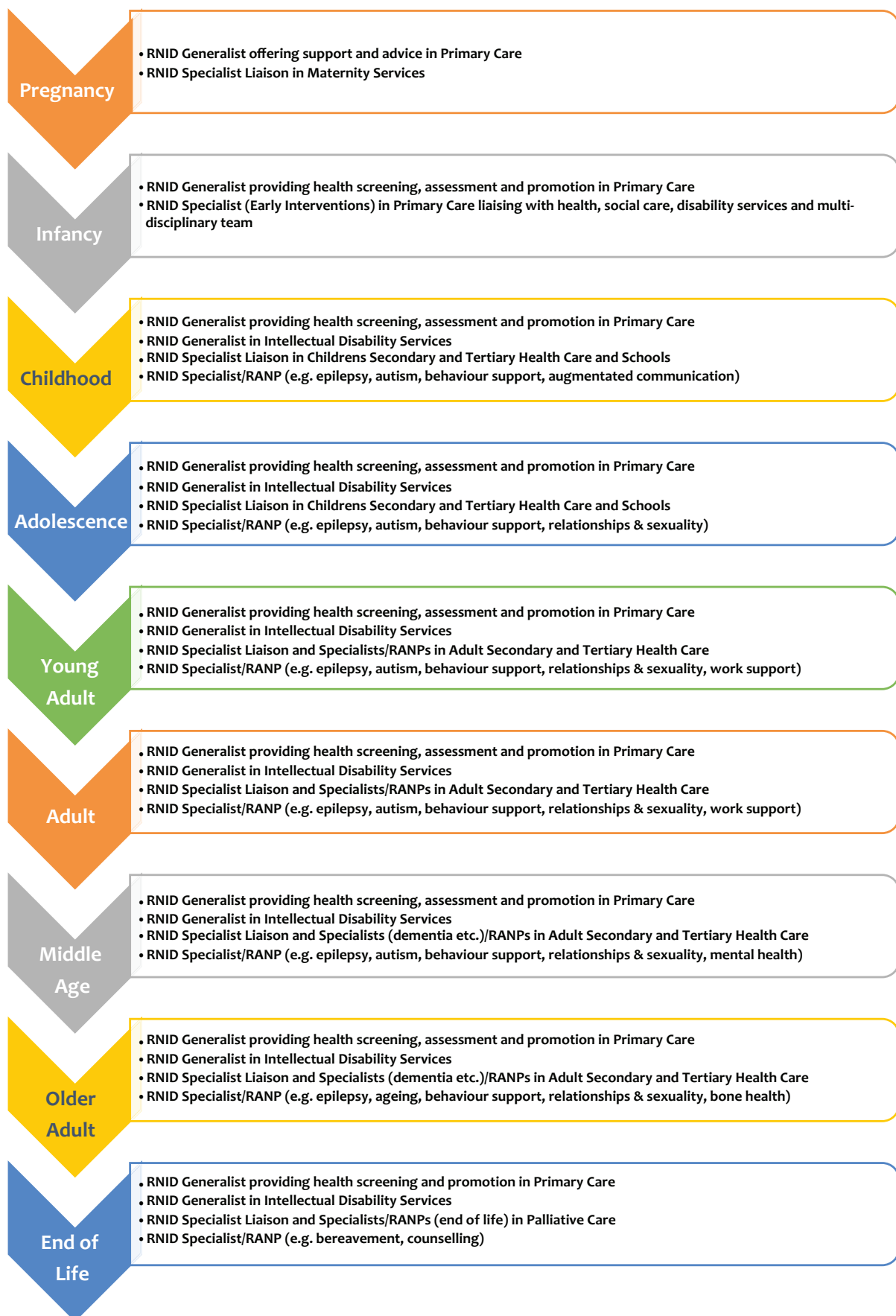
Overall the RNID's professional role may be construed as offering support for people with intellectual disability in most aspects of their daily lives and as one submission notes *"the RNID must (therefore) be central to the provision of all services" (S19)*.

The Registered Nurse Intellectual Disabilities: Support Across the Life-Span

It is increasingly recognised that people with an intellectual disability have a variety of individually-determined support needs and that these vary significantly across the life-span. Some of these relate to the challenges in accessing health and social services and the need for link persons to bridge these gaps. Other support needs may relate to difficulties in engaging with primary, secondary and tertiary health services. In such instances, it may be necessary to modify such services or to provide pathways through them, facilitated by knowledgeable professionals. Finally, while acknowledging the the fact that people with an intellectual disability are not inherently ill, there is growing evidence that they may, for a number of reasons, have poorer health outcomes than those in other parts of society. There is a clear requirement for the provision of accessible and inclusive approaches to health assessment, promotion and treatment, mediated through suitable specialists. Considering the knowledge and expertise the Registered Nurse in Intellectual Disabilities, it is envisaged that they will be central in addressing such issues.

The RNID will work at a number of levels. Having completed an undergraduate degree in intellectual disability nursing, the RNID will be skilled to provide generalist support to people with an intellectual disability in respect of health screening, assessment and promotion across their life-span. They will also be able to support families in liaising with services and other members of the multi-disciplinary team. Experienced RNIDs, who have completed post-graduate studies may be employed as Clinical Nurse Specialists or Registered Advanced Nurse Practitioners in defined areas (for example, augmented communication, autism, behaviour support, dementia etc.) which will allow them to meet the specific support needs of individual people at various points throughout the life-span. Some of the ways that RNIDs will support people with an intellectual disability, through their lives, are set out in the figure on the following page. The exemplars provided are not exhaustive, as the role of the RNID will continually develop to meet people's changing needs.

Figure 3: The roles of the RNID through the life-span

Pregnancy
- RNID Generalist offering support and advice in Primary Care
- RNID Specialist Liaison in Maternity Services

Infancy
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Specialist (Early Interventions) in Primary Care liaising with health, social care, disability services and multi-disciplinary team

Childhood
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison in Childrens Secondary and Tertiary Health Care and Schools
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, augmented communication)

Adolescence
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison in Childrens Secondary and Tertiary Health Care and Schools
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, relationships & sexuality)

Young Adult
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists/RANPs in Adult Secondary and Tertiary Health Care
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, relationships & sexuality, work support)

Adult
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists/RANPs in Adult Secondary and Tertiary Health Care
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, relationships & sexuality, work support)

Middle Age
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists (dementia etc.)/RANPs in Adult Secondary and Tertiary Health Care
- RNID Specialist/RANP (e.g. epilepsy, autism, behaviour support, relationships & sexuality, mental health)

Older Adult
- RNID Generalist providing health screening, assessment and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists (dementia etc.)/RANPs in Adult Secondary and Tertiary Health Care
- RNID Specialist/RANP (e.g. epilepsy, ageing, behaviour support, relationships & sexuality, bone health)

End of Life
- RNID Generalist providing health screening and promotion in Primary Care
- RNID Generalist in Intellectual Disability Services
- RNID Specialist Liaison and Specialists/RANPs (end of life) in Palliative Care
- RNID Specialist/RANP (e.g. bereavement, counselling)

It is therefore recommended that:

Recommendation 7
Individuals with an intellectual disability will have access to the specialist knowledge and skills of the RNID across primary, secondary and tertiary care settings.

Recommendation 8
Consideration will be given to the development of liaison roles within acute hospital services based on service need, to support the individual with an intellectual disability throughout their entire acute hospital journey.

Recommendation 9
RNIDs will be prepared to undertake, as required leadership and governance roles within health and social care services for individuals with an intellectual disability and will be clearly identified as key members of multidisciplinary teams.

Recommendation 10
Specialist RNID roles in a range of locations will support individuals with an intellectual disability with regard to their health needs; for example in community agencies, acute hospitals, day services, schools and other educational facilities, workplaces, legal and business services and the criminal justice system. Such roles will be based on identified service need.

Recommendation 11
RNID's as well as other team members, will undertake a care management and liaison role ensuring timely and appropriate access to health services for individuals with an intellectual disability.

6.4. Developing Nursing Capacity, Capability and Professional Leadership

RNID role development to improve service provided to individuals with an intellectual disability

The RNID performs a diverse range of roles to support the person with an intellectual disability and their family, ranging from holistic nursing (including intensive physical care with individuals with profound and complex disabilities) to providing guidance and support in the management of children, adolescents and adults for the purpose of optimising the life and health of the individual (INMO, 2015).

The literature reviewed also highlighted that the RNID had the following specialist skills:

- Knowledge and awareness of how cognitive and communicative impairments distort clinical presentations away from the norm and the ability to undertake effective assessment and therapeutic interventions in partnership with the person with an intellectual disability, in spite of these factors
- Knowledge and awareness of the strong association of specific intellectual disability syndromes – as well as commonly associated conditions – with heightened areas of health risk
- Being able to establish a person's complex needs based on observable, behavioural signs, often in the absence of subjective accounts
- Knowledge and awareness of how impoverished or otherwise adverse life experiences influence the presentation of signs and symptoms of ill health and making allowance for these factors in working with the person with an intellectual disability
- Recognising the anxiety associated with accessing services and the experience of ill health and working to reduce this through effective communication and co-ordination of the person's experience
- Ability to undertake comprehensive assessments of both health (physical and psychological) and social care needs
- Ability to work in multidisciplinary settings and with different agencies to develop and implement care plans e.g. child protection, education, employment, policy etc.
- Ability to provide nursing care interventions that address health needs for example: support healthy lifestyles and promote public health to improve health and prevent ill health

- Ability to educate and advise persons with an intellectual disability and carers
- Ability to safeguard and protect the rights of people with an intellectual disability especially when they are vulnerable and in need of support

(RCN, 2011a, b; 2013a, b, c, d; Atkinson et al., 2010)

Additional Irish literature (Barr, 2006; Sheerin, 2008; Sheerin & McConkey, 2008; Doody, 2013) outlined specific skills and tasks undertaken by intellectual disability nurses throughout the island.

RNID respondents to the survey and submissions received highlighted that the knowledge, skills and competencies that they need to undertake their role include:
- Person-centredness and person-centred planning
- Advocacy and liaison
- Community integration
- Risk assessment and safety planning
- Interpersonal communications with individuals including their use of assistive technology
- Health promotion and ill health prevention and education
- Service and professional regulation and standards
- Critical thinking and research
- Teamwork and leadership
- Clinical judgement skills as it pertains to health needs
- Capacity assessment and development
- Specific skills to support interventions, for example, in early intervention, behavioural support
- Ability to undertake general and specialist health and social assessments within an overall health and well-being policy
- Ability to evaluate outcomes and undertake a comprehensive reassessment
- Ability to select interventions, based on best evidence, and identify desired goals with the person with an intellectual disability
- Ability to undertake emergent new roles, for example, Person in Charge (PIC) in residential settings
- Ability to support persons with an intellectual disability and their families during transitions e.g., from children's services to adult services
- Managing the balance between self-determination and ensuring safety.

Nursing respondents to the survey and other data collection approaches highlighted the requirement for this knowledge and skill in order to further develop their role in relation to health and social care assessment, resultant targeted interventions, health promotion and social inclusion. They called for an increased emphasis in these areas in order to improve outcomes for the person with an intellectual disability across their lifespan, to provide career advancement opportunities for the profession and to provide greater clarity on the role of the RNID within services.

In addition, the national HIQA standards and regulations require staff within residential centres to be accountable and to have an awareness of policies and procedures and legislative requirements which must be applied in all settings where people with intellectual disability receive support and healthcare (HIQA, 2013). RNID respondents highlighted that they must strive to improve the quality of care and support they offer to service users and be able to demonstrate evidence of this quality. Respondents highly ranked communication, organisational skills and preparation for meeting regulatory standards in support of their practice. Over 50% of survey respondents rated *"ensuring compliance with standards & regulations"* as a priority for RNIDs and over 70% of respondents noted their engagement in such activities on a daily to weekly basis. They also noted, though, that such activities were increasingly drawing them away from engaging with individuals with an intellectual disability and towards spending more and more time on the administrative aspects of those regulations compromising their ability, at times, to provide genuine person-centred care.

