Preparing Nurses to Care for the Whole Person Living with a Disability

Despite 26% of the U.S. population living with a disability and an increasing number of developmental disabilities among children, a survey of the Council on Education for Public Health of accredited health professions schools indicated that only half of the schools incorporated disability content in at least one class (Sinclair et al., 2015). In addition to the inattention of disability content and preparation in curricula, negative implicit attitudes existed among all levels of health care professionals and students (Wilson & Scior, 2014). Most alarming, surveys of medical, nursing, allied health and social work students have shown that nursing students have significantly more negative attitudes toward people living with disabilities (PWD) than other disciplines (Kristotakis et al., 2017, Temple & Murdoch, 2012). Nursing students have been theorized to mirror less than positive attitudes toward PWD similar to that of the general population. Polikandrioti et al., 2020 has asserted that nursing student attitudes toward PWD can be improved through education.

Deficiencies in health care professional education pertaining to the care of PWD contribute to inadequate care and persistent disparities (Ankam et al., 2019, Krahm et al., 2015). There is a preponderance of evidence that education and curricula is grossly deficient across schools of nursing in the care of PWD. In addition, education is provided sporadically for selected disabilities and does not include interprofessional collaboration or a perspective across the lifespan (Geckil et al., 2017). Consequently, many health care professionals are not knowledgeable about primary healthcare needs, prevention and management of secondary health conditions, the transitions of care from pediatric to adult health services, and the challenges related to aging among PWD (Field & Jette, 2007, Krahm et al., 2015, Merten et al., 2015, Okoro et al., 2018). Nursing faculty have also contributed to less than positive student experiences with PWD exacerbated by limited clinical opportunities among PWD (Gillespie & McLaren, 2010).

Multiple international studies validate the positive impact of disability education and clinical exposure on health care professionals’ attitudes, confidence, competence, and comfort in the care of PWD (Anderson et al., 2011, Castro et al., 2017, Hensel et al., 2015; Levet–Jones et al., 2017; Smith et al., 2016). Positive attitudes are influenced by previous exposure to or care of PWD, education, and clinical experiences specific to care of this vulnerable, underserved population. Nursing curricula that includes disability content have demonstrated statistically significant improvement in attitudes and desire to work with PWD (Carne et al., 2021; Symons et al., 2014).

Consistent with national objectives delineating the need for improved education and preparation of health care providers in the care of PWD; Healthy People 2020 (2010), the Institute of Medicine (2007), the Surgeon General (Carmona et al., 2010) and the National Council on Disability (2009), a co-curricular clinical opportunity, approved by the baccalaureate council, for prelicensure nursing students was developed. This Disability Fellowship was developed to address the gaps in education and training ensuring the next generation of nurses will transition to practice competently with requisite Attitudes, Skills and Knowledge assuring delivery of quality care for PWD. The Disability Fellowship is a programmatic innovation offered to first semester senior nursing students providing them with a clinically immersive experience in the care of PWD. The curriculum embody the importance of teaching communication etiquette and ‘person first’ principles. The fellowship consists of a 2-hour course credit comprised of 90 hours of multimodal and comprehensive educational activities. Seven cohorts of students, over the course of the past 2.5 years, have participated in this experience with rotations to primary, secondary, and tertiary care facilities caring for a variety of disabilities and co-morbidities.

Team Collaboration and Sustainability
Following an intensive review of Cizik School of Nursing’s (CSON) current BSN curriculum, a significant deficit in PWD content was revealed. A think tank of interprofessionals and healthcare stakeholders in the 4th largest and the most diverse city in the US was organized to identify priorities to establish the curriculum. The goal was to
design the necessary program components aligned with the mission and vision of CSON and to transform the care of the PWD. Curricula were derived using the Core Competencies on Disability for Health Care Education established by the Alliance for Disability in Health Care Education (2019). These competencies parallel those of the Interprofessional Education Collaborative (2011) encompassed in general concepts outlined by the Health Professions Accreditors Collaborative (2019) as well as the recent competencies identified by Kronk et al. (2020). The faculty coordinator, Dr. Allison Edwards, served on the Alliance for Disability in Health Care Education to establish national competencies and is currently serving on a National Consortium Action Network for Education, Practice and Policy via the Partnering to Transform Health Outcomes with Persons with IDD Project (PATH-PWIDD). PATH-PWIDD is a national, cross-sector consortium of advocates, healthcare providers, community-based workers, leaders in health care workforce education, policy experts, and academics representative of schools of nursing and interprofessional practice partners in several regions. The consortium’s goals are to develop and integrate high-impact and inclusive learning activities into an interprofessional education (IPE) curriculum, ultimately developing a more competent healthcare workforce better equipped to care for PWIDD. As evidence of the scalability and interest in the curriculum, Dr. Edwards was invited to present the Fellowship to PATH-PWIDD. The immense variability in the health of PWD poses unique challenges to educating nursing students, but the comprehensive multimodal approach offered through the Fellowship in a variety of settings provided a rich ground for critical thinking skills application. Over 15 legal clinical affiliations were secured to address the variety of disabilities prevalent in the population including camps, clinics, and settings specific to the care of Autism, primary care, developmental disabilities, spinal cord injuries, acquired/occupational related injuries resulting in amputations, day/residential/group homes/work supported environments for PWIDD, and a pediatric disability inpatient setting. Preceptors at the various sites worked extensively across disabilities and partnered with Dr. Edwards to offer robust clinical experiences aligned with the core competencies. Additionally, a primary care clinic sponsored by Baylor College of Medicine housed in a residential/day facility established in 1950 was initiated following noted gaps in addressing PWD primary care needs. The busy clinic serves an average of 1,000 individuals monthly through supported employment, day, residential, primary care, and dental services for PWD. First semester senior students who participated in the past two years have cumulatively completed 4,230 clinical hours and education in the care of PWD. Program sustainability is assured through an endowed fund established in 2016 that supports tuition for participating students.

