

State of the Profession

The Landscape of Disability Justice, Health Inequities, and Access for Patients With Disabilities



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The nursing profession can both perpetuate inequities and elevate the discourse around disability. Our article uses an intersectional lens to discuss the scope, magnitude, and determinants of health inequities that people with disabilities experience and the ways in which theoretical models of disability used in nursing education can further contribute to inequities. Our article makes the case for an intersectional social justice approach to nursing education by contextualizing the current state of affairs within historical and contemporary models of disability. This has the potential to be a revolutionary leap toward promoting health equity and upholding the *Code of Ethics*. **Key words:** curriculum, disability, diversity, inclusion, intersectionality, leadership, nursing education, social justice

THE CENTERS FOR DISEASE CONTROL and Prevention (CDC) estimates approximately 53 million (1 in 5) American adults live with a disability, and given the growing elderly population, that number is expected to increase.¹ Historically, patients with disabili-

ties (PWD) have been underserved in the US health care system, including but not limited to inequitable access to clinical and preventative care, or public health and wellness initiatives. On the part of health care providers, limited skills in diagnosing, treatment, and providing ongoing care create and exacerbate health inequalities.²

According to the Institute of Medicine (IOM) report, *The Future of Disability in America*, little progress has been made to “prepare healthcare professionals to address problems and issues related to disability and chronic disease.”³ Nevertheless, there is an ethical, moral, and legal obligation for nursing educators to prepare the next generation to uphold Article 25 of the United Nations Convention on the Rights of Persons with Disabilities, which reinforces the rights of persons with disabilities to attain the highest standard of health care.⁴

People with disabilities in the United States, particularly before the advent of the Americans with Disabilities Act (ADA), faced unequal access to health care, including a lack of access to ramps, bathrooms, examination tables, and sign language interpreters in

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We acknowledge and honor the tireless work of disability activists and scholars, particularly those with multiple intersectional identities in advancing the cause of health, health care equity, and access for people with a wide range of disabilities and who are made to experience inequities on a daily basis. We also acknowledge our positionality as a team with a mix of abilities, privileges, and marginalized identities. We put forth our work mindful or cognizant of our own social locations and privilege with regard to disability.

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Statements of Significance

What is known or assumed to be true about this topic:

People with disabilities face a higher risk of health inequities than their nondisabled counterparts. Although people with disabilities comprise 19% of the US population, there is often minimal emphasis in health care provider education on structural factors that contribute to poor health outcomes in this segment of the population. Thus, the current approach to health care provider education can further exacerbate these inequities.

What this article adds:

We provide an overview of the health and health care access disparities faced by people with disabilities, followed by an overview of various models of disability with recommendations for the application of specific models to the nursing curriculum and nursing practice. Our article makes the case for an intersectional social justice approach to nursing education by contextualizing the current state of affairs within historical and contemporary models of disability. By doing so, we can better prepare future nurses to address root causes of inequity and to better care for people with disabilities.

medical facilities. In addition, they faced patronizing attitudes, minimization of symptoms, and a lack of recognition of the autonomy of PWD on the part of the health care provider. These preventable inequities in health care for PWD still persist today and put patients at risk for medical errors and preventable deaths, despite the legal protections in place.

Nurses across practice settings and specialties are in a unique position to fill the gap in health care access for PWD, particularly due to their positions of direct patient care in a variety of settings, case management, advocacy, and policy development. Furthermore, there

are a growing number of nurses with disabilities practicing in a wide variety of settings who are well positioned to provide quality care for PWD.⁵ It has been proposed that Florence Nightingale, often revered in the nursing profession for having established the first modern nursing school, had mental and physical disabilities, and her leadership can serve as a model for guiding the nursing profession forward.⁶ In 2015, of the US population with disabilities, 51% were within the working ages of 18 to 64 years and 7.6% were younger than 17 years. Given that the majority of PWD are or will enter the workforce, it is critical that they get the health care access they need in order to facilitate economic and political participation.⁷

Nurses comprise the largest segment of the health care workforce and play a significant gatekeeping role in schools and universities, clinics, hospitals, health departments, and beyond. A nursing workforce that implements inclusive practices and equitable policies can optimize the quality of life among those with disabilities and maintain this expectation among future generations of nurses. Such responsibilities are outlined in the *Code of Ethics*. In this article, we provide an overview of the health and health care access disparities faced by people with disabilities, followed by an overview of various models of disability with recommendations for the application of specific models to the nursing curriculum and nursing practice.

