

Shaping the future of Intellectual Disability Nursing in Ireland

Introduction

The National Disability Authority is the independent state body providing expert advice on disability policy and practice to the government and the public service.

The National Disability Authority welcomes the opportunity to contribute to Shaping the future of intellectual disability nursing in Ireland project. The National Disability Authority is represented on the national project group for Shaping the Future of Intellectual Disability Nursing in Ireland but is making its response in the context of its own expertise in area of policy and research.

Summary

The National Disability Authority emphasises the following points in particular:

- A very significant programme of change is currently taking place within disability services. This is likely to require a different skill mix to that currently deployed within these services. It will be very important that the core competencies of those working with people with disabilities, including the competencies of intellectual disability nurses, are geared to the new policy context
- Given the health inequalities experienced by people with intellectual disabilities a key consideration for the profession should be how people with intellectual disabilities get access to appropriate mainstream health services. 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
- The nature of initial and ongoing professional training of intellectual disability nurses should be considered in the context of operationalising these changes in service delivery, both for disability services and for inclusive, ID-competent mainstream health services
- The number of intellectual disability nurses to be required in disability services will be related to the new model, and to demographic change

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- The new model of disability services will have implications for numbers of nurses, and of ID nurses, employed within these services. Delivering an ID-confident and competent health service may require additional nurses with specific ID training and experience deployed to these settings.
- In the event that the number of nurses required in the future model of specialist disability services and the number of ID-trained nurses required in mainstream services to support inclusive general health services would total less than the total number of nurses currently deployed in ID services, there would be scope to redeploy nurses who have other qualifications (general nursing, psychiatric nursing or dual qualifications) who would be surplus to requirements in ID services to alternative roles in the mainstream health services or in the mental health service, where there are acknowledged shortages of nursing personnel
- Given the lack of clarity that has existed around the role of intellectual disability nursing, a central consideration of **Shaping the Future of Intellectual Disability Nursing in Ireland** should be s to clearly articulate what the unique added value that intellectual nursing can bring to the lives of people with intellectual disabilities and how that is different to what other professions or staff roles can offer

Context

A review of intellectual disability nursing is welcome but needs to be set within the wider policy context and significant change happening within disability services and, in particular, the **Value for Money and Policy Review of Disability Services**.

The vision for the Disability Services Programme set out in the **Value for Money and Policy Review of Disability Services** is:

To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life and have access to a range of quality personal social supports and services to enhance their quality of life and well-being

The implementation of that vision will have significant implications for the over 4,000 nurses who work in disability services, primarily in intellectual disability services.

Three recommendations in particular will impact on the future role of nurses working in intellectual disability services:

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- The HSE should begin the process of **substituting non-professionally qualified care staff for professionally qualified care staff** to achieve pay savings in the statutory and voluntary sectors. This will be consistent with the new person-centred model envisaged as the future direction of disability policy [Recommendation 4.8, emphasis added]
- Responsibility for the care, safety and general well-being of people who lack full mental capacity should be considered in the context of the increasing move from congregated residential settings to State-supported independent living arrangements. **The State's responsibility in respect of the health needs of people with disabilities, and in particular those with intellectual disabilities, should be examined and clearly articulated** [Recommendation 6.9, emphasis added]
- Where appropriate, **clinical and therapy supports should be provided in a mainstream setting**, i.e. provided by non-disability-specific providers. The precursor to this should be the establishment of the primary care network [Recommendation 7.12, emphasis added]

The reconfiguration of disability services envisaged by the **Value for Money and Policy Review of Disability Services** will have implications for the type and quality of services that it will be delivered to people with intellectual disabilities.

The future orientation of intellectual disability services will involve people with intellectual disabilities being supported to access activities in the community of their choosing. Social care assistant type roles and community connector type roles rather than nursing personnel will be required to support this service model.