However, RNID respondents did appear to understand the balance which needs to be achieved between risk and rights, and found this to be an increasing issue in their day to day work. They were concerned that a risk aversive culture in response to increasing regulation and oversight would impede independence and quality of life for persons with an intellectual disability. A large number of respondents expressed the view that additional nursing skills (and related training) need to be developed in person-centredness, advocacy, risk assessment, supported decision making and measuring nursing and services' quality to support better nurse decisions around therapeutic risk taking. There were requests that regulations and policies and the rights and wishes of people with intellectual disabilities and their families all be considered to ensure consistency in practice and to offer clear direction for RNIDs and other staff.

The provision of services to people with an intellectual disability varies throughout the country; consequently so does the role of the RNID. Concern was articulated during the project that some services appeared not to want to employ staff with the title "nurse" while seeking staff with the specific knowledge and skill set that RNIDs possess. Stakeholders posited that such organisations appeared to link the title nurse with a medical model of care believing that emphasis should be on providing a social model of care. They articulated their belief that services should provide an appropriate level of support to meet the needs of the individual (physical, psychological and social). They noted that the RNID, in line with Government policy, provides a health and wellbeing model of care to the whole of the Irish population including individuals with an intellectual disability. In that regard they highlighted that all citizens have both health and social care needs across their lifespan and questioned why a person with an intellectual disability would be treated any differently. They also articulated that the preparation of the RNID provides them with the knowledge and skills to care for individuals holistically in a health or social care environment depending on the support requirements of the individual.

As such it was highlighted that the knowledge, skill and contribution of the RNID needs to be more clearly articulated, recognised and valued so that the health and social care needs of individuals with an intellectual disability can be met. The role of the RNID is therefore multifaceted: providing direct care with persons with complex needs in some instances - care that adopts a systematic approach, that is person-centred, holistic and directed towards promoting independence; and empowering the person with an intellectual disability and their family, using a collaborative approach. At other times and in other settings the role may have a greater focus on supporting the individual with an intellectual disability during life's major transitions, or in accessing and using general health services in either primary or secondary care. Depending on the client group the role may have a focus on health promotion and supporting the individual to be actively engaged with the community within which he/she lives.

Respondents highlighted that, depending on identified population need, the role of the intellectual disability nurse may be at registered nurse level, specialist practice level or advanced practice level. National frameworks and guidance exist to support role expansion and the development of specialist and advanced practice posts.

Specialist and advanced practice nursing roles

Evidence from multiple sources within the project highlighted the requirement and desirability to develop specialist and advanced practice roles to meet the identified need of persons with an intellectual disability. Irish research has clearly identified health needs of this population that could benefit from this level of expertise (McCarron et al., 2013). Although there are approximately 130 clinical nurse specialists within disability services, there is only 1 advanced nurse practitioner and their development has been slower than in other areas of nursing and this was noted as concerning:

"if the requirement for CNS and RANP roles has been recognised and enshrined in our national health and nursing policy and legislation for all individuals requiring access to our health services why would an individual with an intellectual disability be precluded from such expertise…". (S 9)

Participants noted that in addressing the health and well-being needs of people with intellectual disabilities in the United Kingdom there are examples of advanced nursing roles being established and developed in areas such as behaviours that challenge, care of older people, epilepsy, dementia care, forensics and mental health. In Scotland, there is work to further advanced nursing practice roles in areas such as health improvement, community health, child and adolescent mental health; forensics and offending behaviours and primary and acute care liaison (Scottish Government, 2012). The data here offers indications of immediate priorities in Ireland for specialist and advanced nursing roles in dementia care, chronic and life limiting illness, children with complex needs, palliative care and end of life, epilepsy, autism, bone health, and positive behaviour support. Such specialist and advanced nursing clinical roles provide higher levels of clinical decision making performed by autonomous experienced practitioners.

A Clinical Nurse Specialist (CNS) applies additional knowledge and skills specifically focussed on a defined area of practice. They are required to have a post registration qualification of at least level 8 on the National Framework of Qualifications in the specialist area of practice that they are working in. This education is also underpinned by extensive experience and clinical expertise in the specialist area.

The core components of the CNS role are:
- Clinical focus
- Client advocate
- Education and training
- Audit and research
- Consultant.

Advanced nursing practice requires the individual RNID to be educated to master level to inform advanced autonomous practice, leadership and quality improvement beyond that achieved at the point of registration. It requires significant post registration experience and a defined level of experience in the specialist area of practice including a period of supervised practice at advanced level.

The core concepts of advanced nursing practice in Ireland are:
- Autonomy in clinical practice
- Expert practice
- Professional and clinical leadership and
- Research.

A systematic review of the literature undertaken by Mantsoukas & Watkinson (2007) identified seven generic features of advanced nursing practice:
1. Using advanced knowledge within nursing practice
2. Applying knowledge and practice to enable critical thinking and to apply analytical skills to practice issues
3. Utilising the advanced knowledge to make clinical judgments and decision that impact on and improve care
4. Providing professional leadership for others that draws on advanced knowledge and practice skills
5. Providing clinical supervision and mentoring for others
6. Undertaking evidence-based inquiry and research that impacts on areas of practice
7. Acting as a catalyst for changing, improving and developing practice.

This project noted that specialist and advanced practice posts need to be developed independent of care setting in a variety of ways: for care groups e.g., persons with dementia, intellectual disability and co-existing autism; for early detection of deterioration in an individual's physical or mental health status; in complex needs; according to location, for example, acute hospitals, primary care; or across the lifespan, for example, in children's services or older persons care. In particular, a demand was apparent, in the data, for the development of CNS and ANP posts in the areas of end-of-life and palliative care, mental health, acute liaison, maternity liaison, children with life limiting conditions and health promotion and other areas previously mentioned.

It was particularly noted that, with greater longevity, dementia has become more prevalent in the intellectual disability population requiring its own staffing response:

"Dementia care requires clinical nurses that specialise in memory assessment and subsequent care". (S20)

Another area frequently identified was epilepsy care. A consultant neurologist suggested that some RNIDs' knowledge of epilepsy was superior to that of mainstream nurses working in epilepsy services, and predicted that epilepsy clinics would be an important part of future service provision best populated by nurse specialists from intellectual disability nursing:

"There's big interest in developing specialists in the area of epilepsy in intellectual disability in local clinics". (NFG1PM)

The need for specialist intervention for assessment, treatment and management of consequences of poor bone health arise from the findings. Research shows increasing prevalence of osteopenia and osteoporosis in people with intellectual disability as they age at rates much higher than the general population but with low levels of identification through routine health assessments (Burke et al., 2014).

Many participants indicated that they saw specialist and advanced nursing practitioners being loosely linked to disability services but operating in a more fluid way; linking between the person with an intellectual disability and their families and services. The nurse could be located between intellectual disability services and generic health facilities, undertaking specific assessments, providing interventions, liaising with others, educating the individual and their family and other health professionals and promoting health.

It was emphasised, however, that there was a requirement to increase the availability and widen access to relevant post graduate education to support the development of such nursing posts. The office of the Chief Nursing Officer in the Department of Health has developed a draft policy on Graduate, Specialist and Advanced Nursing and Midwifery Practice. The draft framework currently being piloted, proposes the development of a critical mass of Registered Advanced Nurse Practitioners (RANP) in areas of most service need to address current issues in service delivery. Nurses within intellectual disability services need to grasp this opportunity and highlight service need that the role of an RANP would address and develop their knowledge and skills accordingly.

Undergraduate preparation and continuing professional development

Given growing evidence of an increasing and ageing population with intellectual disabilities, and many people of all ages presenting with a range of complex multiple health needs, greater access to the knowledge and education is necessary to develop skills and shape attitudes for the future in order to protect and promote health and well-being, provide management, leadership and supervision, undertake evidence-based inquiry and provide evidence-based education and training (Parrot et al., 2008; Maulix et al., 2011).

The undergraduate and postgraduate preparation of RNIDs is central to ensuring they have that capacity and capability to provide care and support to persons with an intellectual disability and to enhance their ability to provide professional leadership by drawing on advanced knowledge and practice skills.

Undergraduate preparation

During the course of the project, suggestions regarding the further development of the undergraduate nursing education programme in both the theoretical and practice areas were made. There was significant interest expressed by participants in a greater variety of practice placements in the undergraduate programme being made available, particularly in primary care, the community and in the generic health services including maternity services.

Clinical placements, it was proposed, should be in community based services responding to the changing needs of people with intellectual disabilities and in a wide range of relevant situations in primary, secondary and tertiary care across the life-span. There were additional suggestions that the quality of placements and education be enhanced by developing the teaching roles of nurses, placement coordinators and link lecturers and through greater collaboration and academic partnerships between universities, schools of nurse education and nursing practice development staff.

Building on this changed approach to practice placement, numerous suggestions were made for specific topics which should feature in a modified undergraduate RNID curriculum. Managers in particular identified the need for theoretical education in autism, dementia, ageing, behavioural care and community care. It was suggested that priorities be developed based upon increased collaboration between universities and associated intellectual disability services to ensure that programmes are consistent with the needs of people with an intellectual disability and with the skills and knowledge required for the changing landscape of intellectual disability services. Desired improvements in quality of life, quality of care, health care and person-centredness call for new educational strategies and therefore renewal of educational curricula and supports.

Other suggestions modifying intellectual disability nursing curriculum included: content on health conditions; clinical skills; clinical decision-making skills; personal and social care supports; as well as governance and leadership. There was also significant interest in practice placements throughout the undergraduate programme to build better connections between what students experience on these placements, what they are taught in college, and what they should be prepared for when they enter the workforce.

Post graduate education

The Nurses and Midwives Act (GoI, 2011) emphasises the duty of registered nurses to maintain professional competence to support their practice. It also identifies that he/she will need to demonstrate evidence of this competence to the satisfaction of the Nursing and Midwifery Board of Ireland when a scheme for competence assurance is developed and implemented.

RNIDs also identified the importance of continuing professional development (CPD) to the maintenance and upgrading of knowledge and skills. A number of submissions proposed that some CPD should be mandatory, and leadership programmes should be developed by staff in the Office of the Nursing and Midwifery Services Director (ONMSD).

The need for a greater selection of post-graduate education programmes for RNIDs was highlighted frequently. Appropriate post-graduate courses would present RNIDs with opportunities for professional development and specialisation and would also support some RNIDs to be better prepared to change the nature of the service that is being provided; one with a focus on person-centred planning with the individual with an intellectual disability and their family. Furthermore, it would assist with the ability of services to respond to the needs of the increasingly aged intellectual disability population and the increasing numbers of people with intellectual disability who have complex needs. RNIDs noted however, that time and finance are often barriers to staff being able to engage in such programmes.

Despite this, 76% of nurse respondents to the survey sought additional education and training in the management of multiple health conditions, 72% in palliative and end of life care, 70% in person-centred planning and 68% in evidence based practice methods highlighting a desire for preparation to support a modern disability service.

During the project, examples of other areas of further professional development were highlighted including: (1) autism, dementia, ageing, epilepsy, bone health, behavioural support, advanced and augmented communication; and community care support; and (2) general and specialist health assessments, providing health care, supporting families, and liaising with other professionals in work with people with intellectual disability across the lifespan.

Similarly, as demand was apparent in the data for the development of Clinical Nurse Specialist and Advanced Nurse Practitioner posts in disability services, associated education programmes at level 8 and 9 of the National Qualifications Authority of Ireland (NQAI) will need to be developed and be available so that staff have the necessary knowledge and skills for these autonomous posts.

Having a supportive leader and organisational learning culture are important components in the transfer of learning to nursing practice. The HSE's corporate plan emphasises learning as one of the core values of our organisation noting the importance of encouraging staff to achieve their full potential and supporting learning, innovation and creativity.