NEED FOR STRENGTHENED NURSE WORKFORCE CAPACITY

People with disabilities have historically not been recognized as a group that experiences health disparities. According to Krahn et al, "The IOM reported that health professionals are poorly prepared to meet the complex medical and psychosocial needs of PWD. However, disability competency is not currently a core curriculum requirement for nursing school accreditation or for receipt of federal funding."⁹

Furthermore, even when care of PWD is included in the curriculum, there is limited evidence in the literature that the curriculum frames care using a social justice approach. Transforming nursing education to be mindful of the needs of PWD includes a recognition of the health inequities faced by PWD. Some nurse educators have been able to implicitly situate their work within social inclusion, equality, diversity, and non-discrimination. A few have been able to explicitly integrate social justice principles by examining activism, social inequity, and critical pedagogy. The integration of an intersectional approach that integrates determinants of health can further student understanding of inequities experienced by PWD as well as provide students with tools to be more effective allies with the PWD community.

HISTORICAL CONTEXT

Health care professionals have related to PWD through various approaches and models. Prior to the 20th century, PWD were often institutionalized with inadequate care or support, reflecting the medical model of disability in which disability is situated in the individual and requires expert medical intervention.² In 1927, the Supreme Court upheld the state's power to conduct forced sterilization on women with disabilities. In the mid-19th century, due to media exposure, the movement for deinstitutionalization enabled ever-increasing numbers of PWD to live in the community. By 1935, Title V of the Social Security Act enabled children with disabilities to get access to medical and financial resources, and one-third of the Title V Maternal and Child Health Block Grant is dedicated to children with disabilities. In 1957, Congress authorized clinical demonstration programs supporting training programs for pediatric care for children with disabilities.⁹ Drawing on the successes of the Civil Rights and Women's Liberation movements of the 50s and 60s, PWD began to organize. The Independent Living movement advocated for the right to self-determination and deinsti-

tutionalization. In 1990, as a direct result of the Disability Rights Movement, the ADA was passed, enshrining in law the rights of PWD in multiple sectors for the first time. In 1999, the Supreme Court ruled that PWD had the right to live in the most integrated settings, fostering the social model of disability in which such disabilities are exacerbated by inaccessible social conditions.¹⁰ However, despite these hard-fought gains, borders and gatekeeping mechanisms remain across social institutions, including in nursing education.

HEALTH INEQUITIES EXPERIENCED BY PWD

Health inequities have been experienced by PWD and the deaf and hard-of-hearing in regard to provider-patient communication leading to chronic disease, communicable diseases, mental health, emergency preparedness communication and response, and interpersonal violence, among others.^{11,12} Tracking the epidemiology of disability is critical to improving services and preventing the incidence and prevalence of health inequities, and is supported by the Affordable Care Act (ACA): "Section 4302 of the ACA requires that any federally conducted or supported health care or public program must include separate data on disability status and require collection of disability-specific data regarding the barriers to health care experienced by PWD. It also directs HHS to identify locations where PWD access health care, including determining the number of providers with accessible facilities, accessible medical and diagnostic equipment, and the number of employees trained in disability awareness and caring for patients."¹³

Nationally, adults with disabilities are 4 times more likely to report their health to be fair or poor than people with out disabilities (40.3% vs 9.9%).¹⁴ There is a cascade of disparities leading to poor health outcomes: higher rates of adverse health conditions leading to disparities in attention to care needs, which lead to disparities in preventive care and health promotion practices. This

domino effect leads, to disparities in equitable access to health care, and finally to poorer health outcomes.¹⁵ For example, PWD were 2.5 times more likely to skip or delay medical care due to cost.