People with intellectual disabilities have more health issues than the rest of the population and have significant difficulties in access appropriate health care. There is a need for the health service to improve how it meets the health needs of people with intellectual disabilities. To achieve this improvement mainstream health services will need to play a much greater role in meeting the health needs of people with intellectual disabilities. Intellectual disability nurses, by collaborating and supporting other health professionals, can play a very important role in addressing these health needs.

However, to meet this challenge it is crucial that the intellectual disability nurse profession acknowledge that it is not appropriate for highly qualified and skilled staff to be providing basic personal care. At present the profession has been

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defined by the tasks associated with certain historical or present models of intellectual disability service provision, for example those with their origins in a 'hospital' model of service. Therefore, it is important to clarify the role of the intellectual disability nurse by naming the unique skills and competencies of the profession. Central to defining the unique competencies of the professional should be a consideration of how the profession can contribute to reducing the health inequalities experienced by people with intellectual disabilities in the coming years.

Refocusing the role of intellectual disability nurses towards collaborating and supporting other mainstream health professionals to improve the health outcomes of people with intellectual disabilities will have implications for the number of intellectual disability nurses required in Ireland.

It is within this context that the future role of intellectual disability nursing is best considered, and that the answers below must be viewed

I. Answers to specific consultation questions Accessing healthcare services

In your experience, what are the things that matter for service users accessing healthcare services? What are the things that matter for families accessing healthcare services?

Improved health outcomes

The fundamental healthcare issue for people with intellectual disabilities and their families is improved health outcomes. International research shows that people with intellectual disabilities die younger, have more health issues than the rest of the population but have greater difficulty accessing health care. People with an intellectual disability have a greater variety of healthcare needs than the rest of the population, and are by some estimates two and a half times more likely to have a physical or psychiatric condition than the rest of the population¹.

The Special Interest Research Group on Health of the International Association for the Scientific Study of Intellectual and Developmental Disabilities identified 15 health areas which are highly prevalent in people with intellectual disability and

¹ Lantman-de Valk, H., 2000, Health Problems for People with an Intellectual Disability in General Practice: a comparative study; **Family Practice** 17 (5)

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recommendations (primarily preventative measures, regular screening, appropriate referral) for addressing these issues². The 15 areas are:

- Dental health
- Sensory impairment
- Nutrition
- Prevent and treat chronic constipation
- Epilepsy
- Thyroid disease
- Mental health
- Gastro-esophageal reflux disease (GERD) and *Helicobacter pylori*
- Osteoporosis
- Medication review
- Immunisation status
- Physical activity and exercise
- Comprehensive health assessments
- Genetics
- Women's Health

People with intellectual disabilities in Ireland, as in other developed countries, are living longer than previously. However, we know from studies in jurisdictions that the numbers of people with intellectual disabilities with complex needs (co-morbid health problems and / or challenging behaviours) has increased in recent years. Therefore, the priority in the coming years should be on identifying and implementing strategies which produce better health outcomes for this group. IDS-TILDA data will play a very significant role in improving knowledge of factors which contribute to subsequent health outcomes. A range of actors, including intellectual disability nurses, will have a role to play in implementing these strategies. However, as will be discussed below, there is little evidence of what

² Special interest Research Group on Health, International Association for the Scientific Study of Intellectual and Developmental Disabilities, 1999, **Health Guidelines for an Adult with an Intellectual Disability**

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system or organisation of health supports produce the best outcomes for people with intellectual disabilities.

Accessing health care

The National Disability Authority's 2011 report, **A National Survey of Public Attitudes to Disability in Ireland**³, highlighted the restrictions in accessing a range of health services is a challenge for people with disabilities. The Health Service Executive and the National Disability Authority will shortly publish the **National Guidelines on Accessible Health and Social Care Services**⁴.

These guidelines recognise that all staff in the services contracted or delivered by the Health Service Executive have a role to play in ensuring that health and social services are accessible to people with disabilities. The guidelines don't assign any specific roles to intellectual disability nurses but intellectual disability nurses would clearly be well placed to support other staff or directly support people with intellectual disabilities in relation to, such things as:

- Communications
- Accessible information
- Consent
- Dealing with carers and family members in health contexts

IDS-TILDA highlights the role in particular that communications difficulties play in people with intellectual disabilities accessing health services. This is likely to remain an area where considerable support for people with intellectual disabilities and for health professionals is required.

