

December 1, 2022

VIA EMAIL SUBMISSION:

Dear CCNE Standards Committee,

Thank you for the opportunity to comment on *The Standards for Accreditation of Baccalaureate and Graduate Nursing Programs* (2018). Institute for Exceptional Care (IEC) is a non-profit organization committed to transforming healthcare for people with intellectual and/or developmental disabilities (IDD). IEC is working with national professional societies, accrediting boards, IDD clinical and research organizations, medical education leaders, and self-advocates to scale strategies for engaging, preparing, and supporting clinicians or clinicians-in-training to provide better IDD care. Dr. Allison P. Edwards is an assistant professor and faculty at the Cizik School of Nursing-UTHealth Houston who has published research on the existing knowledge gap of nursing students in the care of people with disabilities (PWD). (Edwards & Hekel, 2021, Edwards et al, 2021, Edwards et al, 2022, Edwards, 2021). While disabilities can be an all-encompassing diagnosis, the deficit of knowledge and skills contributing to the requisite negative attitudes of nursing students for this prevalent population is well documented in the literature.

We would like to provide supporting evidence for the need to incorporate disability education into Standards I, III and addressing existing gaps. The community of interest must incorporate people with disabilities because they are a large and growing population in the United States representing all races/ethnicities, geographic, and demographic groups. Disability education at a minimum should incorporate clinically immersive experiences caring for people with childhood onset intellectual and/or developmental disabilities (IDD) such as Autism Spectrum Disorder (ASD), Down Syndrome (DS), Cerebral Palsy (CP), Spina Bifida, and intellectual disabilities (ID), as well as progressive disabilities (Dementia or neurocognitive disorders), Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis, and acquired disabilities such as amputations or spinal cord injuries. Finally sensory deficits must be included in education as it pertains to visual or hearing deficits.

While the existing standards take the community of interest into consideration, which may include people with disabilities; *we will outline the evidence that there are significant gaps in relation to:*

1. Knowledge surrounding the prevalence of disability;
2. Cultural and clinical preparedness of nurses to serve people with disabilities;
3. The quality of care people with disabilities receive and the outcomes they experience;
4. The degree to which disability education is built into standing curricula.

Prevalence

Based on the prevalence of disability, courses across baccalaureate and graduate nursing programs should include disability education. There is a large and growing population of people with disabilities, however clinical education surrounding disability remains limited. As of 2018, 1 in 4 people in the United States has a disability.¹ Disability impacts people of all ages and status can change over time, but notably, it is likely to impact everyone in their lifetime as a universal human experience.² The life expectancy for people with developmental disabilities is increasing and approaching a similar age to the general population.³ Recent estimates in the United States show that 17% of children from ages 3-17 have one or more developmental disabilities.⁴ All health care professionals can expect to see increasing numbers of patients with disabilities, including nurses. An emphasis on disability education should be implemented into the Standards as statistics show the population of people with disabilities is substantial.

Clinical Preparedness

Nursing students will eventually care for and impact the livelihood of individuals, including those with disabilities. The clinical preparedness of nursing students to serve patients with disabilities falls directly in relation to Standard I; key element C and Standard III; key elements G and H. Persons with disabilities are more likely to have poorer health and higher rates of chronic illness(es) than those who do not.⁵ Negative attitudes are correlated with a lack of formal education on disability, placing strain on nurses who care for people with disabilities.⁶ Research in 2018 showed lack of awareness

¹ Okoro, C. A., Hollis, N. D., Cyrus, A. C., Griffin-Blake, S. (2018). Prevalence of disabilities and health care access by disability status and type among adults – United States. *Morbidity and Mortality Weekly Report*, (67), 882-887. <http://dx.doi.org/10.15585/mmwr.mm6732a3>

² Kirschner, K. L., & Curry, R. H. (2009). Educating health care professionals to care for patients with disabilities. *JAMA*, 302(12), 1334-1335. <https://doi.org/10.1001/jama.20091398>

³ Coppus, A. M. (2013). People with intellectual disability: what do we know about adulthood and life expectancy? *Developmental disability research reviews*, 18(1), 6-16. <https://doi.org/10.1002/ddrr.1123>

⁴ Cogswell, M. E., Coil, E., Tian, L. H., Tinker, S. C., Blythe Ryerson, A., Maenner, M. J., Rice, C. E., Peacock, G. (2022). Health needs and use of services among children with developmental disabilities – United States 2014-2018. *Morbidity and Mortality Weekly Report* (71), 453-458. <https://doi.org/10.15585/mmwr.mm7112a3>

