

Registered Nurse Intellectual Disability R.N.I.D.

The Specialist in Intellectual Disability

How the R.N.I.D. can optimise the lives and health
of individuals with Intellectual Disabilities.

Full utilisation of the role of the R.N.I.D., across all four stages of life, will ensure the full potential of the individual is realised while enjoying the fullest integration with their family and community.



Irish Nurses and Midwives Organisation
Working Together

R.N.I.D. SECTION
(Registered Nurse in Intellectual Disability)

INTELLECTUAL DISABILITY NURSING - LEVEL 8 HONOURS DEGREE - A SUMMARY

The philosophy of care of a person with an intellectual disability contains a number of implicit principles, which embrace the concept that all persons with all levels of ability have the same rights and, in so far as possible, the same responsibilities as other members of society.

They have a right and a need to live within the community like other people and they have a right to receive those services necessary to meet their specialised and changing needs. They should receive, if and when necessary, professional assistance and services which will allow recognition, development and expression of the individuality of each person.

The R.N.I.D. who works with persons with an intellectual disability has a diversity of roles, from intensive physical nursing of 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.

The care of persons with an intellectual disability forms part of the nursing profession as a whole, yet it is specialised and very different from other disciplines of nursing.

The syllabus for the education of an R.N.I.D. is indicative. It allows scope for the continuing development of subject matter and for the extension of new knowledge to accommodate emerging trends. Curriculum planners will be expected to demonstrate that the programme is relevant and responsive with the most recent policy and legislative change.

Clinical Placements

- Education and Development of the Child
- Education and Development of the Adult
- Disorders of human behaviour
- Acute nursing
- Specialist areas
- Regulated placements
- Discretionary

This 4 year honours degree programme is unique and is the only degree specifically designed to equip the graduate to optimise the lives of persons with an intellectual disability. The graduate has the skills, knowledge and competence to support the whole person through the provision of physical/home care, education, and psychological care as appropriate.

The R.N.I.D. honours degree programme holds international recognition and is acknowledged as providing a graduate registered professional specialising in intellectual disability.

WHAT THE R.N.I.D. CAN DO NOW TO OPTIMISE THE LIVES AND HEALTH OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES

In Ireland we have a strong tradition of excellent service provision in the field of Intellectual Disability (I.D.) A significant reason for this is the central role played, for the past 55 years, by the R.N.I.D. in the provision of care, education, supports and mentorship. However, in recent years service provision has become fractured, lacks equity and is dependent on individual service providers and local policies, rather than a co-ordinated approach that could utilise an already present highly skilled specialist workforce - the R.N.I.D.

The full utilisation of the role of the R.N.I.D., in the four stages of life, will continue to ensure the full potential of the individual is realised while s/he enjoys the fullest integration into their family and community. The R.N.I.D. is a registered professional competent, and equipped, to act as lead professional, educator, advocate, mentor and friend to the individual with I.D. providing the appropriate mix of professional care, education, guidance and support.

The role of the R.N.I.D. in all stages of the life and development of a person with an Intellectual Disability

The R.N.I.D. is a graduate of a four year honours degree programme which has a unique and special focus on Intellectual Disability.

Therefore, the R.N.I.D. is the only dedicated specialist in the intellectual disability sector. The R.N.I.D. is in the ideal position to support people with ID as they possess the requisite skills to fulfil this pivotal role. This key role begins upon diagnosis, whether this be earlier or later in a person's life, and links the key transition periods to each stage of life progressing into the twilight years. The R.N.I.D. is a support for clients and families to develop their own solutions, over time, that build on the strengths and capabilities of intellectually disabled people.

Through all stages of life the R.N.I.D. can liaise with other professions in the health service, for example maternity and paediatric hospitals, primary care and palliative care services, as well as with other agencies i.e. the Jack and Jill Foundation and Laura Lynn, in order to prioritise the needs of their clients. The R.N.I.D. is in an ideal position to lead out on the provision of community based services ensuring families are involved in their service delivery thus ensuring family centred practice.