Early identification and treatment

Failure to recognise or delay in recognising health problems in people with intellectual disabilities by health practitioners has been noted in several studies.

³National Disability Authority, 2011, **A National Survey of Public Attitudes to Disability in Ireland**
[http://www.nda.ie/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/90F8D23334D786A880257987004FCF51/\\$File/Public_Attitudes_to_Disability_in_Irelandfinal.pdf](http://www.nda.ie/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/90F8D23334D786A880257987004FCF51/$File/Public_Attitudes_to_Disability_in_Irelandfinal.pdf)

⁴ Health Service Executive and National Disability Authority, 2016 (forthcoming), **National Guidelines on Accessible Health and Social Care Services**

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One study of people with intellectual disabilities living in the community found that of a sample 181 people, 51% had a previously unrecognised health issue⁵.

Training of other primary care professionals

A number of studies have looked at the competency of primary care professionals and general practitioners to meet the health needs of people with intellectual disabilities living in the community. A study in Victoria, Australia of general practitioners of the standard of care provided by GPs to people with intellectual disabilities and their training needs to provide such care found that the areas in which many general practitioners themselves reported to be inadequately trained were the same as those areas that were perceived as being of a poor standard. These areas were behavioural or psychiatric conditions, human relations and sexuality issues, complex medical problems, and preventative and primary health care⁶.

Quality of care and appropriate referral

In both the US and the UK the failure of doctors to adequately investigate and review the health issues of people with intellectual disabilities and make appropriate referrals has been acknowledged⁷. An Australian study on the quality of health care provided to people with intellectual disabilities found that 81% of general practitioners found it harder to provide people with intellectual disabilities with good quality health care than people without intellectual disabilities⁸. Reasons for this difference in the quality of care provided were:

- General communication difficulties
- Poor communication between health professionals
- Difficulties in obtaining a history
- Consultation time restrictions⁹

⁵ Baxter, H., et al, 2006, Previously unidentified morbidity in patients with intellectual disability, **British Journal of General Practice**, vol. 56

⁶ Phillips AI, et al, 2004, General practitioners' educational needs in intellectual disability health. **Journal of Intellect Disability Research**; 48(Pt 2):142-9.

⁷ US Department of Health and Social Service, 2002, **Report of the Surgeon General's Conference on Health Disparities and Mental Retardation**

⁸ Lennox, N.G., et al, 1997, The General Practice Care of People With Intellectual Disability: Barriers and Solutions. **Journal of Intellectual Disability Research** 41 (5)

⁹ Lennox, N.G., et al, 1997, op cit

Other studies have shown that adults with intellectual disabilities are much less likely (less than half as likely) to be referred for hip and knee replacements as other adults (comparable age-adjusted adult group)¹⁰.

Appropriate access to specialist care

Ensuring access to appropriate specialist care has been an issue for people with intellectual disabilities. For example, those with intellectual disability and dementia have encountered difficulties in accessing appropriate specialist care¹¹. Specialists in some fields, Gerontology and Psychiatry of Old Age in this example, can feel that they don't have the appropriate skills and knowledge to assess and treat people with intellectual disabilities.

Health and Wellbeing

A number of factors highlighted in the literature which contribute poor health outcomes are:

- Poor health literacy¹²
- Poor uptake of health promotion, disease prevention, immunisation and screening programmes¹³
- Diet, inactivity and obesity¹⁴

The work underway to implement **Healthy Ireland** could have a significant impact on the health outcomes for people with intellectual disabilities.