⁵ Dixon-Ibarra, A., & Horner-Johnson, W. (2014). Disability status as an antecedent to chronic conditions: National health interview survey, 2006-2012. *Preventing Chronic Disease*, (11), 130251. <https://doi.org/10.5888/pcd11.130251>

⁶ Brown, S., & Kalaitzidis, E. (2013). Barriers preventing high-quality nursing care of people with disabilities within acute care settings: A thematic literature review. *Disability & Society*, 28(7), 937-954. doi.org/10.1080/09687599.2012.748646

Geckil, E., Kaleci, E., Cingil, D., & Hisar, F. (2017). The effect of disability empathy activity on the attitude of nursing students towards disabled people: a pilot study. *Contemporary Nurse*, 53(1), 82-93. doi.org/10.1080/10376178.2017.1292143

Kritsotakis, G., Galanis, P., Papastefanakis, E., Meidani, F., Philalithis, A. E., Kalokairinou, A., & Sourtzi, P. (2017). Attitudes towards people with physical or intellectual disabilities among nursing, social work and medical students. *Journal of Clinical Nursing*, 26(23-24), 4951-4963. [doi:10.1111/jocn.13988](https://doi.org/10.1111/jocn.13988)

Polikandrioti, M., Govina, O., Vasilopoulos, G., Adamakidou, T., Plakas, S., Kalemikerakis, I., . . . & Fouka, G. (2020). Nursing students' attitudes towards people with disabilities. *International Journal of Caring Sciences*, 13(1), 480-488.

and relevant knowledge experienced by registered nurses was a barrier to feeling confident providing quality care to patients with IDD, noting that the only reasonable remedy for this is education.⁷ Educational preparedness and increased exposure to people with IDD improves gaps in confidence and comfort providing care.⁸ The inclusion of disability in learning practices and exposure to patients with a disability in the clinical setting would improve clinical preparedness for nursing students.⁹ In focus groups with nurses that care for people with IDD, IEC heard consistently their belief that early exposure during clinical training was extremely influential in their pursuit of serving the IDD population. As research shows, education and exposure to patients with disabilities has a significant role in building nurses' confidence in their ability to provide care. Without the incorporation of disability education into nursing curricula, Standards I and III are unlikely to be met for this community of interest.

Quality of Care

Access to adequate health care is important for everyone, but especially for people with disabilities who are at heightened risk of negative health outcomes. Access to quality care is greatly impacted by how readily clinicians are available/willing to support people with disabilities. A potential barrier to people with disabilities receiving high quality care is that clinical education surrounding their needs is not prioritized. Americans with disabilities are more likely to have unmet health care needs than the general population and historical research has shown that people with disabilities receive lower quality health care, fewer preventative services, and are less likely to be offered equal treatment.¹⁰ One study in 2012, focusing on the interactions between nurses and people with disabilities found that poor communication, lack of cultural competence, negative attitudes by nursing staff and fears related to quality of care were common experiences

Temple, B., & Mordoch, E. (2012). Nursing student perceptions of disability and preparation to care for people with intellectual disabilities. *Journal of Nursing Education*, 51(7), 407-410. [doi:10.3928/01484834-20120515-01](https://doi.org/10.3928/01484834-20120515-01)

⁷ Appelgren, M., Bahtsevani, C., Persson, K., & Borglin, G. (2018). Nurses' experiences of caring for patients with intellectual developmental disorders: a systematic review using a meta-ethnographic approach. *BMC Nursing*, 17(51). <https://doi.org/10.1186/s12912-018-0316-9>

⁸ Smith, P., Ooms, A., & Marks-Maran, D. (2016). Active involvement of learning disabilities service users in the development and delivery of a teaching session to pre-registration nurses: Students' perspectives. *Nurse Education in Practice*, 16(1), 111-118. [doi:10.1016/j.nepr.2015.09.010](https://doi.org/10.1016/j.nepr.2015.09.010)

Whiteley, A. D., Kurtz, D. L., & Cash, P. A. (2016). Stigma and developmental disabilities in nursing practice and education. *Issues in Mental Health Nursing*, 37(1), 26-33. [doi:10.3109/01612840.2015.1081654](https://doi.org/10.3109/01612840.2015.1081654)

Levett-Jones, T., Lapkin, S., Govind, N., Pich, J., Hoffman, K., Jeong, S. Y., . . . Everson, N. (2017). Measuring the impact of a 'point of view' disability simulation on nursing students' empathy using the comprehensive state empathy scale. *Nurse Education Today*, 59, 75-81. [doi:10.1016/j.nedt.2017.09.007](https://doi.org/10.1016/j.nedt.2017.09.007)

