

# Intellectual and developmental disability nursing: current challenges in the USA

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**Background:** Nursing in the field of intellectual and developmental disability (IDD) has evolved over the last decade. With this evolution new challenges related to this field of nursing practice have surfaced. The field of IDD nursing is complex and considered out of the realm of common nursing practice. Given the complexity and uniqueness of this area of nursing practice, nurses face challenges when supporting this population. The purpose of this commentary is to highlight current challenges faced by nurses working in the field of IDD in the USA in order to generate conversation and solutions.

**Methods:** A review of literature and clinical practice experience was conducted. Articles were analyzed for content related to nursing practice in the field of IDD. Textbook references were incorporated to substantiate key points. Additionally, the author's 24 years of clinical practice and nursing administrative experience were included.

**Results:** Nurses face varied challenges in the field of IDD: lack of education regarding this population, healthcare complexity of this population, role ambiguity, varied practice settings, nursing model of care controversy, and caseload distribution and acuity.

**Conclusion:** Nurses working with the IDD population face challenges that may be distinctive to this field of nursing. Educational preparation for nurses, physicians, and health care professionals is minimal. The multifaceted needs of persons with IDD and diverse practice settings nurses encounter create a fragmented system that is difficult to navigate. Evidence-based interventions to guide IDD nursing practice are lacking. Standardization of care principles and role clarification for the IDD nurse across settings are varied. The IDD field requires a synthesized approach to healthcare management that currently does not appear to exist across settings. An increase in nursing research for this population and area of practice should occur. Nursing and medical programs must seek ways to include or expand content specific to the health intricacies of this population.

**Keywords:** intellectual, disability, learning disability, nursing, challenges, roles

## Significance and background

Nursing in the field of intellectual and developmental disability (IDD) has evolved over the last decade. With this evolution new challenges related to this field of nursing practice have surfaced. The field of IDD nursing is complex and considered out of the realm of common nursing practice. Given the complexity and uniqueness of this area of nursing practice, nurses face challenges when supporting this population. The purpose of this commentary is to highlight current challenges faced by nurses working in the field of IDD in the USA in order to generate conversation and solutions. The methodology used was a review of the literature using the key words intellectual, disability, nursing, challenges, and roles, as well as the sole author's 24-year clinical practice experience.

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IDD nursing is a specialized area of nursing focused on the complex healthcare needs of this population. This field of nursing requires a wide range of specified skills in order to meet the varied health, behavioral, advocacy, and societal needs of persons with IDD. An intellectual disability is defined as a cognitive disability categorized by significant limitations in reasoning, learning, problem solving, and adaptive behavior.<sup>1</sup> A developmental disability can be defined as chronic disability that can be cognitive or physical in nature or can be comprised of both. The disability appears before the age of 22 years and is likely to be permanent.<sup>2</sup> Developmental disabilities include but are not limited to autism, intellectual disability, behavior disorders, cerebral palsy, Down syndrome, and brain injury. For this article the term IDD will be used to identify this population as often the diagnoses co-exist.

### Complexity of providing care

Individuals with IDD have multifaceted healthcare conditions that require a team of healthcare professionals to ensure comprehensive care is provided and appropriate referrals are made. Dixon-Ibarra and Horner-Johnson report there is a strong relationship between IDD and an increased rate of chronic health conditions.<sup>3</sup> Chronic health conditions among people with IDD include aspiration, dehydration, constipation, seizures, motor deficits, allergies, otitis media, gastroesophageal reflux disease, diabetes, dysmenorrhea, sleep disturbances, thyroid disorders, mental illness, vision and hearing impairments, and oral health problems.<sup>4-6</sup> The Center for Disease Control reports a 16.4% increase in diabetes, and a 56.1% increase in depression for persons with IDD over the general population.<sup>6</sup> However, people with IDD often do not receive the healthcare needed, in part because of the unique nuances related to providing treatment. Individuals with IDD may have alternate methods of communication which can inhibit identification of health related issues. Challenging behaviors, multiple care settings, and the increased time to complete assessments contribute to the difficulty of providing care.