¹⁰ Balogh, R, 2003, Hospital utilisation among persons with a developmental disability, Ontario 1995-2001. MsC Thesis, Department of Community Health & Epidemiology, Queen's University, Canada cited in Ouellette-Kuntz, H., 2005, Understanding Health Disparities and Inequalities Faced by Individuals with Intellectual Disabilities. **Journal of Applied Research in Intellectual Disabilities** 18 (2)

¹¹ Cahill, S. et al, 2012, **Future of Dementia Care in Ireland: Sharing the Evidence to Mobilise Action**

¹² O'Leary, L., Taggart, L. and Cousins, W., (2014) Adapted 'healthmatters program': promoting healthy lifestyles in individuals with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27 (4)

¹³ Lennox, N.I., 2011, Effects of health screening for adults with intellectual disability: a pooled analysis **British Journal of General Practice**. Vol 61 (584)

¹⁴ Rubin, S., et al, 1998, Overweight prevalence in persons with Down syndrome. **Mental Retardation**, 36 (3)

Knowledge, research and evidence base

People with intellectual disability have tended to be paid inadequate attention in major health surveillance programmes and health has traditionally been a low priority in intellectual disability research¹⁵. Therefore, the evidence base around the impact of life-styles and environmental factors and various interventions on health outcomes still has very significant research gaps. Future **IDS-TILDA** data should be invaluable in this regard.

Some of the issues highlighted in **IDS-TILDA** data to date, such as, the high levels of medication among participants (and those taking multiple medications in particular without review and without clear evidence of efficacy and impact of side-effects), highlight a significant gap in the evidence base around the treatment of health issues for people with intellectual disabilities.

Mental Health

Almost a quarter of a community sample of over 42,000 Australian adults with an intellectual disability were found to have a significant (“disabling”) mental health condition which had lasted for more than 6 months and which was of a severity to be disabling¹⁶. Other studies have shown that over 40% of adults with intellectual disability experience mental ill-health of some kind¹⁷. This literature shows that mental health professionals find it difficult to detect and assess people with intellectual disabilities.

Autism

Studies from the UK show that one third of people with severe and profound intellectual disabilities, also have an associated autism spectrum disorder. This raises questions about how well equipped intellectual disability nurses and other professionals, working with people with intellectual disabilities, are in dealing with

¹⁵ US Department of Health and Social Service, 2002, op cit

¹⁶ White, P., et al , 2005, Prevalence of intellectual disability and co-morbid mental illness in an Australian community sample, **Australian and New Zealand Journal of Psychiatry** Volume 39 (5)

¹⁷ Cooper, S., 2007, Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. **British Journal of Psychiatry** vol. 190

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the social, behavioural and health needs of people with intellectual disabilities, who also have an associated autism spectrum disorder¹⁸.

Ageing and dementia

The literature shows that people with intellectual disabilities can have health problems associated with ageing earlier than the general population and that there is a higher than average incidence of dementia within some groups¹⁹.

Consent

The Health Service Executive currently has a **National Consent Policy** and this policy is reflected throughout the **National Guidelines on Accessible Health and Social Care Services**. The law around consent will change once the legal capacity legislation is enacted.

Research from the UK shows that despite the passing of the **Mental Capacity Act 2005**, publication of guidance and provision of training that psychiatrists²⁰, doctors and nurses in mainstream health settings²¹ and teams providing health and social care to adults with intellectual disabilities, still have significant knowledge / training gaps around capacity issues (around assessing capacity and best interests in relation to health care) for people with intellectual disabilities²².

This would suggest that after the passing of the legislation in Ireland there will continue to be a need for support for people with intellectual disability around health care decisions and ongoing training and support for a range of health professionals around assessing the capacity of people with intellectual disabilities.