Ensuring practice is evidence based

The use of reliable evidence to support and underpin nursing decision making and practice is becoming increasingly important in all health services and nurses' ability to source and evaluate the evidence that is available is variable (Doody & Doody, 2011). RNIDs and their managers and nurse leaders need to ensure that practice is underpinned and supported by policies, procedures, protocols and guidelines that are informed by evidence.

Evidence, where it exists, to underpin intellectual disability nursing practice should be evaluated against the degree to which it meets the principles of feasibility, appropriateness, meaningfulness and effectiveness (NICE, 2003).

Supports should be provided to RNIDs to develop their capacity to access and assess evidence available. This would also require the supports to facilitate the change required to implement the evidence based approaches and initiatives. One approach that could be explored to progress this is the use of practice development,

"Practice development is a continuous process of improvement towards increased effectiveness in patient centred care. This is brought about by enabling health care teams to develop their knowledge and skills and to transform the culture and context of care. It is enabled and supported by facilitators committed to systematic, rigorous continuous processes of emancipatory change that reflect the perspectives of service users and service providers". (McCormack & Garbett, 2002 as cited in DoH, 2010b)

More latterly definitions have expanded

"Practice development is a continuous journey of developing, and innovating in care settings, so that patients/residents, families and the team engage with each other in person-centred ways. This engagement is brought about by teams developing their knowledge and skills and changing the culture and organisation of care. It is helped to happen by the team working with systematic and continuous processes of development and evaluation that evolve and include the views, experiences and needs of patients/residents, families, the team and others". (Dewing, McCormack & Titchen, 2014, p.9; adapted from Garbett & McCormack, 2002).

Although there is increasing evidence in the literature pertaining to intellectual disability services and nursing therein, as healthcare strives to ensure an increased evidence base, there is a requirement for staff in academia to work with individuals with an intellectual disability, nurses in practice and other relevant stakeholders to identify areas that require further evidence and research. It will also be increasingly important to provide a stronger evidence base for practice. In doing so there will be a requirement to foster a culture within intellectual disability nursing that examines the effectiveness of nursing interventions and continually seeks to develop new ones based on evidence and nursing outcomes.

Respondents noted the importance of involving individuals with an intellectual disability and their families in all aspects of research through real partnerships. In addition, they noted it will be important to ensure that research skills of nurses are developed; specifically to develop their ability to search for and access evidence, to critically evaluate it and then to be able to select appropriate pieces for implementation into practice and to evaluate its effectiveness. They noted that the availability of advanced nurse practitioners, formal academic partnerships and lecturer/practitioner roles would assist with this process as they could act as champions:

"Lecturers should participate in clinical practice or have greater exposure to contemporary healthcare delivery". (S9)

Evidence from submissions highlighted a number of initiatives that would support increasing the use of evidence in practice:
- The appointment of advanced nurse practitioners within disability services
- The development of joint practice/academic posts
- Availability of appropriate technology in practice areas to access evidence
- Support by commissioners and managers in services for RNIDs to engage with and undertake service based research
- The provision of specific education programmes around evidence based practice, specifically skills relating to searching for and critiquing evidence, undertaking audit and research methodologies
- Support and encouragement by managers to developing professional networks to increase the sharing of practice within services, across services regionally or nationally or internationally
- Support provided through academic partnerships, by academic staff to RNIDs in clinical practice to write and publish papers pertaining to their practice
- Support by nurse leaders to develop mechanisms for sharing and discussing research – e.g. journal clubs, involvement with UK counterparts through their initiative (Sharing the Commitment).

Such activity would not only provide the evidence base to advance the quality of care provided to individuals with an intellectual disability but would also assist with the promotion and development of a learning culture in intellectual disability nursing within services and within the overall health system.

Professional leadership

The national implementation framework Transforming Lives: the programme to implement the recommendations of the *Value for Money and Policy Review of Disability Services in Ireland* (DoH, 2015) notes that greater accountability and transparency are needed in services and in service provision. Leadership is central to this and its success is dependent on leaders who listen to the wishes of individuals with an intellectual disability and families.

There were also arguments by respondents that the advancement of governance and accountability required grounding in transformational leadership and the implementation of best practices. They highlighted that providing a person-centred service that includes a process of review will help develop accountability:

"The application of transformational leadership supports a person-centred culture. Leaders need to enable staff to transform the way they plan and provide care so it is based on need and not on custom and tradition unsupported by evidence". (S28)

As intellectual disability services develop in line with policy, effective nursing leadership will be essential to continually improve the quality of services provided to individuals with an intellectual disability locally and to address variation within and across organisations. Effective nurse leaders will also be required to support the ongoing development and sustainability of person-centred cultures of care for the person with an intellectual disability, their families and for staff. In doing so nurse leaders will need to actively engage with individuals with an intellectual disability, their families and colleagues developing a collaborative and consultative leadership approach. This will help define priorities, provide feedback and lead to a more open, transparent and engaged organisational culture (NHS, 2015).

RNIDs in leadership positions require knowledge and skills in setting directions, effective communication, change and the ability to motivate their teams to continually innovate. This will require the HSE to invest in current and future nurse leaders. The RNID must be supported to take on these leadership and change management roles and encouraged to network with RNIDs nationally and internationally to learn from their experience in this regard. Specifically, nurse leaders within disability services are encouraged to network with members of the 5 nation membership of the "Strengthening the Commitment" steering group. This group is supported in its functions by the Governments of each of the nations through the offices of the Chief Nursing Officers of each country including Northern Ireland, Scotland, Wales, England and Ireland.

Nursing leadership will also need to develop and maintain increased visibility within the overall health system e.g., HSE, ONMSD and DoH, generating through measurement and research, evidence of the nursing contribution and value to the lives of people with an intellectual disability, as well as ensuring support for the required ongoing development of the profession.

'Transformational leadership is the only style that supports a person-centred culture. Leaders need to enable staff to transform the way they plan and provide care so that it is based on need and not on custom and tradition unsupported by evidence'. (S28)

How person-centredness will be both maintained and advanced in changing services systems and embedded in community-based health and social care provision was identified as a major challenge for RNIDs in the coming years and would require that they and others be strong voices for disability in the strategic planning and development of health services. This includes a need for service planners to engage in a meaningful way with individuals with an intellectual disability, families, clinicians and others to advance this agenda:

"...we should have some sort of a national disability council that's providing strong leadership and advocacy into the health service". (E6)

Visible, high profile intellectual disability nursing leadership would ensure RNIDs are positioned to utilise skills and competencies, optimise evidence-based approaches to the health and well-being of people with an intellectual disability, and help increase the effectiveness of health services in order to progress policy to support persons with an intellectual disability. Affirming in this way the contribution of intellectual disability nursing to the health and social care support requirements of individuals with an intellectual disability will help ensure that their contribution moves intellectual disabilities services and intellectual disability nursing emphatically into the future.

Where the RNID is the Person in Charge (PIC), it will be vital that they are supported in this regard and that they have the autonomy and authority to make decisions which can impact positively on the standard and quality of care in the areas for which they are accountable. In recognition of this, they will be facilitated to oversee the provision of all necessary supports to the individual with an intellectual disability.

It is therefore recommended that:

Recommendation 12
Pre and post-registration educational curricula will be strengthened to better prepare RNIDs to respond effectively to the increased complexity of health, well being and social care needs of people with an intellectual disability across the lifespan.

Recommendation 13
A broader range of intellectual disability placement opportunities will be developed for undergraduate nursing students and new supervision guidelines developed so that RNID supervision requirements do not preclude the utilisation of some important placement opportunities.

Recommendation 14
Continuing professional development and postgraduate education programmes for RNIDs will be developed in response to the changing care and support requirements of individuals with an intellectual disability across the lifespan. These will be delivered using a blended learning approach as appropriate.

Recommendation 15
Higher Education Institutions will further develop collaborative partnerships with intellectual disability services to enhance the skills and competencies of nurses and to ensure positive health outcomes for individuals with an intellectual disability.

Recommendation 16
Individuals with an intellectual disability will increasingly be involved in the design and delivery of education programmes and policy.

Recommendation 17
RNIDs will ensure their practice is evidence based by strengthening their involvement with practice development initiatives, availing of continuing professional development, engaging with research activity and participating in professional supervision.

Recommendation 18
RNIDs will be actively involved in the development of policies, procedures, protocols and guidelines to support intellectual disability nursing practice.

Recommendation 19
In the context of integrated workforce planning, a national staffing framework; inclusive of decision support tools to calculate nurse staffing requirements within intellectual disability services will be developed based on the best available international evidence.

Recommendation 20
Clinical Nurse Specialist and Advanced Nurse Practitioner roles will be developed in accordance with Nursing and Midwifery Board of Ireland criteria and in response to identified service need. These roles will be designed to specifically address disparities in health policy implementation, health service delivery and health outcomes for individuals with an intellectual disability.

Recommendation 21

Consideration will be given to the appointment of joint posts between intellectual disability services and higher education institutions to further progress the development of evidence based intellectual disability nursing practice.

Recommendation 22

Leadership development programmes will be provided for nurses working at all levels within intellectual disability services.

Recommendation 23

RNIDs throughout the health sector will explore mechanisms to network and share practice and research including the use of journal clubs, networks, conferences and seminars and social media. RNIDs are also encouraged to build networks with colleagues at Community Health Organisation level to be informed about local developments and training opportunities. RNIDs are also encouraged to further develop professional networks with the international "Strengthening the Commitment" steering group which spans membership from Northern Ireland, Scotland, Wales, England and Ireland.

Recommendation 24

RNIDs will respond to contemporary health, well-being and social care policy recommendations and will provide leadership to ensure its timely implementation.

Recommendation 25

Opportunities will be created for RNIDs to contribute to national policy; in particular addressing health disparities for individuals with an intellectual disability.

6.5. Improving the Experience & Outcomes for Individuals with an Intellectual Disability

In Ireland, quality is defined by the four quality domains set out in the Safer Better Healthcare Standards (HIQA, 2012):

1. Person centred - care that is respectful and responsive to individuals needs and values and partners with them in designing and delivering that care
2. Effective - care that is delivered according to the best evidence as to what is clinically effective in improving an individual's health outcomes
3. Safe - care that avoids prevents and minimises harm to patients and learns from when things go wrong
4. Better health and wellbeing - care that seeks to identify and take opportunities to support patients in improving their own health and wellbeing.

The provision of quality care and service and its assurance are central to the HSE Corporate plan which emphasises that people will be at the centre of how services are delivered, that we will increase our focus on better outcomes for those who access services and that we need to ensure that our practice is underpinned by the values of Care, Compassion, Trust and Learning (HSE, 2015a). We need to identify how we can build capacity together so that our organisations can respond to what each individual person wants and needs to live the life of their choosing. The challenge for services is to support people to choose where they live; who they live with, and ensure that they have choices around what they do every day, with tailored supports for each person.

Quality care in Irish intellectual disability residential services is regulated by the Health Act 2007 (amended) (GoI, 2007) and National Standards for Residential Services for Children and Adults with Disabilities (HIQA, 2013). This framework provides for the monitoring of human rights and quality service standards for people with intellectual disabilities receiving residential health and social care services other than mental health services, which come under The Mental Health Act (GoI, 2001) and The Quality Framework for Mental Health Services in Ireland (MHC, 2007).

These national quality frameworks set the standards to be performed by intellectual disability services and the criteria against which they are measured. In addition to developing intellectual disability services the framework aims to promote access by the individual with an intellectual disability to mainstream health services and to reduce health inequalities (HIQA, 2013).

