Assisting Individuals With Intellectual Disabilities
Do We, as Nurses, Still Have a Role?

EDITOR'S NOTE
October is Learning Disabilities Awareness Month, and we are happy to publish this guest editorial about learning and intellectual disabilities by Journal of Psychosocial Nursing and Mental Health Services Editorial Board member Frances Hughes, RN, DNurs, ONZM, and her colleague Julia Hennessy, RN, PhD. Dr. Hughes has worked for non-government organizations (NGOs) in the areas of disability and service evaluation and mental health. She held the position as Executive Officer in a national disability group and established a NGO that provided community residential support to individuals with complex mental illness. Currently, she serves as Executive Director of Cutting Edge Oceania, where she works for northern hemisphere organizations representing their interests in Australia and New Zealand. For 2 years prior, she held the position of Chief Executive Officer of the International Council of Nursing in Geneva, Switzerland. Before that, Dr. Hughes worked for the World Health Organization as the Facilitator for the Pacific Island Mental Health Network, where she worked with 16 governments to help develop policies to improve mental health. Dr. Hughes’ coauthor, Dr. Julia Hennessy, has held a number of senior positions within health and education and has undertaken a number of consultant roles in her home country of New Zealand and internationally. She is currently an assessor and peer reviewer for competency-based practicing certificate for RNs and has been a panel member for the assessment of nurse practitioners. She is a Fellow of the College of Nurses and a member of the College of Mental Health Nurses. In the editorial below, Drs. Hughes and Hennessy use their collective mental health and policy experiences to describe new models of care for individuals with learning and intellectual disabilities, which provide context and perhaps a roadmap for what nurses can do in the United States and abroad.

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Around the world, countries and services are facing health care challenges, with escalating health care costs and a predicted shortage of more than 18 million health professionals worldwide by 2030 (World Health Organization [WHO], 2016) complicating the global role of nursing. Although shortages have a significant impact on what is seen as mainstream nursing, the flow-on effect will be experienced in areas that have lacked global planning and development, particularly learning disability nursing. New Zealand, like many other countries, no longer offers specialist nursing intellectual disability education. Consequently, the country is becoming reliant on overseas recruitment to meet workforce shortages. These same shortages are also occurring across other nations.

Learning disability nursing is widely defined, which is important for not only consumers to understand but also mainstream nursing. Although recognizing that each individual’s potential will differ, the role of learning development nurses is in advising against, preventing, and/or removing obstacles that limit the extent to which individuals with intellectual disabilities are able to achieve their potential (NHS Foundation Trust, 2014). According to Northway, Hutchinson, and Kingdom (2006), the primary focus of learning disability nursing interventions within the social model of disability is to reduce or eliminate barriers to good health thereby increasing opportunities for social inclusion.

Our interest in this field of health was stimulated by the recent service review of forensic intellectual disability services undertaken in New Zealand.

According to an official analysis by Health Education England, the National Health Service will face “up to a 35% shortfall in learning disability nurses by 2020 unless action is taken to address the current education and recruitment ‘crisis’” (Stephenson, 2018, para. 1). The analysis suggests a “really scary” 30% to 35% gap between the supply and demand for learning
disability nurses (Stephenson, 2018, para. 1).

Within this context, a significant program of change is also taking place within disability services. This new model, which is based on reducing health disparities and creating opportunities for consumers with intellectual disabilities, will have implications for nursing practice for a number of nurses, including learning disability nurses, employed within these services requiring a different skillset, with the area of forensic intellectual disabilities providing even greater challenges. Delivering a confident and competent intellectual disabilities health service will require additional nurses with specific intellectual disabilities education and experience deployed to these practice area settings.

Learning disability or psychopaedic nursing has changed considerably over the past decades, with the introduction of new models of care and settings in which care is delivered (Department of Health, 2007). Learning disability nurses work across the lifespan with clients and their families, addressing barriers to living a functioning life. This group of nurses is often invisible to and not advocated for by mainstream nursing. These new models of care will require a different skill mix to that currently deployed within these services. The core competencies of those working with individuals with disabilities, including the competencies of learning disability nurses, must be geared to the new delivery context, which is humanistic in its approach (Sheerin & McConkey, 2008). RNs working in intellectual disability services need specialist knowledge to work effectively with clients with autism spectrum disorder (ASD), challenging behavior, complex health issues, epilepsy, forensic backgrounds, mental health issues, and dementia.

Another emerging theme is the need for nurses working with individuals with intellectual disabilities to also consider the physical needs of individuals. A report commissioned by the WHO (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2000) identified 15 health areas that are highly prevalent in individuals with intellectual disabilities and recommended preventive measures, regular screening, and appropriate referrals for addressing these issues (Table).

A study by Baxter et al. (2006) reinforced the lack of attention to physical health needs in individuals with intellectual disabilities. In a sample of 181 individuals with intellectual disabilities living in the community, 51% had an unrecognized health issue (Baxter et al., 2006).