Population-level differences were found between people with and without disabilities concerning indicators of health care access, health behavior, and social determinants of health. Based on the Behavioral Risk Factor Surveillance System 2010, a nationwide, cross-sectional telephone survey assessing prevalence of risk factors and health behaviors, PWD were more likely to report needing to see a doctor but not doing so due to cost (27% vs 12.1%).¹⁶ According to the National Health and Nutrition Examination Survey 2009-2010, a nationwide, in-person survey of physical health using both physiometric and survey response data, PWD were more likely to report obesity in both children and adolescents (21.1% vs 15.2%) as well as adults (44.6% vs 34.2%).¹⁷ According to the National Health Interview Survey 2010, a nationwide, in-person household interview, PWD are also more likely to smoke (28.8% vs 18.0%).¹⁸

Results from these broad surveys are supported by smaller, more targeted studies of people with specific disabilities. For example,⁸ people with significant vision loss experience a greater prevalence of obesity, hypertension and heart disease, and cigarette use than the general public, indicating a need for accessible health education or intervention programs.⁸

Similar patterns of disparities have been noted among adults with cognitive disabilities. Adults with cognitive disabilities are almost 5 times more likely to have diabetes, almost 3 times more likely to have arthritis, and more than twice as likely to have cardiovascular disease and asthma.¹⁹ Adults with intellectual disabilities are more likely to be hospitalized for conditions such as asthma and diabetes that should be manageable on an outpatient basis.²⁰ It has also been noted that though chronic conditions do not have an obvious causal relationship with cognitive disability, poor health behaviors, inadequate

attention from health care providers, underlying prenatal influences, and chronic lifelong stress play a role.²¹

VARIOUS DETERMINANTS/DIMENSIONS OF HEALTH FOR PWD

So often in nursing education, the focus of patient care is at the individual level, thus maintaining the invisibility of the role that social institutions play in health outcomes of PWD. A closer look at the determinants of health helps to explicitly amplify the practices and policies of various institutions that inequitably impact the health of communities, including those with disabilities.

Barriers to access to health care for PWD

Based on data collected from more than 2300 primary care provider facilities in 18 of California's 58 counties, which serve approximately 2.5 million Medicaid enrollees (and an unknown number of non-Medicaid enrollees, since the majority of providers do not see Medicaid patients alone), it was found that "[only] 8.4% of provider sites have a height-adjustable exam table, and [only] 3.6% have an accessible weight scale . . . Wheelchair users are examined in their chair or offered a rug on the floor. Individual patients and medical staff risk injury in lifts, or patients are just turned away or told to bring someone to lift them next time."²² In addition, deaf and hard-of-hearing patients report poor patient-provider communication and inadequate access to interpreter services impacting the quality of health care education and treatment, and increasing the likelihood of acquiring or exacerbating the severity of multiple chronic and mental health conditions. Research points to a potentially decreased likelihood of cancer screening¹² or knowledge of HIV/AIDS treatment²³ and prevention.²⁴ Given the breadth of health inequities that PWD face, it is notable that multiple identities and social locations influence health status and experiences while engaging in the health care system.

Housing

A determinant of health that cannot be overstated is affordable and accessible housing for PWD.²⁵ Based on the 2018 budget cuts to the Housing and Urban Development proposed on May 23, 2017, an estimated \$2 586 487 will be cut from Section 811 Housing for Persons with Disabilities across the state of California.²⁵

Transportation

The National Aging and Disability Transportation Center highlighted a number of recent trends within the context of supporting the availability of accessible transportation options for PWD in its 2016 Transportation Trends Report. Safe navigation of public transportation is a concern; it encompasses issues such as physical stability and available space when entering or exiting vehicles, the degree to which caregivers of people with physical and developmental disabilities have fostered use of public transportation, and accessibility issues related to safety and lighting of sidewalks and the maintenance of accessible public transportation infrastructure.²⁶

Education

Formal schooling, recognized as a social determinant of health for PWD, is associated with income and overall health. The US Department of Education is required to submit annual reports to Congress describing the progress made toward providing free and appropriate public education to all children with disabilities. This is a provision of the Individuals with Disabilities Education Act, which has been laden with implementation breakdowns disproportionately impacting students of color with disabilities.²⁷ The National Council on Disability found that racial and ethnic disparities in disciplinary actions suggest implicit bias contributing to the school-to-prison pipeline and that local and state government entities are not consistently enforcing mandatory data collection and reporting.²⁷