An understanding and implementation of these quality frameworks and the Nurses Code of Professional Conduct and Ethics (NMBI, 2014) are fundamental to the improvement of the intellectual disability nursing service. Intellectual disability nurses will be required to demonstrate the effectiveness of their practice and justify how this enhances the quality of the service provided to and experienced by persons with an intellectual disability. As Cusack and colleagues (2014) state *"Measuring quality is central to providing a healthcare system that is open, transparent and accountable and one which is focussed on organisational improvement and learning" (p.14).*

Transforming Lives: the programme to implement the recommendations of the *Value for Money and Policy Review of Disability Services in Ireland 2015* recommended that a governance framework be established for disability services that would include systems for information to support service design, delivery and evaluation, systems for quality assurance and processes for performance management by services. This would ensure accountability within the system and support evidence based decision making. RNIDs at all levels will need to be clear as to their role and responsibilities within this governance framework.

Evidence from the focus groups held with individuals with an intellectual disability, their families and responses by RNIDs in the survey highlighted that quality and safety was of great and increasing importance although it was noted in previous reports that this is variable within services nationally (DoHC, 2008). Variance has also been evident in HIQA inspection reports, some of which have highlighted examples of high quality person-centred services that are valued by people with an intellectual disability and their families and by the staff who work within them. Conversely, some inspections have identified deficits in some services in meeting regulatory standards and providing quality person-centred care with individuals with an intellectual disability and their families. RNIDs are central to improving quality in services in which they are employed.

Governance for Quality and Safety

To build on the ten Guiding Principles for Clinical Governance updated by the HSE in 2016 to support disability services (Appendix 13), the HSE published a "Framework for Improving Quality in our Health Service" in April 2016. By implementing the six drivers of this framework it seeks to develop a culture that:
- places the person with an intellectual disability at the centre of all we do
- reliably delivers safe, effective, equitable, personalised care and
- continuously seeks improvement

Quality improvement (QI) is the combined and unceasing efforts of everyone - healthcare professionals, patients and their families, researchers, commissioners, providers and educators - to make the changes that will lead to
1. better patient outcomes
2. better experience of care
3. continued development and
   supporting of staff in delivering quality care.

Figure 4: Framework for Improving Quality (HSE 2016)

Leadership for Quality

Person and Family Engagement

Governance for Quality

A Culture of Person Centred Quality Care that continuously inproves

Staff Engagement

Measurement for Quality

Use of Improvement Methods

The RNID is required to provide high quality care within the Irish legal and policy framework (DoHC, 2008a,b; HSE, 2009b; NMBI, 2014; HSE, 2015a).

Whilst various definitions of quality exist, one definition within a person-centred practice approach that also clearly fits with the framework above is *"The extent to which service delivery and/or service outcomes meet with the informed expectations and defined needs of the customer"* (NESF, 2006; p.3).

Individual changes and achievements for people with an intellectual disability are the hallmark of successful person-centred planning, through well-managed planning activities, determined support of implementation plans and the creation of person-centred environments and staffing in health and social care services. These need to be evident in every area where people with an intellectual disability live, work, play and interact. The centrality of person-centredness and person-centred planning for RNIDs and the RNID role now and in the future strongly emerged throughout this project.

Many respondents felt the success of using a person-centred approach will always be best measured in terms of the quality of life and health outcomes for people with intellectual disabilities:

"…people have to be able to demonstrate what they're achieving for individuals with learning disability". (E3)

To ensure that a culture of personalised quality care that continuously improves becomes a reality, there is an opportunity for the intellectual disability nurse to work with the person with an intellectual disability and their family to define, provide and evaluate their care. The intellectual disability nurse will also seek to focus, from the person's perspective, on enhancing and extending their environment and assisting them to develop their own talents, abilities, preferences, lifestyles and goals in the wider community.

Furthermore, the nurse will be required to enhance their partnership working with the individual's formal supports e.g., multi-disciplinary and multi-agency team members within disability and mainstream health and social services, as well as informal supports, such as family and friends. Both these aspects can contribute greatly to the service user's quality of life. (Keith & Schalock, 2000; Keith, 2001; Cummins, 2002; Schalock et al., 2007; Brown et al., 2009; NDA, 2010a, b).

Working in this way will involve sharing information and educating others so that all involved in care have a clear understanding of the individual's perspective and support requirements and how these may be best addressed. International evidence emphasises that people with an intellectual disability experience poorer physical and mental health and experience greater inequalities to health and social care than the general population. Ensuring integration of effort between all individuals and groups should increase equality for the person with an intellectual disability. Employing a health, wellbeing and social care policy should promote inclusiveness within the wider Irish society.

Quality improvement is also strongly linked to analysing and intelligently using information about the service (HSE, 2015a). Having access to accurate, valid, reliable, timely, relevant, legible and complete information is important to this process (HIQA, 2013). In addition to regulatory and thematic inspections by HIQA, a number of other mechanisms to identify, collect, collate and analyse data are currently being developed or are in use within services in Ireland to measure the quality of nursing care as outlined in the literature review:

- Key performance indicators
- Quality Care-Metrics
- Caring Behaviours Assurance System-Ireland (CBAS-I)
- Staff engagement

Key performance indicators within disability services currently measure a mix of structure, process and outcome indicators. At a national level rate based, count and sentinel KPIs such as activity relating to the personal assistant or home support service, indicators relating to implementation plans for children's services, number of children receiving a residential service, access to services etc., are measured, reported and used by the Social Care Division in the HSE to further improve the service provided.

RNIDs at all levels within services will need to work in partnership with individuals with an intellectual disability and with other stakeholders to identify structure, process and outcome metrics/key performance indicators in relation to the care/service they provide using both existing and emerging national frameworks as outlined in the literature review. The following table outlines suggestions from a variety of respondents regarding possible areas of practice for measurement.

Table 22: Indicators for Measurement

Type of Metric/Indicator	Description	Examples for nursing in disability services
Structure	Monitor the attributes of a health system that contribute to its ability to meet the healthcare needs of the population. They relate to the resources used by the organisation to deliver health and social care and include buildings, equipment, the availability of specialist personnel and available finances (HIQA, 2013).	Staff, management structures, numbers available, rosters, qualifications, training undertaken, turnover rates, use of temporary staff, availability of specialist or advanced practice staff, unplanned absence rates etc.
Process	Monitor what is actually done for the person with an intellectual disability and how well it is done. It relates to the transactions between the person with an intellectual disability and their care providers. They measure the activities undertaken in terms of acceptability, appropriateness, completeness and competency. It includes dimensions such as communication, engagement, patient knowledge, the quality of the interventions and the interpersonal aspect of the relationship.	Engagement with individuals with an intellectual disability, provision of information, person-centred plans and nursing care plans, integration, environment, nursing documentation, medication, falls risk or pressure ulcer risk. Staff engagement within service provider organisations.
Outcome	Monitor the stage of health of the individual or population resulting from their interaction with the healthcare system. It can include the measurement of lifestyle improvements, emotional responses to illness or its care, alterations in levels of pain, morbidity and mortality rates, improvement in the quality of life or increased level of knowledge.	Health improvements for the person with an intellectual disability, or improvements in their experience of accessing general hospital or primary care services, improvements in health promotion activities, measurement of community integration as a consequence of supports/intervention, falls or pressure ulcer incidence, self limiting behaviours.

Over 90% of RNID survey respondents noted that they had a "fairly good" understanding of the HIQA standards, however over 50% highlighted that they would like additional education and training in relation to the standard setting, quality measurement and ensuring that the learning gained from quality measurement is applied in their practice setting.

Some RNID respondents described the complexity in implementing regulations and standards that they believed to have been designed to reduce risk perceiving this to be in contrast with concepts of a rights based approach to caring for an individual with an intellectual disability and person-centred planning.

Risk assessment and safety planning

The safety of people with an intellectual disability is of paramount concern for intellectual disability nursing as it is a basic human right (HSE, 2014a; HIQA, 2013; HIQA, 2009).

The HSE, Social Care Division define a Vulnerable Person *"…as an adult who is restricted in capacity to guard himself/herself against harm or exploitation or to report such harm or exploitation. This may arise as a result of physical or intellectual impairment and risk of abuse may be influenced by both context and individual circumstances."* (HSE, 2014a: p.5).

Safeguarding Vulnerable Persons at Risk of Abuse (HSE, 2014a) provides the intellectual disability nurse, working in collaboration with others with clear policies and procedures to adhere to with regard to their roles and responsibilities in understanding, detecting and responding to abuse in terms of reporting and investigating abuse, and supporting the abused individual. The intellectual disability nurse should utilise this and other policies to support their practice in this regard.

While risk is a major part of everyday life for persons with an intellectual disability because of their potential vulnerability, needs and the activities they choose to partake in (Northway, 2002; HSE, 2014a), traditional approaches to managing risk have often lead to severe restrictions being imposed on people with an intellectual disability and increased their dependent on others as a result (Aldridge, 2007).

Respondents with an intellectual disability reinforced this experience as evidenced in the following quote:

"Yeah inappropriate behaviour, they don't want you to do that…. it's ridiculous when we're somebody with a disability and we're not allowed a relationship". (SU1P4)

According to Morgan (2000 as cited in Jukes & Aldridge, 2007; p.282) risk may be viewed as *'…the likelihood of an event happening with potentially harmful or beneficial outcomes for self and/or others'.* As intellectual disability nurses promote the self-advocacy, independence and integration of the person with an intellectual disability within the wider community, they are called on to plan and deliver this jointly with the service-user within a context that acknowledges and manages safety and assesses risk. Intellectual disability nurses may see risk as having the potential to empower, if assessed and managed in a systematic and positive way, whereby community access is increased, opportunities are realised, talents are developed and potential harm is minimised (Titterton, 2005; Aldridge, 2007; Bonardi, 2009; HSE, 2009b; RCN, 2013d).

In developing safety management systems, regulations and RNIDs training must support the inclusion of an individual's and their family's own assessment of risk in pursuing their desire to make choices. Positive risk-taking with appropriate safeguards including organisational and team support is to be encouraged as an integral component of their person-centred plan for the development of individual capacity.

It is most important that data systems gathering and identifying information on factors that place people at risk of harm underpin commitment to preparing the work force to facilitate choice and negotiate "risk dilemmas". Applying a safety management framework allows for a review of the planned progress toward the goal, and the barriers that may arise.

While a move away from institutional living has enhanced the lives of many, living in the community typically involves greater choice and may expose people to greater potential risk of adverse events. Where such adverse events occur, professionals must respond with appropriate supportive interventions (McCallion, 2003). RNIDs may play a critical educational role in this regard, as well as enabling individuals to identify and manage such situations. It is important that individuals with an intellectual disability are not exposed to undue risk and that staff undertake activities that promote wellbeing and safety. Risk management and the maintenance of safety of the person with an intellectual disability is, thus, a key element of service planning. However, there is a variable and inconsistent approach to safety planning across the intellectual disability service system.

Nurses working in intellectual disability services therefore need to have the cognitive (knowledge, reasoning and decision making) and attitudinal skills to take a whole systems approach to risk taking and safety management.

RNID respondents did understand the balance to be achieved between risk and rights, and found this to be an increasing issue in their day to day work. They were concerned that a risk aversive culture would impede the independence, opportunity for human flourishing and quality of life for service users. A large number of respondents expressed the view that additional nursing skills needed to be developed in person-centredness, advocacy, risk assessment, safety management and supported decision making. These they perceived as necessary to support better nurse decisions around therapeutic and positive risk taking.

It is therefore recommended that:

Recommendation 26
Nurse leaders and others who are designated Persons in Charge within intellectual disability services will be supported to undertake and engage in relevant education and provided with subsequent support to develop a systematic approach to quality measurement and improvement.

Recommendation 27
Nurse leaders and Persons in Charge will participate in the wider professional nursing fora at a regional, national and international level and engage in quality related development activities.

Recommendation 28
The capacity and capability of nurses within intellectual disability services will be developed to implement and evaluate evidence -based quality improvement methodologies through the provision of relevant education programmes and subsequent support.

Recommendation 29
Nurses at all levels working in intellectual disability services will access, use and evaluate the resources and tools developed by the HSE's Quality Improvement Division to achieve a culture of person-centred quality care which is continuously improving.