Given the health inequalities experienced by individuals with intellectual disabilities, a key consideration for the profession should be how these individuals obtain access to appropriate mainstream health services. Considerable work and planning are required to design and operationalize a system in which learning disability nurses are based in or across several specialist and mainstream health and social care settings, supporting a range of professionals to achieve better health outcomes for individuals with intellectual disabilities. Individuals with intellectual disabilities have more health issues than the rest of the population and have significant difficulties accessing appropriate health care. There is a need for the health service to improve how it meets the health needs of this population. By collaborating and supporting other health professionals, learning disability nurses can play an important role in addressing these health needs.

The management of comorbidities and physical health needs of clients with high and complex intellectual disability is key to rehabilitation. The ability, skill, and access of staff to monitor, assess, and provide interventions on an ongoing manner is crucial. Nurses and specialist medical staff are key to this area.

### MODELS OF CARE

A small but high and complex needs service for forensic intellectual disability services in New Zealand has created a model of care, “Good Lives.” This model provides a philosophical position that details the paradigms intellectual disability services ascribe to in their care, treatment, and rehabilitation of their client group. The model outlines the clinical methodology, details therapeutic and rehabilitative practices and goals, and can best be summarized by the following statement:

The Overarching Clinical Framework for the Intellectual Disability Service is a comprehensive approach to the provision of care and rehabilitation for offenders with intellectual disabilities. The Framework draws on the strengths of clients and staff while also recognising and being responsive to the risk that
is inherent in working with this client group. Specifically, the Framework draws upon the Good Lives Model of Offender Rehabilitation, comprehensive risk assessment, a Positive Behaviour Support approach to direct care, and a staff supervision and education programme. (Intellectual Disability Services, 2018)

This model provides clinicians with a systematic framework to guide case conceptualization and targeted rehabilitation planning from admission through discharge. The model also promotes interdisciplinary cohesion and works to reduce length of admission and rates of reoffending. The model is a rehabilitation wellness model, which defines the differences between intellectual disabilities services and mental health. This definition is further expanded within the proposed service model developed for this project.

Another way of working with this complex group is through the Cognitve Rehabilitation Model (CRM), which was developed at the Ashworth Special Hospital in the United Kingdom. Savage (2009) introduced this concept and described the development of a rehabilitation unit in a high secure setting where service users are managed using a program of cognitive rehabilitation therapy in combination with psychosocial intervention (PI). This model is worthy of consideration with respect to furthering the Good Life Model. The model highlights the need for highly skilled staff to deliver services. The CRM and PI training has provided valuable insight for staff and has been shown to reduce burnout in staff (Savage, 2009).

In recent years, learning disability nursing has been diverted from health-focused roles to embrace more social care management activities, whereas in some instances, health needs have not been fully met (Department of Health, 2007). Given that individuals with intellectual disabilities often have complex needs and poorer health, it is clear that intellectual disability clinical nurse specialists (CNSs) are too valuable to be in non-health-focused roles. Therefore, intellectual disability CNSs need to refocus their activities on health-related areas and support social care through delivering education, support, advice, and consultancy to primary, acute, and secondary health care providers, thereby enhancing their ability to work with individuals with intellectual disabilities and promote a more inclusive service (Atkinson, Boutler, Pointu, Thomas, & Moulster, 2010).

Various reports from the United Kingdom, including Treat Me Right! (MENCAP, 2004), Death by Indifference (MENCAP, 2007), and Six Lives (Local Government Ombudsman, 2009), have publicized that acute and primary health care services need to improve their care and treatment of individuals with intellectual disabilities. Using learning disability nurses and CNSs in primary health care services would acknowledge the relevance and transferability of their intellectual disability specialist nursing skills.

A model of practice was developed by Hughes and Hennessy (2018) that identified the domain required for all practitioners delivering services to individuals with intellectual disabilities. The model was expanded and modified to make it applicable for RNs working in the field of intellectual disabilities (Hughes & Hennessy, 2018). The model developed provides an important framework to support under- and post-graduate preparation of RNs. RNs need to use their skills and knowledge to provide a more holistic, age-appropriate service to this complex group of clients (Figure).

**SUMMARY**
Nurses have a vital part to play in the care and treatment of individuals with intellectual disabilities. However, in many countries, there is a significant shortfall in the preparation of RNs to work in this field, indicating that these clients, with some of the highest and most complex needs, are not receiving optimal care. RNs need to advocate for significant changes to practice in this evolving field. As new evidence-based models of care are developed, nurses need to consider and integrate them into their practice. To achieve implementation of these new models, it is important for schools of
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nursing to carefully consider their curriculum, ensuring that new nurses are more adequately prepared in this discipline, as well as how to best educate RNs who have been working in the field for some time but may not have contemporary knowledge to support their skillset. If nurses consider that they still have a role in the care and management of individuals with intellectual disabilities, they need to be advocates for change. When considering this field of practice, nurses must take a more holistic approach to ensure the best outcomes for their clients.

REFERENCES


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