⁹ Levett-Jones, T., Lapkin, S., Govind, N., Pich, J., Hoffman, K., Jeong, S. Y., . . . Everson, N. (2017). Measuring the impact of a 'point of view' disability simulation on nursing students' empathy using the comprehensive state empathy scale. *Nurse Education Today*, 59, 75-81. [doi:10.1016/j.nedt.2017.09.007](https://doi.org/10.1016/j.nedt.2017.09.007)

Smith, P., Ooms, A., & Marks-Maran, D. (2016). Active involvement of learning disabilities service users in the development and delivery of a teaching session to pre-registration nurses: Students' perspectives. *Nurse Education in Practice*, 16(1), 111-118. [doi:10.1016/j.nepr.2015.09.010](https://doi.org/10.1016/j.nepr.2015.09.010)

¹⁰ Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American journal of public health*, 105(S2), S198-S206.

during hospitalization.¹¹ People with disabilities are more likely to find healthcare provider skills and equipment inadequate to meet their needs, three times more likely to be denied care, and are four times as likely to be mistreated by healthcare professionals.¹² As a consequence, people with disabilities are less likely to trust the healthcare system and less likely to seek care when they need it. Improvements in training for nurses are essential to support better access and quality in healthcare for people with IDD.¹³ Education and clinical training for serving this population must be built into the expected program outcomes, with an emphasis on its direct correlation to achieving the goals outlined in Standards I and III.

Curriculum

The role of CCNE in addressing inequities in healthcare for people with disabilities stems directly from how expected program outcomes are developed and measured. Clinical programs have established meaningful curricula to achieve outcomes focused on cultural competency, patient-centered care, and health disparities; but people with disabilities have been overlooked in these efforts. An analysis of textbooks commonly used by nursing programs revealed that content related to disability was largely absent.¹⁴ **As part of Standard III, teaching-learning practices should expose students to people with diverse life experiences, perspectives, and backgrounds. Some researchers suggest that all student nurses receive mandatory content about the intersection of disability and health in partnership with a person with disability, and when possible, be offered opportunities for clinical placements specific to disability.**¹⁵ The National Council on Disability, Surgeon General and Healthy People 2020 determined there was deficient care and a need for disability content. The National Council on Disability (2009) noted, “the absence of professional training on disability competency issues for healthcare practitioners is one of the most significant barriers that prevent people with disabilities from receiving appropriate and effective health care” (Professional Training and Education, para 1).¹⁶ The planned incorporation and inclusion of disability in educational materials, clinical training experiences, and assessments are required for

¹¹ Smeltzer, S. C., Avery, C., Haynor, P. (2012). Interactions of people with disabilities and nursing staff during hospitalization. *American Journal of Nursing*, 112(4), 30-52

¹² Trollor, J. N., Eagleson, C., Turner, B., Salomon, C., Cashin, A., Iacono, T., . . . Lennox, N. (2016). Intellectual disability health content within nursing curriculum: An audit of what our future nurses are taught. *Nurse Education Today*, 45, 72-79. [doi:10.1016/j.nedt.2016.06.011](https://doi.org/10.1016/j.nedt.2016.06.011)

¹³ Whiteley, A. D., Kurtz, D. L., & Cash, P. A. (2016). Stigma and developmental disabilities in nursing practice and education. *Issues in Mental Health Nursing*, 37(1), 26-33. [doi:10.3109/01612840.2015.1081654](https://doi.org/10.3109/01612840.2015.1081654)

¹⁴ Smeltzer, S. C., Robinson-Smith, G., Dolen, M. A., Duffin, J. M., & Al-Maqbali, M. (2010). Disability-related content in nursing textbooks. *Nursing Education Perspectives*, 31(3), 148-155.

¹⁵ Desroches, M. L., Howie, V. A., Wilson, N. J., & Lewis, P. (2022). Nurses' attitudes and emotions toward caring for adults with intellectual disability: An international replication study. *Journal of Nursing Scholarship* 54, 117-124. <https://doi.org/10.1111/jnu.12713>

¹⁶ National Council on Disability. (2009). *Current state of health care for people with disabilities. Executive Summary: Professional training and education*. Retrieved from <https://ncd.gov/publications/2009/Sept302009#Professional>

effectively preparing students to meet the needs of the diverse *prevalent* communities they will encounter and serve.