Recommendation 30
RNIDs will be supported to undertake training in the HSE national risk assessment and safety management guidance for intellectual disability services. The RNID should be key in its application to practice; specifically in areas of incident reporting, investigation and using findings to inform learning and change.

Recommendation 31
RNID practice will demonstrate an acknowledgement of the dynamic nature of risk, ensuring that there is ongoing multidisciplinary and collaborative review of the type and level of risk and associated updating of safety plans for individuals with an intellectual disability.

6.6. Summary

This chapter has addressed significant issues that arose in the study findings, placed those issues in the context of policy and practice in Ireland, confirmed the centrality of person-centredness and person-centred planning, and considered both the international literature and emerging practices particularly in the UK where RNIDs are also available to the intellectual disability and healthcare workforce. The applied and comprehensive nature of the data that emerged during the study offers specific and useful recommendations both for intellectual disability nursing practice in Ireland and for the implementation of pressing public policy intent. More importantly, the data and recommendations offer specific mechanisms for the enhancement of quality of lives of all people with intellectual disability in Ireland.
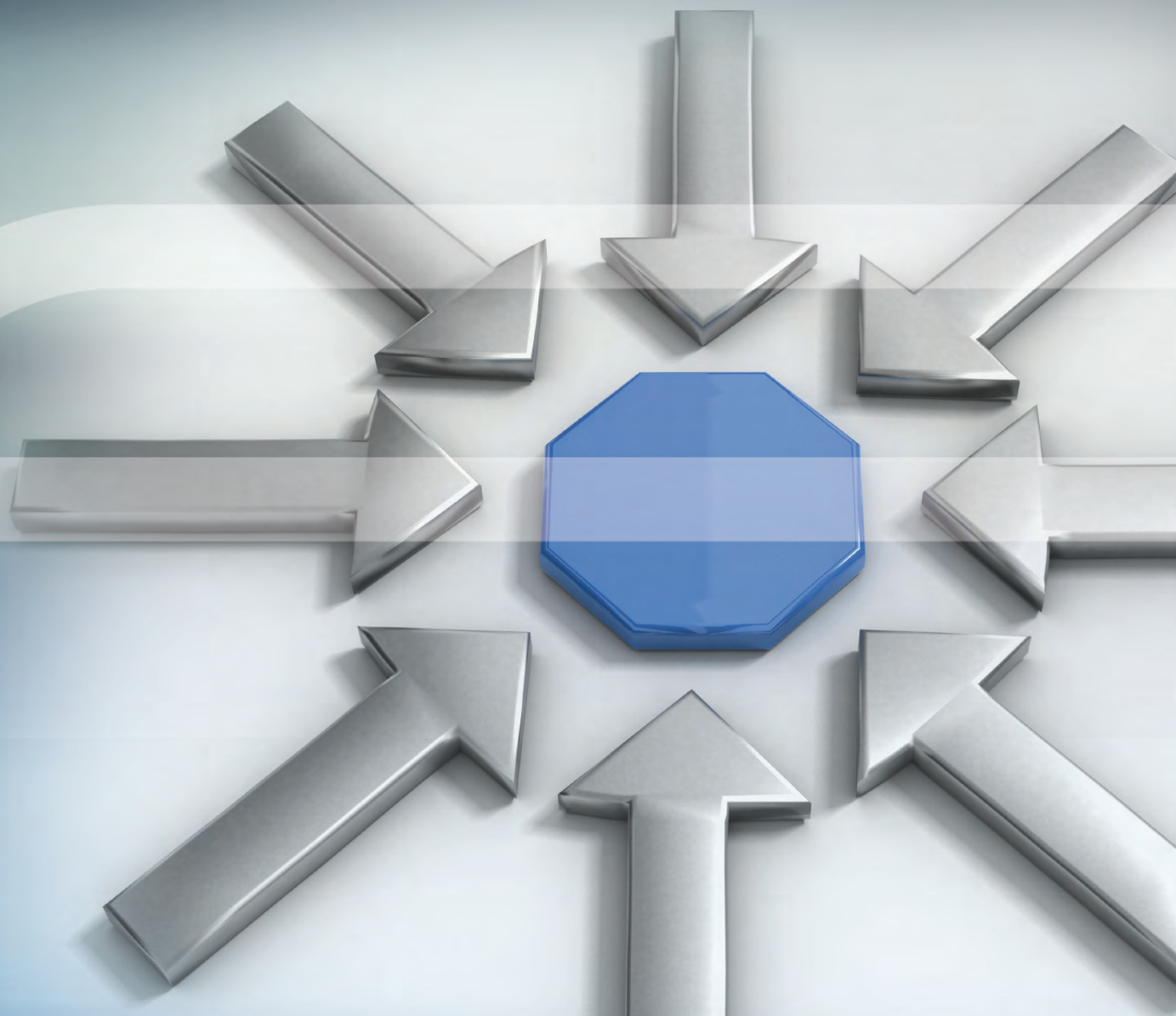
Chapter Seven

Conclusion

Shaping the Future of Intellectual Disability Nursing in Ireland
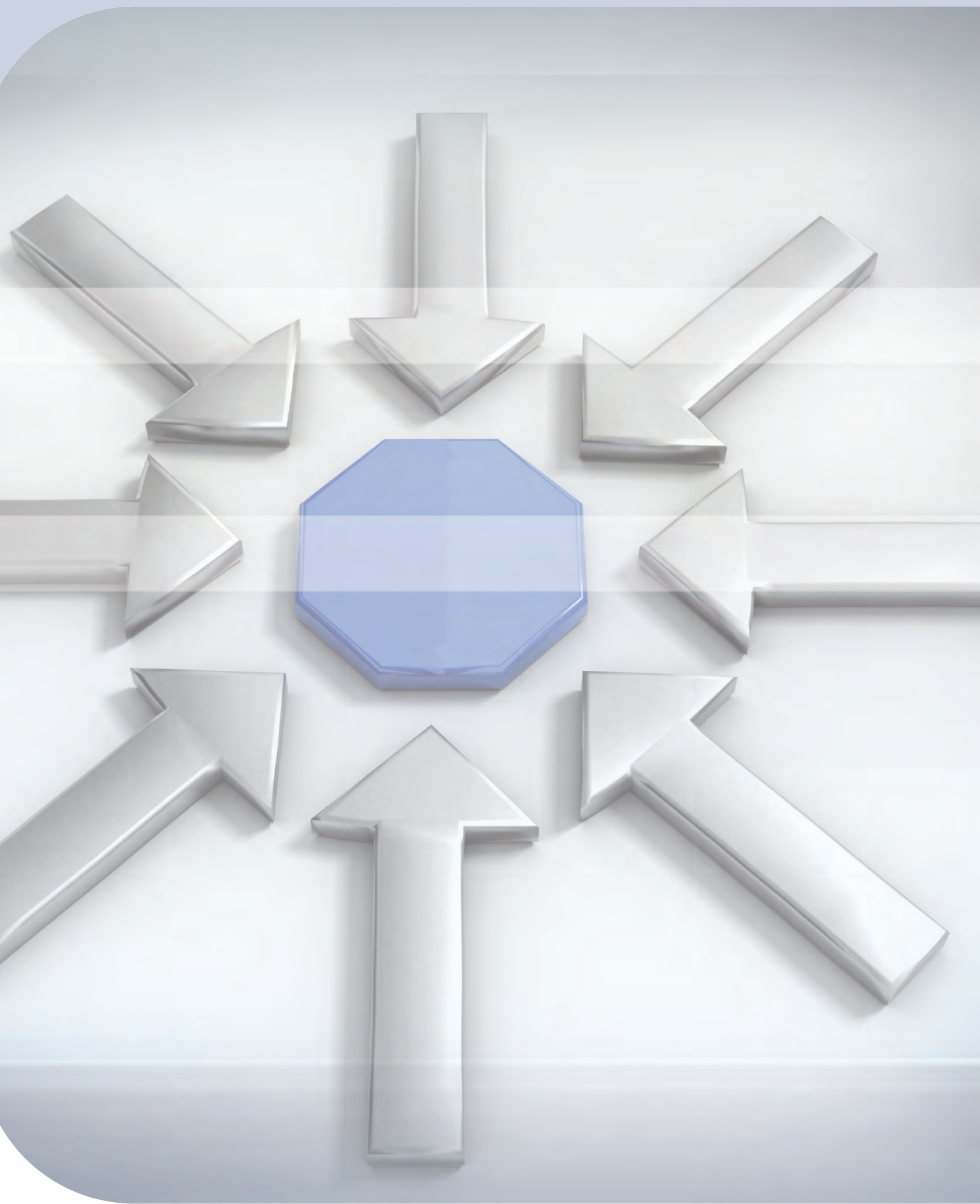
Chapter 7

Conclusion:

Key policy documents guiding change within disability services highlight the need for greater integration with general population health and community services as well as interventions to address specific health and social care issues of individuals with an intellectual disability. All of these have implications for the development of professional skills to meet the care and support requirements of people with intellectual disability and of their families. It is therefore timely to review the role of the Registered Nurse Intellectual Disability (RNID) in Ireland with a view to making evident and further promoting their significant contribution to future disability services thereby ensuring the delivery of high quality, accountable, person-centred support to individuals and their families across the health and social care system.

The aim of the project was to determine the future role of the Registered Nurse Intellectual Disability (RNID) within a health, well-being and social care model in the support of individuals with an intellectual disability to *"live ordinary lives in ordinary places".* An extensive consultation process was undertaken with a number of internal and external stakeholders, including individuals with an intellectual disability, their families, and RNIDs using a mixed methods design to facilitate data collection to inform the report.

Whilst recognising and acknowledging the existing knowledge, skills, expertise and commitment of RNIDs, both the literature and findings recognised that, in the context of changing demographics and models of service provision, there is a requirement to plan the future development of the discipline to increase its responsiveness to the needs of people with intellectual disabilities based upon a health, wellbeing and social care model for the total population.

The findings make clear that the changing landscape of service provision does, and will continue to present new challenges for stakeholders and service providers alike. It will also offer new opportunities for a reconfiguration of provision which will provide a new context within which the unique skills of the RNID will be embraced and enhanced. This will lead to continuing quality improvement in the health, well-being and quality of life of people with an intellectual disability and of their families.

This report provides an overarching framework to assist all nurses working in disability services to respond to the varying support requirements of individuals with an intellectual disability and their families. In the adoption of person-centredness as the philosophy underpinning intellectual disability nursing practice in all settings, nurses are provided with approaches to advance the health and social care support requirement of individuals with an intellectual disability, develop the profession's capacity and capability to do this and measure its outcome on the health and overall lives of those they serve.

Recommendation 32
Services for persons with a disability, in partnership with the Office of the Nursing and Midwifery Services Director will establish the appropriate structures and processes to lead, drive and monitor the implementation of recommendations 1-31 of this report.

In doing so, a Joint Implementation Group comprising Service User representatives, RNIDs, HSE, Staff representative organisations, Educators, NMBI and other relevant stakeholders will be established to undertake this work.

Their role in respect to each of the recommendations will be to:
a) Develop a detailed action plan
b) Identify who has lead responsibility
c) Identify the resources required (human and financial)
d) Outline the time frames for the implementation of the recommendations
e) Drive and monitor the implementation plan.

A formal evaluation of the implementation of the recommendations will be undertaken in 5 years from publication.