### Limited nursing and healthcare professional education

Given the complexity of providing healthcare to persons with IDD, nurses in this field should ideally work as part of a team dedicated to ensuring each person receives appropriate healthcare and is offered the same healthcare access in their community as the general population. However, nurses in this field are often required to work independently and are charged with independent decision-making in regard to clinical care.<sup>7</sup>

The stress of independent decision-making can add to IDD nursing burnout. The emotional cost of this type of caring has been identified as a major factor in nursing workplace stress.<sup>8</sup> This independent decision-making by IDD nurses can be a result of unprepared healthcare team members, including the IDD nurse at times, to recognize and interpret key signs and symptoms of illness in order to guide care for the distinctive needs of this population.

Nurses replied in the study by Sowney and Barr<sup>9</sup> that they received no formal education or practice experience with the disability population prior to providing nursing care. Additionally, McKeon's<sup>10</sup> findings determined that community nurses regarded their knowledge and skill related to caring for those with intellectual disability as inadequate and noted a need for knowledge and skill training specifically related to disability nursing care. In the author's personal experience this was a common theme. The lack of knowledge may be a barrier to ensuring quality care for persons with IDD. Nursing knowledge deficit also places an undue burden on the nurses who support them.

Formal education to prepare nurses to work in the field of IDD is insufficient in the USA. Smeltzer et al<sup>11</sup> offer lack of funding and faculty knowledge as two reasons for not including IDD education in nursing curricula. Nevertheless, an article by Cervasio<sup>13</sup> outlines the necessity for schools of nursing to include courses in IDD in their programs. At present, most didactic courses and practicum settings do not include content specific to the healthcare needs of the IDD population.

Adding to the lack of health expertise is limited medical education for physicians related to the intricacies of caring for this population. Tyler and Baker<sup>14</sup> acknowledge that beyond a few talks in first-year genetics, most physicians have very little exposure to persons with IDD. Attempts to increase education for physicians regarding the health needs of persons with IDD have been increasing.<sup>15,16</sup> However, there is currently still not an adequate number of physicians to provide quality healthcare specific to this population.<sup>16</sup> The American Association of Developmental Medicine and Dentistry<sup>16</sup> recognizes that most medical residents do not receive suitable preparation to meet the healthcare needs of persons with IDD. The reality of deficient healthcare team education places further pressure on the IDD nurse when providing clinical care.

### Role ambiguity

The National Developmental Disabilities Nurses Association categorizes the responsibilities of IDD nurses as fitting

into eleven categories: establishing a therapeutic relationship, member of the interdisciplinary team, data collection, identification of healthcare needs, planning, implementation, evaluation, quality assurance, advocate, educator, and continued compliance.<sup>17</sup> The responsibilities of delegation and authority contribute to the ambiguous role of the IDD nurse. Delegation is the process by which responsibility and authority for performing a task is transferred to another individual. In the delegation process, the delegator remains accountable for the task that has been delegated.<sup>18</sup> The National Council of State Boards of Nursing<sup>19</sup> lists five rights of delegation: the right task, the right circumstance, the right person, the right direction and communication, and the right supervision. Authority is the practice of directing, guiding, and influencing the outcome of a person's performance of a task.<sup>18</sup> However, in many settings the IDD nurse does not have supervisory authority over the unlicensed direct support staff who provide much of the hands on day to day care of people with IDD.<sup>20</sup> The responsibilities of unlicensed support staff in the IDD field is wide-ranging and encompasses providing direct care, administering medications and treatments, and implementing behavior plans.<sup>21</sup> Many of these duties in other fields of nursing are delegated only to licensed healthcare professionals or to unlicensed support staff under the direct authoritative supervision of registered nurses.<sup>18</sup> The American Nurses Association<sup>18</sup> describes unlicensed support staff as individuals trained to function in an assistive role to the registered nurse. Without supervisory authority, IDD nurses have little opportunity to intervene when necessary to ensure safe and appropriate healthcare. This inability to practice to the full extent of licensure can lead to frustration for the IDD nurse. Given the complexity of providing care for this population, the lack of nursing authority may place undue risk on the person with IDD receiving care. It also brings into question the legality of such delegation in some settings, and the jeopardy that may be imposed on the IDD nurse's license.