Conclusion

For the reasons detailed in these comments regarding Standards I, III and existing gaps, we strongly recommend the integration of disability content throughout the most common courses in both didactic and clinical curricula. Such content could entail utilizing case scenarios, standardized patients and case simulations of people with IDD or other disabilities who also have common medical conditions. The learning contexts in which disability content appears in existing courses should parallel those covered within licensure exams, such as cases in specialty areas (e.g. OBGYN, primary care, etc.). In tandem, a half-credit mandatory course should be offered on issues like person-centered care, the nature of disabilities, and key historical context (e.g. ADA).

There are numerous disability and IDD curricula that can be used as sources of both competencies and teaching content, such as: Alliance for Disability in Health Care Education, Partnering to Transform Health Outcomes With Persons With Intellectual and Developmental Disabilities (PATH-PWIDD), Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND), and IntellectAbility.

- 1) Alliance for Disability in Health Care Education partnered with Ohio State University Nisonger Center to establish core competencies. The Core Competencies on Disability for Health Care Education are outlined by guiding principles and shared values for providing quality care to people with disabilities, the core competencies include: contextual and conceptual frameworks on disability, professionalism and patient-centered care, legal obligations and responsibilities for caring for patients with disabilities, teams and systems-based practice, clinical assessment, and clinical care over the lifespan and during transitions.¹⁷
- 2) PATH-PWIDD is introducing an interprofessional health education curriculum for pre- and post- licensure clinical students. The goal is to develop and integrate high-impact and inclusive learning activities into an interprofessional education curriculum that will contribute to a competent healthcare workforce that is prepared to care for people with IDD.¹⁸
- 3) Vanderbilt LEND has worked with experts to create curriculum resources for training programs on more than 30 neurodevelopmental disability topics that include readings,

¹⁷ Alliance for Disability in Health Care Education. (2019). Core Competencies on Disability for Health Care Education. Peapack, NJ: Alliance for Disability in Health Care Education. <http://www.adhce.org/>

¹⁸ Partnering to Transform Health Outcomes With Persons With Intellectual and Developmental Disabilities. (2022). *Advocating for people with intellectual and developmental disabilities*. <https://path-pwidd.org/about-us>

assignments, discussion prompts, case studies and additional resources.¹⁹

- 4) IntellectAbility has created an e-learning curriculum to provide fundamentals in IDD healthcare; the curriculum consists of six modules with real world case studies to help students and clinicians improve their skillset.²⁰

In conclusion, we believe the immediate incorporation of disability education is necessary to meet the mission and goals established in Standards I and III. There are significant gaps where disability is not adequately reflected in the planned student exposure to providing care, and the degree to which students are expected to demonstrate attainment of program outcomes for meeting the needs and experiences of the community of interest. The implementation of disability education into course content, learning practices, and assessment will effectively equip nursing students with the knowledge they need to feel prepared and provide high quality care to patients with disabilities.

We hope you will carefully consider what this research implies regarding the need for disability education to be incorporated into graduate and baccalaureate nursing programs as standardized requirements.

Sincerely,

Allison P. Edwards, DrPH, MS, RN, CNE
Assistant Professor, UTHealth Cizik School of Nursing

Hoangmai Pham, MD, MPH
President & CEO
Institute for Exceptional Care

References:

Edwards, Allison P. & Hekel, Barbara E. (2021). Appraisal of disability attitudes and curriculum of nursing students: a literature review. *International Journal of Nursing Education Scholarship*, 18(1). <https://doi.org/10.1515/ijnes-2021-0029>

Edwards, Allison P., Cron, Stanley, & Shonk, Cameron (2022). Comparative effects of disability education on attitudes, knowledge and skills of baccalaureate nursing students. *Nurse Education in Practice*, 61, 103330–103330. <https://doi.org/10.1016/j.nepr.2022.103330>

¹⁹ Vanderbilt Kennedy Center. (2022). *Vanderbilt University Medical Center: LEND brochures and flyers*. <https://vkc.vumc.org/vkc/resources/lend/>

²⁰ IntellectAbility. (2022). *Curriculum in IDD healthcare e-learn*. <https://replacingrisk.com/curriculum-in-idd-healthcare-elearn/>

Edwards, A. P., Hekel, B. E., & Cron, S. (2021). Disability Attitudes of Nursing Students: A Curriculum Intervention. *Nursing Education Perspectives*, 43(4), 255-257.
<https://doi.org/10.1097/01.NEP.0000000000000870>