¹⁸ 5. Emerson E, Baines S (2010) The Estimated Prevalence of Autism among Adults with Learning Disabilities in England (for the Department of Health, London)

¹⁹ 6 Torr J, Davis R (2007) Ageing and mental health problems in people with intellectual disability. **Current Opinion in Psychiatry**. 29(5)

²⁰ Sawhney, I., et al, 2009, Mental Capacity Act 2005: views and experience of learning disability psychiatrists. **Psychiatrists Bulletin** 33

²¹ Evans, A., et al How much do emergency healthcare workers know about capacity and consent? **Emergency Medicine Journal** 24 (6)

²² Willner, P et al, 2011, Knowledge of Mental Capacity Issues in Community Teams for Adults with Learning Disabilities. **Journal of Applied Research in Intellectual Disabilities**: 24 (2)

2. Future role of the RNID

In general, how would you describe the future intellectual disability service model and the role played by RNIDs within the service?

The vision of future disability policy is set out in the **Value for Money and Policy Review of Disability Services in Ireland**, as follows:

“To contribute to the realisation of a society where people with disabilities are supported, as far as possible, to participate to their full potential in economic and social life, and have access to a range of quality personal social supports and services to enhance their quality of life and well-being²³”

This vision can be summed up as people with disabilities should be living ordinary lives in the community. However, this shift to model based mainstreaming / inclusion does have implications for how health services (service addressing health needs) are provided to people with disabilities and people with intellectual disabilities in particular. As McKenzie notes:

“One important aspect of social inclusion [perspective on disability], which has been neglected for people with learning disabilities is health”²⁴

Balogh makes a similar point specifically related to de-congregation programmes.

Deinstitutionalization has been credited with improving the lives of persons with an intellectual disability; however, in doing so it has shifted the responsibility of the many specialised health care needs to the community without sufficient preparation or financial support. Different countries have developed various models of care to deal with this shift in responsibility²⁵

²³ Department of Health, 2013, **Value for Money and Policy Review of Disability Services in Ireland**

²⁴ Fiona McKenzie, 2005, The roots of biomedical diagnosis, in Grant, G., et al **Learning Disability: A Life Cycle Approach to Valuing People**

²⁵ Balogh, R, et al, 2009, **Organising health care services for persons with an intellectual disability** (Review) Cochrane Library 2009, (1)

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In the National Disability Authority's commissioned review of outcomes for people with intellectual disabilities in clustered versus dispersed housing, this issue of health outcomes or, at least, contact with health professionals, was highlighted as the one area where people had better outcomes in clustered housing.

“In the physical well-being domain, campus or clustered settings have been found to be superior in hours of recreational activity, contact with dentists, psychiatrists and psychologists, some health screening, some aspects of safety, contact with family and friends, visitors to the home and satisfaction with relationships”²⁶

Therefore, this issue of ensuring that mainstream health services meet the needs of people with intellectual disabilities living in the community, will be a major consideration for the Congregated Settings implementation group.

Given the scale of change envisioned by the Value for Money and Policy Review implementation process underway at the moment, it would seem that now would be a very appropriate time to review:

- How to improve health services to people with intellectual disabilities
- How to improve health outcomes for people with intellectual disabilities

These are broader questions than the question addressed within the project on Shaping the future role of Intellectual Disability Nursing in Ireland and would involve a review of a range of professions.

The shift in intellectual disability policy will mean that the mainstream health system will need to play greater role in addressing the health needs of people with intellectual disabilities. On the basis of international evidence, there is little reason to believe that the mainstream health service has the capacity or expertise to meet all the challenges that this change will present. Registered Intellectual Disability Nurses would appear to be well placed to play a key liaison role / specialist resource to facilitate the mainstream health services to address:

- Issues related to the legacy of poor health outcomes and health access for people with intellectual disabilities

²⁶ Mansell, J. and Beadle-Brown, J. ,2008, **Dispersed or clustered housing for disabled adults: a systematic review.**

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- The health issues which will result from more people with intellectual disabilities living in ordinary community settings and participating in mainstream social, educational and economic activities

In order to fulfil these goals the role of the intellectual disability nurse will need to change significantly. At present, the limited available evidence suggests that the role of the intellectual disability nurse is difficult to differentiate from the role of the social care assistant or the role of the general nurses working in intellectual disability services²⁷. Based on the limited evidence, it would appear that the actual role performed by intellectual disability nurse is more defined by employment location than by professional skills and competencies.