Curriculum Based Catalyst for Change
The acquisition of improved knowledge, attitudes, and skills derived from this immersive experiential disability education experience has been disseminated through peer reviewed education journals. Additionally, the curricula template has been published in the Journal of Nursing Education (Edwards, 2021) and disseminated through national avenues such as PATH PWIDD conference (2022) as well as through interprofessional advocates and institutional partners (Caring Minds, 2019; UTHouston News, 2019; Summer Health Professions Education Program 2019, 2020, 2021). Positive testimony from past student participants, course evaluations, and sustained enrollment is also evidence that the Fellowship serves as a catalyst for change within the nursing curriculum. This innovative Fellowship aligns with the University of Texas Health Science Center at Houston’s Mission and Vision in the promotion of individual health and community well-being by addressing a prevalent population that is underserved: “To educate health science professionals, discover and translate advances in the biomedical and social sciences, and model the best practices in clinical care and public health. We pursue this mission to advance the quality of human life by enhancing the diagnosis, treatment, and prevention of disease and injury, as well as promoting individual health and community well-being.”

Further, the Fellowship was recently recognized as part of an interprofessional grant awarded by the American Dental Education Association GIES foundation (ADEAGIES) to educate health care professionals on the
importance of oral health for people with disabilities. ADEAGIES foundation is an ‘incubator of innovation and structures its philanthropic work around an actionable call to advance dental education.’

Evidence of Scalability, Replication, and Dissemination
The use of established competencies to develop knowledge-based outcome measures and tools to evaluate skills in the clinical setting can feasibly be integrated into curricula for replication by other health professional academic centers. The structure of this innovative education intervention accommodates all schools by enabling course credit to be obtained as an elective or independent study, providing precepted experiences, and providing learning opportunities that are both asynchronous and synchronous. Additionally, educational resources from the Center for Disease Control and Prevention (physical/sensory and developmental modules), Fatal Five, and Paralysis Resource Guide published by the Christopher and Dana Reeves Foundation are available at no charge.

Research studies and clinical papers pertaining to the impact of disability education on nursing students have both addressed the gap in education and emanated from the fellowship. See Edwards, Allison P., Hekel, Barbara and Cron, Stanley, 2021; Edwards, Allison & Hekel, Barbara, 2021; Edwards, Allison, 2021; and Edwards, Allison, Cron, Stanley and Shonk, Cameron, 2022.

Alignment with American Association of Colleges of Nursing’s (AACN) Vision and Mission
Faculty and educators should incorporate disability curricula utilizing this innovative program as a framework. It has been found to improve confidence, competence, and advocacy for nursing students especially in the areas of communication and skills application (Domain 2). When nursing students transition to practice, irrespective of employment location, they will encounter people living with a disability and will be prepared to care for this prevalent population (Domain 3). Adopting disability education is justified in the literature and accompanied by specific competencies which frame various methods for exposing nursing students to this vulnerable, underserved population. Advocacy for PWD begins with exposure of students through education and role models which must precede development and implementation of policies. (Domain 3).

Demonstration of the Advancement of Professional Nursing Education
Published quantitative research using the pre and post student participation surveys showed improvement across all measures for knowledge, attitudes, and skills with the largest increase being in skills. At baseline, the majority of students felt that disability education was insufficient in nursing school. Qualitative analysis of five cohorts revealed the emergence of three predominant themes for PWD care: value of the learning opportunity, a shift in perspective, and heightened awareness. End of semester course evaluations with selected course criteria rated on a Likert scale from excellent=4, above average=3, average=2, and needs improvement =1 revealed teaching methods utilized to help understand course content and the overall course were excellent, evidence based information presented within the course and fostered critical thinking were excellent range, and 100% of the respondents rated the course as excellent in developing their competencies in specific skills Comments included: “hands-on skills, exposure to many different environments/patients and professionals, an encouraging learning environment,” “amazing clinical placements, great resources for learning about people with disabilities,” and “I truly believe I have learned more from this fellowship than I have learned from any of my clinical experiences thus far.” The acquisition of improved knowledge, attitudes, and skills derived from this immersive experiential disability approach enhances student’s readiness to innovate the provision of care for those with disabilities through evidence based, patient-centered practice and quality of care.

References:
https://docs.google.com/document/d/1FncG_gC2Yr0qpNRP83dpm7W0myF7ijWQ/edit?usp=sharing&ouid=114853377260864375967&rtpof=true&sd=true