The R.N.I.D. is equipped to provide support across all environments – within home settings (within the family home, residential settings and respite), educational (mainstream schools, special schools and specialist educational models), and community settings (including after school clubs, social settings, accessing mainstream healthcare etc.). The R.N.I.D. can assess, plan, implement, and evaluate care for a caseload of patients within the community to both deliver and monitor all appropriate services are provided. The R.N.I.D. can ensure all supports are person centred involving care planning, accessing services and health promotion.

Here are examples of how the fully realised potential of the R.N.I.D. can proactively optimise the potential and quality of life of the person with an I.D., despite their challenges, across the stages of life and personal development.

The R.N.I.D. - Supporting - Optimising - Realising the Individuals Full Potential

0-5 years

The R.N.I.D. is equipped to work with diverse groups of infants and children including but not limited to:

1. Specific syndromes e.g Down Syndrome
2. Children with Global Developmental Delay
3. Children with complex medical needs
4. Children with a diagnosis of Autism and learning disability

The R.N.I.D. can:

Observe the infant and young child within a family context in the home (natural environment) and draw up development plans.

Support infants and young children, who are medically fragile, in hospital thus assisting discharge to the home / community.

Provide frontline support and care for the child, from moderate to severe intellectual disability, and with multi-complex needs.

Leads out on parent/sibling education programs and information sharing sessions such as:

- Parents plus
- Lamh training
- Early Bird Program for children with Autism that have been newly diagnosed
- Moving into preschool education and onto mainstream school
- Toilet training
- Playing with your child
- School readiness skills

Works with other agencies including:

- Crèche staff
- Preschool assistants
- School staff
- Family support worker

REQUIRED ACTION:

It is imperative the R.N.I.D. be linked to maternity hospitals. This will ensure all babies born with an intellectual disability are immediately partnered, with the R.N.I.D. (key member of the Primary Care Team), in order to help families to understand the situation and plan for the future.

5-18 years

The R.N.I.D. is competent to provide ongoing care and support for the young person with ID and their families, as they grow from child to young adult.

This support and care should be provided through a flexible approach e.g. 7/7 with evening and early morning home visits to maintain home routine and ensure appropriate support.

The R.N.I.D. can:

Provide regular support, guidance and where needed education across all natural family routines i.e. from the child getting up in the morning to going to bed at night.

Undertake specific assessments pertaining to areas of speciality e.g. functional behaviour assessment.

Continue the provision of training to families in defined core areas including Early Bird Plus (Autism training), Parents Plus, Lamh, Toilet Training, Challenging Behaviour, Feeding Difficulties etc.

Act as an advocate for the child and their families within the health care team.

Provide specific training to other staff and clinicians in identified core areas.

Promote health promotion within the family unit and also during early school days particularly in such areas as diet/exercise.

Participate in wider community work in identified areas of need e.g. development of summer projects for children and their family.

Give ongoing support and training to parents and siblings as needs arise.

Assist the child and family as they move through primary school, on to secondary school and then to adult day services, ensuring that this process is planned well in advance.

REQUIRED ACTION:

It is crucial that the R.N.I.D., and the role they must play, is central to all service development particularly in Primary and Community services. Currently, there is no provision for the R.N.I.D. which greatly weakens service quality and ignores the needs of these citizens.

18-40 years old

The R.N.I.D. provides care, practical support and education for families and clients in the transition from adolescence to adulthood.

The R.N.I.D. can:

Act as advocate to ensure proper planning to meet areas of need.

Continue to teach key life skills, including literacy, in preparation for independent or semi-independent living.

Complete assessments for correct placement suitability - further education, day care and organised work placement.

Teach practical life skills e.g. using buses safely, money management skills, equal rights.

Provides health promotion/screening programmes including disease screening (such as cervical and breast cancer) and mental health screening.

Ensures clients receive full access to appropriate health care services.

Ensures medication management, compliance and reconciliation in conjunction as required with the clients GP/consultant.