To fulfil the role of key liaison role / specialist resource to facilitate the mainstream health services to meet the needs of people with intellectual disabilities the role would need to 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

How can the role be developed to improve the range and quality of services to Service Users and families in:

- Primary care
- Secondary ID services - Adult & Child including Early Development
- Tertiary ID services

How can these roles be reflected in the new healthcare structures?

These questions to a large extent presuppose decisions around future healthcare structures. As mentioned above, the primary consideration should be how the health care needs of people with intellectual disabilities can be best met by mainstream health services when disability services are more community based. The roles of different professions in meeting those needs should be considered subsequently.

Primary services

Intellectual disability nurses should have a role in:

²⁷ Sheerin, F and McConkey, R, 2008, **Frontline Care in Irish Intellectual Disability Services: The Contribution of Nurses and Non-Nurse Care Staff**

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- Training and supporting other primary care professionals
- Health promotion and preventative health activities
- Health screenings [consideration could be given to how all people with intellectual disabilities get regular health screening regardless of whether they reside in a HSE funded residential setting]
- The development and conducting of joint intellectual nurse / GP assessments [in light of the evidence that GPs find assessing the health needs of people with intellectual disabilities difficult]

Secondary services - adult

In relation to secondary services, adult intellectual disability teams (integrated health and social care teams) have been developed in England and Wales. However, the published literature is inconclusive as to whether these teams have contributed to better outcomes for people with intellectual disabilities.

“In England for example, Community Learning Disability Teams were created to provide a diverse range of clinical services to meet the comprehensive mental and physical health needs of persons with an intellectual disability (O’Hara 2000). This model of care has been criticised for frequently bypassing mainstream primary care services. This review uses the term mainstream to describe health care that could potentially be used by any person in the general population including persons with an intellectual disability”²⁸

“The results of the meta-analysis suggest that there is no evidence assertive community treatment is superior to standard community treatment as practiced in England: this should not be taken as evidence that assertive community treatment is not effective, only that, to date, there is insufficient evidence to support it over standard treatment”²⁹

Secondary services - Child including Early Development

Given their skills and expertise, intellectual disability nurses could contribute to meeting the health needs of school age and younger children with intellectual disability by collaborating with these teams. However, given the re-configuration of these teams into area-based generic teams, intellectual disability nurses may be

²⁸ Balogh R, et al, op cit

²⁹ Balogh R, et al, op cit

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required to support a greater range of children. This may have training / re-training implications.

Tertiary services

Intellectual disability nurses could have a role to play in:

- Improving the accessibility of tertiary health services for people with intellectual disabilities (along with other professionals)
- Training and supporting tertiary health service staff in the health needs of people with intellectual disabilities
- Liaising between tertiary specialists / specialist teams (gerontology, dementia, neurology, cardio etc) and primary care / disability social care staff

What type and range of services would be missing to Service Users, their families and healthcare services if RNIDs were not available?

The limited available research suggests that there may be no strong basis for differentiating the role of intellectual disability nurses in the current service model.

“it can be concluded on the basis of this study, that interventional caring in intellectual disability services may be a generic entity which transcends professional boundaries and overlaps greatly with the tasks undertaken by non-nursing care staff. Thus, it could be argued that specialised nursing has, with very few exceptions, no specialist interventional complement to add to such caring in residential settings for this population, and that it is no longer relevant to the needs of people with intellectual disability”³⁰

As noted above, that does not mean that there is not a requirement for highly skilled health personnel to meet the needs of people with intellectual disabilities and that intellectual disability nurses could not assume a key liaison role / specialist resource within a mainstream context.

What are the values and principles that should underpin Intellectual Disability Nursing needed for the service of the future?