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Appendix 1

Project Steering Group

Ms Ailish Byrne	Irish Nurses and Midwives Organisation
Mr Paddy Connolly	Inclusion Ireland
Ms Breda Crehan-Roche	National Federation of Voluntary Bodies
Ms Eithne Cusack	HSE Director, NMPD Dublin North
Mr Liam Doran	Irish Nurses and Midwives Organisation
Ms Teresa Dykes	Service Manager Intellectual Disability, HSE, Sligo
Mr Kevin Figgis	Services Industrial Professional Trade Union (SIPTU)
Ms Maureen Flynn	Quality Improvement Division, HSE
Ms Sinead Foran	*Waterford Institute of Technology
Ms Marie Gilligan	Director of Nursing Services/ Association of Nurse Managers
Mr Liam Hamill	Psychiatric Nurses Association
Ms Paula Hand	Director of Nursing, St John of Gods Services
Sr Marian Harte	Director of Nursing, Daughters of Charity/Association of Nurse Managers
Ms Susan Kent	**Deputy, Office of the Chief Nursing Officer,Department of Health
Dr Siobhan O'Halloran	**Chief Nursing Officer, Department of Health
Ms Marie O' Donoghue	SIPTU
Mr Ronán O Murchu	Advanced Nurse Practitioner. Cork Autism
Mr Donie P O' Shea	National Disability Association.
Ms Liz Roche	Area Director, Nursing and Midwifery Planning and Development – DML, HSE [Joint Chairperson]
Ms Anne Marie Ryan	Social Care Division, HSE [Joint Chairperson]
Ms Judy Ryan	Nurse Practice Development Officer [Intellectual Disability Services]
Ms Sonia Shortt	Human Resources, HSE
Dr John Sweeney	Nursing and Midwifery Board of Ireland
Professor Mary McCarron	Professor and Dean of the Faculty of Health Sciences and Principal Investigator
Dr Fintan Sheerin	Co-Principal Investigator, Trinity College Dublin
Dr Colin Griffiths	Project Manager, Trinity College Dublin

* Representing the Institutes of Technology

** Ms Kent replaced Dr O'Halloran

The Project Team and Expert Group Members

Mary McCarron, Professor and Dean of the Faculty of Health Sciences University of Dublin Trinity College and Project PI.
Fintan Sheerin, Lecturer, University of Dublin Trinity College and Project Co PI.
Colin Griffiths, Assistant Professor University of Dublin Trinity College and Project Manager.
Prof. Philip McCallion, Temple University and Visiting Professor University of Dublin Trinity College
Kathleen Byrne, Clinical Tutor University of Dublin Trinity College.
Dr Elizabeth Curtis, Assistant Professor University of Dublin Trinity College.
Dr. Caroline Dalton, Lecturer University College Cork.
Maureen D'Eath, Research Assistant University of Dublin Trinity College.
Dr Owen Doody, Lecturer University College Limerick.
Carmel Doyle, Assistant Professor University of Dublin Trinity College.
Sandra Fleming, Assistant Professor University of Dublin Trinity College.
Paul Horan, Assistant Professor University of Dublin Trinity College.
Paul Keenan, Assistant Professor University of Dublin Trinity College.
Michael McKeon, Lecturer, Dublin City University.

Appendix 1

Expert group [The Convening group] members

Evelyn Reilly, Clinical Nurse Specialist in Dementia, Daughters of Charity Services
Liz Roche, Area Director, Nursing and Midwifery Planning and Development, Dublin Mid-Leinster,
The Health Service Executive
Anne Marie Ryan, Chief Education Officer, Nursing and Midwifery Board, Health and Social Care Regulatory Forum,
The Health Service Executive
Dr John Sweeney, Independent Advisor, Nursing and Midwifery Board of Ireland
Dr Janet Swinburne, IDS-TILDA, Trinity College Dublin
Florence Connolly,   Intellectual Disability Services. The Health Service Executive, Co Donegal
Liam Hamill, Psychiatric Nurses Association
Marie O' Donoghue, Services Industrial Professional Trade Union
Ronán O Murchu, Advanced Nurse Practitioner in Positive Behaviour Support, Cork Autism
Maurice Healy, Behaviour Specialist, Brothers of Charity Galway
Teresa O' Loughlin, Regional Manager Children's Service, Daughters of Charity Service
Dr. Donal Fitzsimons, Manager of Disability Services, Health Services Executive, Midland Area
Paudie Galvin Services/Director of nursing/ Director of Beechpark Autism Service at Health Service Executive
Gerry Mulholland, CEO, Stewarts Care
Joan Murphy, Research Nurse and Coordinator, Coombe Women and Infant University Hospital
John Hannigan, CEO, Sunbeam House Services
Sheila O' Neill, Regional Director, Muiriosa Foundation
Liam Doran, Irish Nurses and Midwives Organisation
Maureen Brennan, Early Intervention Services Enable Ireland
Brendan Broderick, CEO, Muiriosa Foundation.
Eilish Burke, Project Manager, The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA),
Trinity College Dublin
Ailish Byrne, Executive Council Member, The Irish Nurses and Midwives Organisation
Paddy Connolly, CEO, Inclusion Ireland
Frances Coughlan, CEO, SOS, Kilkenny
Sinead Foran, Lecturer, Department of Nursing, Waterford Institute of Technology
Maureen Flynn, Quality Improvement Division, The Health Service Executive
Professor Bob Gates, Professor of Learning Disabilities, University of West London.
Sinead Griffin Gillick, Early Intervention Services Enable Ireland
Marie Grimes McGrath, Administrator Residential Services, St. Anne's Roscrea, Daughters of Charity Service
Bernadette Halpenny, Client Services Manager, Sunbeam House Services
Susan Kent, Deputy Chief Nursing Officer, The Department of Health
Dr Jean Lane, General Practitioner, Daughters of Charity Service
Catriona Larkin, Services Manager, Daughters of Charity Service
Edel Lynn, Lecturer in Social Studies, Athlone Institute of Technology
Dr Joanne McCarthy, Senior Executive Officer Policy and Research, Disability Federation of Ireland
Brian McDonald, Positive Behaviour Support Manager, National Federation of Voluntary Bodies Representative
Michael McKeon, Department of Nursing and Human Sciences, Dublin City University
Hayley McMahon, Clinical Nurse Specialist in Dementia, Cregg House, Co. Sligo, The Health Service Executive
Mary O' Connor, Team Leader, Lean Ar Aghaidh Resource Centre, Brothers of Charity
Dr Siobhan O' Halloran, Chief Nursing Officer,The Department of Health
Teresa O'Malley, Nurse Practice Development Lettterkenny, The Health Service Executive
Lorna Peelo-Kilroe, Nursing Lead, HSE National Clinical Programme for Palliative Care, Office Nursing and Midwifery Services Director,
The Health Service Executive

Appendix 2: Survey Tool

TRINITY
COLLEGE
DUBLIN

THE UNIVERSITY OF DUBLIN
COLÁISTE NA TRÍONÓIDE

HSE
Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Shaping the Future of Intellectual Disability Nursing in Ireland

Registered Nurse Intellectual Disability Survey Questionnaire

Trinity College Dublin,
School of Nursing & Midwifery,
24 D'Olier Street,
Dublin 2,
Ireland

Appendix 2: Survey Tool

The Project

As an intellectual disability (ID) nurse, you are keenly aware of the shifting landscape of service provision to people with an intellectual disability in Ireland. This has resulted from changing demographics, renewed movement into community settings and newly emerging health care needs among the people whom you care for and support. These changes represent both opportunities and challenges for intellectual disability nursing and it is against this backdrop that the project, led by Professor Mary McCarron and Dr. Fintan Sheerin *Shaping the Future of Intellectual Disability Nursing in Ireland*, is set.

The Survey Questionnaire

As one of several information gathering efforts this survey questionnaire will elicit your experiences and opinions on the current and future roles of the registered nurse intellectual disability. It seeks to find out whether you feel that you are adequately prepared for the challenges and opportunities of the changing realities in the lives of people with ID and gather opinions on what can be done to ensure that intellectual disability nurses will remain prepared to offer support and ensure quality service.

Your responses are vital to helping shape the future role of intellectual disability nursing in Ireland as we continue to care for and support individuals with an intellectual disability and their families/carers.

All information provided by you will remain anonymous and will be treated confidentially.

The questionnaire should take you about 20 to 30 minutes to complete

Thank you for taking part in this study

Appendix 2: Survey Tool

1. Please indicate your sex

Sex	Tick [√] one box only
Male	
Female	

2. Please indicate your age range

Age Range	Tick [√] one box only
21-35	
36-50	
51-65	

3. On which divisions of the Nursing and Midwifery Register are you registered?

Division	Tick [√] all that apply
Intellectual Disability Nurse	
Psychiatric Nurse	
General Nurse	
Children's Nurse	
Midwife	
Other (please specify)	

4. What is the highest level of education you have completed?

Education Level	Tick [√] one box only
Certificate	
Diploma	
Undergraduate Degree	
Higher/Post-graduate Diploma	
Masters Degree	
Clinical Doctorate	
PhD	

5. Which HSE region do you work in?

Region	Tick [√] one box only
HSE Dublin North East	
HSE Dublin Mid Leinster	
HSE West	
HSE South	

Other (please specify)

6. What type of service do you work in?

Type	Tick [√] one box only
HSE service	
HSE-funded agency (Section 38)	
HSE-funded agency (Section 39)	
Not for profit agency	

Other (please specify)

Appendix 2: Survey Tool

7. Which of the following best describes your current area of professional practice?

Practice	Tick [√] one box only
Care coordination of people living independently	
Family support	
Community group home	
Residential service/group home in a campus setting	
Intensive/specialist service (specify, ie dementia; autism)	
Sheltered work/employment setting	
Early intervention team	
Day service	
Education setting (e.g. pre-school; special school; third level) (please specify)	
Nursing home	
Specialist Clinic in an intellectual disability service, primary, secondary or tertiary service. (specify)	
School-age team 16-18 years (assessment)	
Other (please specify)	

8. How long have you been working in your current area of professional practice?

Duration	Tick [√] one box only
Less than 1 year	
2-5 years	
6-10 years	
11-15 years	
16-20 years	
Greater than 20 years	
Not applicable	

9. What is your current job title?

Title	Tick [√] one box only
Staff nurse	
Clinical nurse manager 1	
Clinical nurse manager 2	
Clinical nurse manager 3	
Clinical nurse specialist	
Advanced nurse practitioner	
Assistant director of nursing	
Director of nursing	
Other (please specify)	

Appendix 2: Survey Tool

10. What level of intellectual disability have the people you support.

Level of intellectual disability	Tick all that apply [√]
Mild	
Moderate	
Severe/profound	
I do not care for/support people with an intellectual disability	

11. The people you care for and support are in the following age groups.

	Tick all that apply [√]
0-9 yrs	
10-19 yrs	
20-49 yrs	
50-65 yrs	
65+ years	

12. Please review the following list of areas of practice for RNIDs. Based upon your experience working as an RNID, rank the importance of these practice areas from 1 through to 11 (place a '1' beside the most important, a '2' beside the next highest in importance and so forth).

Area of Practice	Rank
General physical care (e.g. Activities of Daily Living suppor; enhancing safety; promoting self-care; addressing oral and dental health)	
Psychosocial support (e.g. Communication; emotional and psychological support; counselling; family support; education)	
Management & administration (e.g. Interacting with other multidisciplinary team members and agencies; meetings; liaising with external agencies; supervision of the activities of other staff	
Health related care (e.g. Health assessment; addressing complex health needs in terms of nutrition; epilepsy; medication management; infection control; palliative and end of life care; sexuality education; health promotion)	
Promotion of optimal mental health (e.g. Liaising with psychiatrists and other mental health staff; implementing behaviour management support plans)	
Education & training with service users (e.g. Employing play or other educative/development approaches; providing employment support for people with an intellectual disability; human resources/staffing; budgets)	
Education & training with staff or volunteers (e.g. Communication skills; monitoring medication side effects)	
Advocacy (e.g. Promoting services user autonomy; facilitating participation by families and people with an intellectual disability)	
Using assistive technology (Supporting use of assisted communication devices; electronic monitoring and compensatory assistive devices)	
Services to support community integration (e.g. person-centred planning; community development; community liaison work; providing personal assistance)	
Preparation for meeting standards/regulations (e.g. HIQA Standards, Code of Professional Conduct, National Reports on Autism/Respite care/Congregated Settings/New Directions)	
Other (please specify)	

Appendix 2: Survey Tool

13. Please review the following list of areas of practice for RNIDs. Based upon your experience working as an RNID in a typical month, how often do you engage in these activities? Tick one box for each listed activity.