Promote "safe risk" for client and family based on exposure, education and coaching to ensure full inclusion.

Continue to support and assist persons with challenging behaviours by developing programmes.

Continue to assess and provide practical support to meet the needs for home care support e.g. enteral feeding care/catheter care/cerebral palsy - to maintain social integration.

Plan respite care and share a break schemes.

Support families to avert crisis when care is overwhelming e.g. for elderly parents or behaviours of concern.

Provide cognitive global functional assessments.

REQUIRED ACTION:

The R.N.I.D. can lead out in such areas as

- Ensuring equal citizenship through advocacy
- Service planning to include consistent support across the country
- Specialist ANP posts to improve quality of life and societal integration.
- Immediate post on primary care teams
- Early Intervention Teams
- Health promotion in a targeted way
- Development of database to capture true picture of all services including those outside the HSE

40 years to old age

This is the stage of life in which growing numbers of persons, with I.D. will be found.

The R.N.I.D. is key to the provision of all supports recognising the challenges ageing will bring.

Age related disorders/diseases come to the fore at this stage of the life cycle (may occur much earlier than in the general population) in particular dementia and Alzheimer's Disease. This requires specialised supports and intervention within the competence of the R.N.I.D.

The R.N.I.D. can:

Provide ageing specific supports for the person with ID for example:

- Determining need for specialised care living.
- Ensuring close living as appropriate with peers / families.
- Provide assessment and screening for diseases/ disorders e.g. dementia.
- Manage and control the symptoms appearing with these diseases.
- Ensure availability and access to appropriate respite care services.
- Develop and provide appropriate home care packages.
- Provide care, support and education in the process of ageing.
- Palliative care provisions.

REQUIRED ACTION:

Specialist roles in palliative and dementia care.

Develop and deliver home support services to maintain community living.

Development of C.N.S. liaison to support care when in acute health care settings.

This is an area as with the changing demographic across the whole of society, where expert services will be required in the years ahead.

0-5 years

R.N.I.D. can:

Act as advocate for the family dealing with these challenges.

Teach proactive skills necessary to prevent behaviours of distress.

Develop behavioural support plans in the family home, school and community settings.

Empower families by engaging them in skills teaching, training and education formally and informally.

Develop specific respite supports if necessary.

Assess and access local community supports.

Provide training to e.g. local crèches, play groups, toddler groups to ensure early inclusion and equality to services.

Accept referrals from G.P. services regarding early signs of behavioural distress.

Act as a co-ordinator organising contact with other services if, and when, necessary.

5-18 years

R.N.I.D. can:

Commence/continue skills teaching in essential areas, e.g. communication, sexuality, civil rights, advocacy, etc.

Develop behavioural support plans in the family home, school and community settings.

Give ongoing support and training to parents and siblings as needs change.

Accept referrals from G.P. services regarding early signs of behavioural distress.

Continue to support ongoing skills teaching dependant on needs of child.

Clear role for the CNS/ANP to co-ordinate behavioural support plans across settings.

Support siblings and wider family.



18-40 years old

R.N.I.D. can:

Continue to support ongoing skills teaching and behavioural supports, which are rights based, and dependant on the needs of the young adult.

Conduct in-depth behavioural analysis, e.g. functional analysis, hypothesis testing, evidence based practice, etc.

Support the family via education training and practical support within the home including accessing respite if, and when, necessary.

Accept referrals from G.P. services regarding early signs of behavioural distress.

Provide specialist on-going training of other family members, friends and other staff.

Establish a clear business case for the on-going need of the CNS/ANP in behaviours of distress.

Develop behavioural support plans in the family home, school and community settings.



40 years to old age

R.N.I.D. can:

Deliver a holistic service to the person by assessing their complex needs and providing them with appropriate (physical, educational and psychological) care.

Care for the whole person identifying and meeting the needs of the individual.

Develop behavioural support plans in the family home and community settings.

Ensure life's journey is travelled with dignity and enjoyment.



THE
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From Birth to End of Life



Irish Nurses and Midwives Organisation
Working Together

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