According to Schilling et al<sup>22</sup> each nurse practicing in an alternate setting (such as community settings) must be knowledgeable about the legal risks involved and abide by their nurse practice guidelines. The Standards of Intellectual and Developmental Disability were articulated through the Nursing Division of the American Association on Intellectual and Developmental Disabilities.<sup>23</sup> In part, the standard states the IDD nurse must adhere to professional practice standards and guidelines as well as relevant statutes, rules, and regulations. However, the diverse evolving policy in community settings<sup>24</sup> fragments rules and regulations guiding IDD nursing practice in the USA. This context may prevent

the IDD nurse from understanding their role in delegation and other areas of their practice, as well as from appreciating the risks involved.

## Practice settings

Historically, IDD nurses most often worked in large facilities that housed persons with IDD.<sup>25</sup> A philosophical and funding movement in the 1990s resulted in the closing of many large institutions.<sup>26</sup> Today, most IDD nurses work in community settings of various types such as residential homes, clinics, small facilities, special education settings in schools, or personal homes.<sup>26</sup> This varied landscape of settings may propose diverse expectations and role definitions for the IDD nurse.<sup>27</sup>

The transition of individuals out of institutions and into community settings has further added to the ambiguous role of the IDD nurse.<sup>28</sup> As previously stated IDD nurses work within an assortment of community settings and these settings may have varied views regarding the role of the IDD nurse. IDD nurses working in community settings may work as consultants, supervisors, or administrators. However, the clarity of these roles and the value that IDD nurses bring to individuals in community settings cannot be substantiated in the current literature.<sup>27</sup> This marginalization may be due in part to failure of the IDD nursing field to fully encompass the 'medical model' of care that is embedded within the nursing profession.

## Balancing conflicting roles and healthcare models

The medical model approach views disability healthcare as being controlled by health professionals who are considered the experts. The disability is determined to be a deviation from normal and individuals with disability are assumed to accept the healthcare offered by the healthcare professionals.<sup>12</sup> This medical model interpretation is often not shared by persons with IDD. In their view, the medical model emphasizes that only physicians, nurses, and other healthcare professionals are best capable to make decisions about their health issues.<sup>12</sup> In practice, this has not been the author's experience. IDD nurses do not necessarily support and/or practice according to the medical model approach. However, the concern over the use of the 'medical model' method often overshadows the expert support that IDD nurses can bring to persons with IDD. Again, this is due in part to the ambiguous role of the IDD nurse in community settings as well as confusion over the perceived use of this model by nurses in the field of IDD. The challenge of providing quality care while ensuring the rights and autonomy of persons with IDD is central to IDD nursing care and can be difficult

to navigate.<sup>12</sup> In the author's personal experience IDD nurses most often subscribe to the 'person-centered approach' to healthcare for individuals with IDD and support them in their quest for autonomy in their lives.

Person-centered healthcare support can be described as an approach to healthcare that considers individuals' values, desires, family situation, and goals when developing a plan of care. The individual is recognized as an equal partner with the nurse in developing and monitoring the agreed upon plan of care.<sup>29</sup> Person-centered planning puts the individual with disability at the center of planning. The difference between the nursing profession's use of the medical model of care, and the use of the person-centered model of care by IDD nurses can create separation and controversy within the nursing profession. Additionally, social stigma that can be applied to persons with disability may carry over to the nurses who care for this population, resulting in further separation and controversy.<sup>30</sup> This separation and controversy may diminish the role of the IDD nurse within the scope of the nursing profession as a whole. The subsequent disunion may impact the IDD nurse's formal support from the nursing profession, impacting areas such as IDD nurse-to-patient caseload numbers and ensuring comparable IDD nursing salaries.