Area of Practice	Daily	Weeky	Monthly	Less than monthly	Never
General physical care (e.g. Activities of Daily Living support; enhancing safety; promoting self-care; addressing oral and dental health)					
Psychosocial support (e.g. Communication; emotional and psychological support; counselling; family support; education)					
Management & administration (e.g. Interacting with other multidisciplinary team members and agencies; meetings; liaising with external agencies; supervision of the activities of other staff					
Health related care (e.g. Health assessment; addressing complex health needs in terms of nutrition; epilepsy; medication management; infection control; palliative and end of life care; sexuality education; health promotion)					
Promotion of optimal mental health (e.g. Liaising with psychiatrists and other mental health staff; implementing behaviour management support plans)					
Education & training with service users (e.g. Employing play or other educative/development approaches; providing employment support for people with an intellectual disability)					
Education & training with staff or volunteers (e.g. Communication skills; monitoring medication side effects)					
Advocacy (e.g. Promoting services user autonomy; facilitating participation by families and people with an intellectual disability)					
Using assistive technology (Supporting use of assisted communication devices; electronic monitoring and compensatory assistive devices)					
Services to support community integration (e.g. person-centred planning; community development; community liaison work; providing personal assistance)					
Preparation for meeting standards/ regulations (e.g. HIQA Standards, Code of Professional Conduct, National Reports on Autism/Respite care/Congregated Settings/New Directions)					
Other (please specify)					

Appendix 2: Survey Tool

14. From the following list of key RNID skills, please select the 18 top key skills required to work in your current area. Please rank skills in order of importance from 1 through 18 (place a "1" beside the most important skill, a "2" beside the next most important skill and so forth).

Key Nursing Skills	Rank
Clinical assessment and observational skills	
Communication skills (including augmentative methods)	
Early intervention skills	
Dementia care skills	
Clinical decision making skills	
Education skills	
Group facilitation skills	
Nursing care intervention skills	
Skills relating to the assessment, support and interventions for behaviours that challenge	
Health promotion and education skills	
Sexual health and relationship skills	
End of life and palliative care skills	
Community integration skills	
Advocacy skills	
Organisational skills	
Administration skills	
Case management skills	
Person centred planning skills	
Feeding, eating, drinking and swallowing disorder skills	
Preparation for meeting standards/regulations	
Services to support community integration	
Other (please specify)	

15. Are your existing skills and knowledge utilised to their full potential?

Utilisation of Skills and Knowledge	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
My existing skills are utilised to their full potential					
My existing knowledge is utilised to its full potential					

Appendix 2: Survey Tool

16. To what extent do you understand the strategies and policy documents listed below?

Document	No understanding	Little understanding	Unsure about understanding	Some understanding	Fully understand
HIQA Standards for Children					
HIQA Standards for Adults					
HSE National Review of Autism Services. Past Present and Way Forward					
New Directions Review of HSE Day Services and Implementation Plan Working Group Report					
Respite/Residential Care with Host Families in Community Settings Working Group Report					
Time to Move on from Congregated Settings A Strategy for Community Inclusion HSE					
Value for Money and Policy Review of Disability Services Programme					
Value for Money and Policy Review of Disability Services in Ireland. National Implementation Framework. Department of Health					
Progressing Disability Services for Children and Young People					
National Disability Strategy Towards Department of Health and Children					

Appendix 2: Survey Tool

17. We would like to understand what areas of service provision will, in your opinion, most need to be focused on over the next five years. (please rank these in order of priority: 'place a '1' beside the area of highest priority, a '2' beside the area of next highest priority and so forth)

Area of Practice	Rank
Services for older persons with an intellectual disability including retirement	
Specialist services to support people with dementia including specialist memory clinics	
Services to support children with complex disability	
School to work transition	
Services to manage complex medical needs (e.g. palliative; end of life care)	
Bereavement support services	
Adolescent services	
Sexual health and parenting services	
Acute hospital liaison services	
Services to support people with mental health concerns	
Respite and family support services	
Services to support people with autism	
Advocacy services	
Supporting people in the criminal justice system	
Specialist health visiting services (community group homes, acute hospitals, and primary care services etc)	
Life skills training and life building	
Services to support community integration	
Health education and health promotion services	
Developing innovative approaches to communication.	
Assistive technology assessment and management	
Ensuring compliance with standards and regulations	
Services within primary care settings	
Management and administration	

Other (please specify and then give a ranking if you consider this to be a priority area)

Appendix 2: Survey Tool

18. To address the priority areas you identified, what areas of additional education and training do you feel RNIDs require to better support the needs of people with an intellectual disability.

Area of Education/Training	Tick all that apply
Person-centred planning	
Advocacy	
Supporting decision-making	
Dementia assessment and care	
Management of multiple health conditions	
Diabetes care	
Epilepsy care	
Medication management	
Care planning and report development	
Counselling with people with an intellectual disability	
Psychosocial interventions such as providing emotional support, enhancing a person's ability to communicate or offering complementary therapy.	
Educating care staff	
Evidence based care programmes	
Health promotion	
Sexuality and parenting support for people with an intellectual disability	
Supporting transitions (child to adult and adult to old age services)	
Supporting family carers	
Palliative and end of life care	
Community development such as building support mechanisms in the community	
Ethical decision-making	
Home and hospital care management and communication	
Personal assistance	
Clinical decision making	
Assessment of capacity	
Measuring nursing and services quality	
Clinical risk assessment	
Technological supports of people with intellectual disability	
Evidence based practice methods	

Other (please specify)

Appendix 2: Survey Tool

The remaining two questions on the questionnaire relate to the development of clinical nurse specialist (CNS) and advanced nurse practice (ANP) roles. This issue is an important focus of this study and you are therefore urged to provide as comprehensive a response as possible to both questions.

19. Is there scope for the development of CNS roles in your current area of practice?

	Tick [√] one box only
Yes	
No	

If 'Yes' Please give examples of CNS role and how they may enhance services to people with intellectual disabilities

CNS Role	How role can enhance Services

20. – Is there scope for the development of ANP roles in your current area of practice?

	Tick [√] one box only
Yes	
No	

If 'Yes' Please give examples of ANP role and how they may enhance services to people with intellectual disabilities

ANP Role	How role can enhance Services

Appendix 2: Survey Tool

21. Is there anything else that you would like to add or share?

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Thank you for taking the time to compete this questionnaire.

Please return the competed questionnaire in the stamped addressed envelope provided by

Date

If you have any questions, please feel free to contact the research team on:
01 – 896 4072 or 01 – 896 3115 or email sheerinf@tcd.ie or cgriffi@tcd.ie

Appendix 3: Family Focus Group Topic Guide

Introduction

- As family members of someone with an intellectual disability you probably experience particular challenges on an ongoing basis.

- Can you describe those challenges?
- Are there tasks you need help with — can describe them?

- What types of supports would help you and your family member to meet those challenges?

- Who should provide the support that your family needs?
- What kind of service do you want/need?
- What support do you want from services?

- From time to time you may experience crises. Are the challenges different during times of crisis? In what way?

- What really works/ would have helped at a time of crisis?

- Some of you may have experience of your family member being in hospital.

- Are there any particular difficulties that arise in this situation?
- Do you think that the nurses who cared for your family member in hospital had the skills that they needed to care for a patient with intellectual disability?
- What skills do nurses need to care for people with intellectual disability in hospital?

- Some families have been supported to care for their family member in their own home by nurses.

- If you have had this experience, were nurses helpful in this setting and if so what did they do that was helpful?
- was there anything else that would have helped? Who should have provided that support?

- What kind of life do you / your family member want?

- Is there anything that you think is important that we haven't covered this evening/morning/afternoon?
  Probes:

1. Can you elaborate on that?
2. Could you explain why that happened?
3. Tell me more about that.

Appendix 4: Service User Focus Group Topic Guide

Introduction to the research

What are the particular challenges/hard tasks that you experience in life? tasks/chores/jobs you need help with? Can you describe them?

Tell me about them/can you describe those challenges/ do you face challenges every day or just sometimes?

What types of supports would help you to meet those challenges/hard tasks?

Who supports you when you are ill or need help?
Who should provide the support that you need?

What experience have you had being in hospital?

Were there any bad or good experiences?
Do you think that the nurses who cared for you in hospital were good?
Was the nurse able to care for you and your disability?

Some people are cared for/looked after in their own home by nurses.
What kind of care do nurses do for people or you in your own home?

If so what did nurses do that was helpful?
Was there anything else that would have helped look after you at home?
If so, who should have provided that support?

Many people with ID are cared for in residential settings, whether community group homes or units.

Were the carers helpful in residential/community group homes or units, if so what did they do that was helpful?

Do you know if the carers were ID nurses, other nurses or social care professionals?

Was there any difference in the type care/support provided by different types of staff? Tell me about it.

Was there anything else that would have helped? If so, who should have provided that support?

If you had a wish what kind of life would you wish for

Is there anything that you think is important that we haven't covered in this discussion?

Probes:
Can you elaborate on that?
Could you explain why that happened?
Tell me more about that

Appendix 5: RNID Focus Group Topic Guide

Introduction

■ How do you see intellectual disability services changing in the future?

■ To what degree do you consider that RNIDs are prepared for providing a responsive service to people with intellectual disability within that changing context?

■ What mix of skills will you need for the service of the future?

■ What role would you see for nursing in the skill mix of the future?

■ How would the nursing role be expected to change?

  Probe: Identify the potential future role of the RNID in primary care and how it will interface /integrate with other roles within primary care.

■ Traditionally the RNID had a clear role in Education, Day Services, Respite and Residential Services. Current trends are to mainstream services. How would you like to see the RNID's role moving forward in line with these trends?

■ With new policies such as Moving on from Congregated Settings, Value for Money, New Directions the role of the RNID nurse is changing fast. In what key areas do you see the competencies of the RNID would be best placed? [Example — the elderly, forensics, complex intellectual disability]

Probes:
Can you elaborate on that?
Could you explain why that happened?

Appendix 6: Managers' Focus Group Topic Guide

■ How would you describe your service on a continuum from "care" to "support?

■ How do you see the service change in the future?

■ What mix of skills will you need for the service of the future?

■ What role would you see for nursing in the skill mix of the future?

■ How would the nursing role be expected to change? What is the potential future role of the RNID in your service?

■ How will the future role of the RNID interface with the roles of social care workers, care staff, other health care professionals, the multi-disciplinary team, and volunteers in supporting people with an intellectual disability?

■ What are the core and specialist/advanced clinical skills and competencies RNIDs require?

■ What is the gap between the current roles of nurses in intellectual disabilities and what will be required of them in the future?

Probes:
Can you elaborate on that?
Could you explain why that happened?

Appendix 7: Interface Staff Focus Group Topic Guide

Introduction

■ How do you see intellectual disability services changing in the future?

■ What mix of skills do you think will be needed for the service of the future?

■ What role would you see for nursing in the skill mix of the future?

■ How would the role of nursing be expected to change?
Probe: Identify the potential future role of the RNID in primary care and how it will interface /integrate with other roles within primary care.

■ Traditionally, intellectual disability nurses have had a clear role in Education, Day Services, Respite and Residential Services. Current trends are to mainstream services. How would you see RNIDs moving forward in line with these trends?

■ With new policies such as Moving on from Congregated Settings, Value for Money, New Directions the role of the intellectual disability nurse is changing fast. In what key areas do you see the competencies of the RNID would be best placed? [Example— the elderly, forensics, complex intellectual disability]

■ How do you see your role intersecting with that of the RNIDs in the future?

■ What is the gap between the current roles of RNIDs and what will be required of them in the future?