The principles of Healthy Ireland seem appropriate:

- Better Governance and Leadership

³⁰ Sheerin, F and McConkey, R, 2008, op cit

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- Better use of People and Resources
- Better Partnerships
- Better Systems for Healthcare
- Better use of Evidence
- Better Measurement and Evaluation
- Better Programme Management

What skills and competencies will ID Nurses require to improve service delivery and outcomes in the future for:

- Service Users
- Families & Carers
- Primary care services
- Other Nurses who are not ID trained

Better skills and expertise in key health areas impacting on people with intellectual disabilities, including:

- Dementia
- Mental health
- Oral health
- Epilepsy
- Gastro-health problems
- Thyroid disease
- Osteoporosis

Intellectual disability nurses' skills and experience in communicating with people with intellectual disabilities and their carers / families have the potential to make the mainstream health system much more accessible to people with intellectual disabilities.

In addition to the above, there is a need for enhanced skills around liaising with and working in collaboration with professionals across the health system to ensure that primary, secondary and tertiary health level health professionals / teams are better equipped to deliver care to people with intellectual disabilities.

What changes are required in the Undergraduate Programme to support the development of such roles?

Given the current disability policy direction, some part of the clinical practice placements and internship elements of the Undergraduate Programme should be within mainstream health settings, rather than, in intellectual disability service providers.

Given the number of individuals with a dual diagnosis of intellectual disability and mental health; and intellectual disability and autism; consideration should be given to having more mental health modules and autism modules should be required or available as options/requirements for undergraduate courses.

3. Healthy living outcomes for people with an intellectual disability

What are the issues that RNIDs need to consider in order to support healthy living outcomes for people with an intellectual disability?

How should they be prepared to do this?

Intellectual disability nurses should have a key role in working with the person with and intellectual disability to develop health and health and wellbeing aspects of person centred plans.

Intellectual disability nurses, working in a variety of settings and roles, could take a lead in:

- Screening
- Health promotion
- Preventative health measures

Intellectual disability nurses could promote better health outcomes by training and up-skilling other health professionals or collaborating with other health professionals in different circumstances.

4. Evidence-based approaches

What is required to increase the use by RNIDs of evidence-based approaches in practice and service delivery?

There are areas where the evidence base around the health care needs of people with intellectual disabilities, and the effectiveness of interventions for people with intellectual disabilities needs to be considerably strengthened. Intellectual disability nurses and other health professionals and researchers in Ireland should

be supported to undertake this research. **IDS-TILDA** data will be extremely useful in this regard.

Enhanced opportunities for intellectual disability nurses to engage in research and intervention monitoring and evaluation should be supported. The review of intellectual disability nursing in the UK emphasised the importance of those being sponsored to undertake research not being completely withdrawn from service delivery³¹.

However, ensuring that intellectual disabilities, who are currently well-trained in the health needs of people with intellectual disabilities, end up in roles which are clearly demarcated by expertise in the health needs of people with intellectual disabilities is also required.

5. Leadership

What are the areas where effective leadership is critical in disability services?

How can effective leadership be developed and supported in intellectual disability nursing?

Experience in the UK would suggest that where intellectual disability nurses are working in a variety of settings (mainstream and specialist) that reporting / supervision relationships become more difficult to manage.

Therefore, leadership post and leadership training for intellectual disability nursing should focus on:

- Collaboration
- Team / multi-disciplinary working

5. Clinical practice

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.

Yes, but these should focus in particular on collaboration with mainstream health services.

³¹ Department of Health (UK), 2012, Strengthening the commitment The report of the UK Modernising Learning Disabilities Nursing Review

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Advance skills are also required to meet specific needs. These could be achieved by developing:

- Further expertise in areas such as:
 - Health promotion and preventative health measures
 - Telehealth
- Skills around meeting the health needs of people with intellectual disabilities in specific mainstream settings such as the criminal justice system or the child protection system
- The capacity to work across the other areas of the health services, such as:
 - Mental health services
 - Older persons services, particularly dementia services
 - Autism services

Conclusion

The National Disability Authority is happy to discuss this submission further and clarify any issues raised.