### Caseload distribution and acuity

Literature suggests there is no uniform process for determining a suitable number or 'safe caseload' of individuals an IDD nurse will serve in community-based settings.<sup>31</sup> This lack of uniformity may result in IDD nurses having caseloads of medically intense individuals without the necessary support to manage care effectively.<sup>32</sup> The National League of Nursing<sup>33</sup> does offer a specific tool for assessing someone with a disability. While the Assessment of the Patient with a Disability® tool offers guidance, it does not address caseload number or distribution. The Bureau of Developmental Disability Services in Indiana provides a needs assessment tool and rubric for IDD nurses to implement.<sup>34</sup> However, the needs assessment and rubric do not determine the number of individuals an IDD nurse can have on their caseload. This is determined by the agency or organization where the IDD nurse is employed.

Along with fragmented methods of determining the number of individuals IDD nurses will have on their caseload, their caseload may also be geographically vast. The time spent traveling between sites may reduce time the IDD nurse can spend with each person. In a study by Ndengeyingoma and Ruel,<sup>35</sup> IDD nurses acknowledged two major concerns when caring for this population. First, insufficient time to understand the individual's needs and to intervene thoroughly.

Secondly, the number of individuals on their caseload did not allow enough time for communicating effectively with the individuals so sufficient comprehension by the person with IDD could occur.

### Salary

IDD nurses' specialized knowledge and skills are necessary for individuals to receive optimal care. However, the significance of IDD nurses' knowledge and skill is not recognized in their wages. The compensation for IDD nurses is reported to be lower than nurses in other fields of nursing.<sup>7</sup> While many nurses report high satisfaction when working with this population, the financial reward is unacceptable.<sup>36</sup> The rationale for lower wages is not clearly understood but may be impacted by the lack of recognition regarding the specialty of IDD nursing within the nursing profession, ambiguous nature of the IDD nursing role, and lack of research to guide IDD practice.

### Research to guide IDD nursing practice

To improve the visibility of IDD nursing and better impact healthcare of this population, more research in the field is necessary. IDD nurses are reported to conduct less research than other areas of nursing.<sup>37</sup> In a review by Jenkins<sup>38</sup> it is noted that while IDD nurses are undertaking important work, it is often not published or disseminated for the greater good of the IDD nursing profession. Without the results of this work, IDD nurses lack evidence-based research to frame their clinical practice. The lack of published work inhibits the value and specific nature of the IDD nurses' role. Importantly, the work and the care they provide may continue to be marginalized within the broader scope of nursing and healthcare.

### Implications for practice

Nurses working with this population face challenges that may be distinctive to this field of nursing. Educational preparation for nurses and physicians is minimal. This gap in knowledge may create a health risk for persons with IDD. It may also increase work related stress for the IDD nurse. Nursing and medical programs should seek ways to include or expand content specific to the health intricacies of this population.

The multifaceted needs of persons with IDD and diverse practice settings nurses encounter create a fragmented system that is difficult to navigate. The IDD field requires a synthesized approach to healthcare management that currently does not appear to exist across settings. Additionally, standardization of care principles and role clarification for

the IDD nurse across settings is a necessity. Identifying the specific role of the IDD nurse would illuminate the skill and knowledge necessary to meet the challenges of working within this field of nursing.

IDD nurses must take on the responsibility of conducting and disseminating research. Without evidence-based interventions to guide IDD nursing, nurses lack a framework for expertly guiding their practice. Research can improve the environment where nurses practice. For example, implementing a uniformed method of determining nursing caseloads based not just on numbers but on acuity and geographical spread. Additionally, nurses working within the IDD field are best positioned to identify healthcare needs of this population and trial interventions aimed at improving healthcare.

Lastly, we need effective leadership in IDD nursing. Proper leadership can help to shape the current and future practice of IDD nursing. Leaders can assist in establishing educational goals, influencing practice, encouraging research, and helping to bridge relationships between the field of IDD nursing and the entire nursing profession.

## Disclosure

The author reports no conflicts of interest in this work.

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