   Probes:
   Can you elaborate on that?
   Could you explain why that happened?

Appendix 8: Student RNID Focus Group Topic Guide

■ How do you see intellectual disability services changing in the future?

■ What mix of skills do you think you will you need for the service of the future?

■ What role would you see for nursing in the skill mix of the future?

■ How would the role of nursing be expected to change?
Probe: Identify the potential future role of the RNID in primary care and how it will interface /integrate with other roles within primary care.

■ Traditionally the RNID had a clear role in Education, Day Services, Respite and Residential Services. Current trends are to mainstream services. How would you like to see the RNID's role moving forward in line with these trends?

■ With new policies such as Moving on from Congregated Settings, Value for Money, New Directions the role of the intellectual disability nurse is changing fast. In what key areas do you see the competencies of the RNID would be best placed? [Example— the elderly, forensics, complex intellectual disability]

■ What is the gap between the current roles of RNIDs and what will be required of them in the future?

Probes:
Can you elaborate on that?
Could you explain why that happened?

Appendix 9: Educators' Focus Group Topic Guide

Objective: To gather additional information on future and changing roles, training needs, opportunities for greater collaboration with social care staff and multidisciplinary team members and support for person-centred and community based care.

- How do you see intellectual disability services changing in the future?
- What mix of skills do you think will be needed for the service of the future?
- What role would you see for nursing in the skill mix of the future? How would the role of nursing be expected to change?

   Probe: Identify the potential future role of the RNID in primary care and how it will interface /integrate with other roles within primary care.

- Traditionally the RNID had a clear role in Education, Day Services, Respite and Residential Services. Current trends are to mainstream services. How would you like to see the RNID's role moving forward in line with these trends?

- With new policies such as Moving on from Congregated Settings, Value for Money, New Directions the role of the intellectual disability nurse is changing fast. In what key areas do you see the competencies of the RNID would be best placed? [Example— the elderly, forensics, complex intellectual disability].

- What is the gap between the current roles of RNIDs and what will be required of them in the future?

Probes:
Can you elaborate on that?
Could you explain why that happened?

Appendix 10: Key Informant Interview Invitation and Interview Guide

Background

The landscape for service provision to people with an intellectual disability in Ireland is changing. Renewed movement into community settings, changing demographics and culture, provision for newly emerging health care needs among people with intellectual disability as well as the advent of personalised supports and funding mechanisms mean that the role of the Registered Nurse in Intellectual Disability (RNID) will develop and change over the next decade.

These changes represent both opportunities and challenges for RNIDs and the HSE have commissioned Trinity College Dublin to work with them on a national project to shape the future role of the RNID in Ireland. There are several strands of data collection for this project: surveys, focus groups, interviews and invitations to make written submissions to the team. A project steering group has been convened by the HSE to oversee the project on an ongoing basis.

We would like to hear about your assessment of the key opportunities and challenges facing the RNID, your suggestions on the development of future roles for the RNID as well as changes in the preparation and deployment of RNIDs that should be considered. We would also like to hear about the important RNID contributions to the lives of people with an intellectual disability that should be preserved.

Because of your connection to disability services, you have been identified as someone with a unique perspective who may have important ideas on this issue. So we are asking you to contribute your views by answering the questions listed below.

Key Questions

1. a) What do you think has been the role of RNIDs in supporting people with intellectual disability and what should be their role in the future?

   b) Are there challenges to the role of the nurse in supporting people with intellectual disability?

2. a) In your experience, what are the biggest challenges/concerns for service users accessing healthcare services?
   b) What are the biggest challenges/concerns for families accessing healthcare services on behalf of people with intellectual disability?
   c) What are the biggest challenges/concerns for provider staff accessing healthcare services on behalf of people with intellectual disability?

3. What additional educational preparation do RNIDs require or would benefit from to better care for and support people with intellectual disability?

4. a) What are the areas where effective leadership and staff competence are critical in disability services?
   b) Who should provide such leadership?
   c) How can such effective leadership and staff competence be developed and supported in intellectual disability nursing?

5. Are there areas where a higher level of clinical practice is required to meet service user need? e.g. Clinical Nurse Specialists/Advanced Nurse Practitioners? Please elaborate.

6. With regard to the future role of the RNID and the judicial system/forensic services, what kind of undergraduate theory content and practice experience would you suggest that might best help an RNID to gain the knowledge and skills to support a person with an Intellectual Disability in their dealings with the judicial system?

7. Are there any other matters that you consider to be important in examining and planning for the future role of nurses in the care and support of people intellectual disability?

Appendix 11: Invitation to make a Submission

Shaping the future of Intellectual Disability Nursing in Ireland

INVITATION TO PARTICIPATE IN THE CONSULTATION

Background
The landscape of service provision to people with an intellectual disability in Ireland is changing. Renewed movement into community settings, changing demographics and culture, provision for newly emerging health care needs among people with intellectual disability as well as the advent of personalised supports and funding mechanisms mean that the role of the Registered Intellectual Disability Nurse will develop and change over the next decade.

These changes represent both opportunities and challenges for Registered Intellectual Disability Nurses and the HSE have commissioned Trinity College Dublin to work with them on a national project to shape the future role of the Registered Nurse Intellectual Disability (RNID) in Ireland. There are several strands of data collection for this project: surveys, focus groups, interviews and invitations to make written submissions to the team. A project steering group has been convened by the HSE to oversee the project on an ongoing basis.

We would like to hear about your assessment of the key opportunities and challenges facing the Registered Intellectual Disability Nurse (RNID), your suggestions on the development of future roles for the RNID as well as changes in the preparation and deployment of RNIDs that should be considered. We would also like to hear about the important RNID contributions to the lives of people with an intellectual disability that should be preserved.

Because of your connection to disability services, you have been identified as someone with a unique perspective that may have important ideas on this issue. So we are asking you to contribute your views by answering the questions listed below.

This is a broad consultation but if there are particular questions that are most pertinent to your experience please focus on these. Please note that the overall word limit is 1000 words and that submissions must be submitted electronically by email to deathm@tcd.ie by September 18th 2014.

Key Questions
1. a)   In your experience, what are the things that matter for service users accessing healthcare services?
   b)   What are the things that matter for families accessing healthcare services?

2. We would like you to tell us how you envisage the role of the RNID, ten years from now in 2024 and how it will differ from the current role. Please address this under the following questions:

   a)   In general, how would you describe the future intellectual disability service model and the role played by RNIDs within the service?
   b)   How can the role be developed to improve the range and quality of services to Service Users and families in :

1. Primary care
2. Secondary ID services – Adult & Child including Early Development
3. Tertiary ID services
   c)   How can these roles be reflected in the new healthcare structures?
   d)   What type and range of services would be missing to Service Users, their families and healthcare services if RNIDs were not available?
   e)   What are the values and principles that should underpin Intellectual Disability Nursing needed for the service of the future?
   f)   What skills and competencies will ID Nurses require to improve service delivery and outcomes in the future for:
      1)   Service Users
      2)   Families & Carers
      3)   Primary care services
      4)   Other Nurses who are not ID trained
   g)   What changes are required in the Undergraduate Programme to support the development of such roles?

3. a)   What are the issues that RNIDs need to consider in order to support healthy living outcomes for people with an intellectual disability?
   b)   How should they be prepared to do this?

4. What is required to increase the use by RNIDs of evidence-based approaches in practice and service delivery?

5. a)   What are the areas where effective leadership is critical in disability services?
   b)   How can effective leadership be developed and supported in intellectual disability nursing?

6.   Are there areas where a higher level of clinical practice is required to meet service user need? e.g. Clinical Nurse Specialists/Advanced Nurse Practitioners? If yes, please elaborate.

Appendix 12: Written Submissions Received

Brothers of Charity Cork

Dublin City University

ID Nursing Forum, Dublin Mid-Leinster

Practice Development Team, Donegal Intellectual Disability Service

Nursing and Midwifery Planning and Development Units: HSE - Dublin North, Dublin Mid-Leinster, West/MidWest, North West, South and Midlands

Irish Nurses and Midwives Organisation

Next Steps, National Federation of Voluntary Bodies

Nursing and Midwifery Board of Ireland

Office of the Nursing and Midwifery Services Director

St Mary's Drumcar, St John of Gods Community Services

Services Industrial Professional Trade Union (SIPTU)

SONAS

Waterford Institute of Technology, Intellectual Disability Programme

Professor Owen Barr	Head of School of Nursing, University of Ulster
Ms Margaret Conway	Nurse Practice Development Co-ordinator, St Otteran's Hospital, Waterford.
Mr Jim Fleming	Assistant National Director of Human Resources, Health Service Executive.
Professor Bob Gates	Professor of Learning Disabilities at the University of West London.
M Brennan and S Griffin	Enable Ireland Early Intervention Services.
Mr Liam Hamill	Psychiatric Nurses Association
Sr Marian Harte	Director of Client Services/ Director of Nursing, Daughter of Charity Services
Dr Verena Keane	Consultant Psychiatrist.
Ms Catriona Larkin	Services Manager, Daughters of Charity Service
Ms Breda Leitrim	
Ms Mary O'Connor	Team Leader, Brother of Charity Services, Roscommon.
Mr Donie O' Shea	National Disability Authority
Ms Josephine Ryan	Clinical Placement Co-ordinator, BSc Intellectual Disability Programme, Nurse Practice Development Unit, St Otteran's Hospital, Waterford
Ms Sonia Shortt	Human Resources, HSE

Appendix 13: Guiding Principles for Quality and Safety

APPENDIX 13: GUIDING PRINCIPLES FOR QUALITY AND SAFETY

To assist health service/social care providers, a suite of ten principles for quality and safety, in the Irish health context, have been developed with a title and descriptor.

Each decision (at every level) can be tested against the quality and safety principles. A descriptor for each principle is set out below.

Table 1: Quality and Safety Guiding Principles Descriptor

Principle	Descriptor
Service user first	Based on a partnership of care between service users/families, carers and healthcare providers in achieving safe, easily accessible, timely and high quality service across the continuum of care.
Safety	Identification and control of risks to achieve effective, efficient and positive outcomes for service users and staff.
Personal responsibility	Where individuals as members of healthcare/social care teams, service users and members of the population take personal responsibility for their own and others health needs. Where each employee has a current job-description setting out the purpose, responsibilities, accountabilities and standards required in their role.
Defined authority	The scope given to staff at each level of the organisation to carry out their responsibilities. The individual's authority to act, the resources available and the boundaries of the role are confirmed by their direct line manager.
Clear accountability	A system whereby individuals, functions or committees agree accountability to a single individual. Where each person can give an account of their practice and can justify their actions or inactions.
Leadership	Motivating people towards a common goal and driving sustainable change to ensure safe high quality delivery of clinical and social care.
Multi-disciplinary working	Work processes that respect and support the unique contribution of each individual member of a team in the provision of clinical and social care. Multi-disciplinary working focuses on the interdependence between individuals and groups in delivering services. This requires proactive collaboration between all members.
Supporting performance	Managing performance in a supportive way, in a continuous process, taking account of professionalism and autonomy in the organisation setting. Supporting a director/manager in managing the service and employees thereby contributing to the capability and the capacity of the individual and organisation. Measurement of the service user experience being central in performance measurement (as set out in the National Charter, 2010).
Open culture	A culture of trust, openness, respect and caring where achievements are recognised. Open discussion of adverse events are embedded in everyday practice and communicated openly to service users and/or their family. Staff willingly report adverse events and errors, so there can be a focus on learning, research and improvement, and appropriate action taken where there have been failings in the delivery of care.
Continuous quality improvement	A learning environment and system that seeks to improve the provision of services with an emphasis on maintaining quality in the future, not just controlling processes. Once specific expectations and the means to measure them have been established, implementation aims at preventing future failures and involves the setting of goals, education, and the measurement of results so that the improvement is ongoing.

(Health Services Executive 2016)