Employment

The Office of Disability Employment Policy found that almost two-thirds of American Job Centers were not fully accessible to PWD. While almost all centers are physically accessible, only approximately half were programmatically accessible.²⁸ Physical accessibility includes the ability to enter and use facilities, programmatic accessibility is more complex. It includes employing a staff member with expertise about accessibility, availability of a benefits counselor, collaboration with other agencies or organizations that support PWD, and involving PWD in accessibility. The report found disparities by geography, noting that urban American Job Centers were more likely to be accessible than non-urban centers and that those operated by for-profit firms were more likely to be fully accessible than public-operated centers.²⁹

Family

While there has long been a research focus on the subject of raising children with disabilities, to the point where researchers are now starting to look at positive as well as negative impacts, less attention has been paid to the subject of being a parent with a disability. The 2012 report published by the National Center for Parents with Disabilities documented the struggles parents with disabilities face to retain custody of their children. Parents with disabilities face discrimination in the form of removal of children, loss of parental rights, difficulty accessing reproductive health care, and barriers to adoption.³⁰

Carcerality

Youth with disabilities are inequitably impacted by law enforcement intervention. The vast majority (85%) of incarcerated youth in the United States have learning and/or emotional disabilities.²⁴ Suspension rates for students with disabilities are also double (13%) the rate among their counterparts without disabilities (7%). The rates are even more disparate for students of color with disabilities.

The cumulative probability of arrest is greater among youth of color with disabilities, with black youth with disabilities experiencing the highest probability of arrest.³¹

THE HEALTH OF PWD: AN INTERSECTIONAL LENS

PWD are simultaneously individuals and members of socially stratified groups. As such, PWD are subject to various forms of oppression simultaneously and in ways that shift depending on their role, setting, and other factors. According to Kraus, “Disability rates vary by ethnicity, ranging from 10.4% among Asians to 22.6% among non-Hispanic black to 31.3% among American Indians and Alaska Natives.”⁷ There is a compounding effect among people of color who also have disabilities, and they experience greater health disparities than adults of color or PWD. They face an increased likelihood of depression, diabetes, stroke, obesity, decreased physical activity, difficulty with activities of daily living, and a decreased likelihood of workforce participation. In addition, more than 1 in 5 (21.2%) working-age Americans with disabilities live in poverty compared with 13.8% of Americans without disabilities.⁷

Although the life expectancy for people with Down syndrome has increased, even taking into account the gap in life expectancy between white and black Americans, the life expectancy for black people with Down syndrome is significantly lower than that of white people with Down syndrome. As of 1997, the life expectancy of a white person with Down syndrome is double that of a black person with Down syndrome (50 years vs 25 years).³²

According to Bowen and Gonzalez,³³ African Americans and Hispanics/Latinos older than 50 years are more likely to have a mobility disability than similarly situated whites, and also use hospital services more often than whites. There is a connection between race, disability, and poverty, in which PWD are less likely to get needed medical or dental care connected with financial hardship.³⁴

Barriers to satisfactory care occur at the personal, clinical, and health care system levels for women with disabilities. Although research found that women with disabilities had similar or better potential health care coverage and access than nondisabled women, they generally had worse realized health care.³⁵ They were also more likely to postpone receiving needed care in the last 12 months.^{36,37} Women with mobility impairments were significantly less likely to receive Pap smear tests and breast examinations.^{36,37}

THEORETICAL MODELS OF DISABILITY

Given the health and health care access disparities faced by people with disabilities, it is critical to consider the wide variety of education models currently emphasized in nursing education (Table). Nursing educators and the nursing workforce can cultivate an accessible mindset by incorporating innovative theoretical models of disability in the curriculum and applying it to nursing practice.

Over the course of history, PWD have been viewed through the lens of various models, including the medical model and expert/professional model/rehabilitation model, the tragedy/charity model, the social or minority model, empowerment/rights-based model/interactional social-political model, and the independent living model.³⁸ For the purposes of this article, we promote the intersectional justice framework and strength-based models.

Deficit-based models

Medical model

The medical model or expert/professional model, the most frequently used model in nursing education, as evidenced by its curriculum and educational materials, holds that disability results from an individual person's physical or mental limitations, and is largely unconnected to the social or geographical environments. In other words, disability is considered as purely a deviance from accepted medical “norms” and can be framed as

Table. Overview of Models of Disability

Model	Submodels	Historical Example
Social	Cultural model, minority model	Disability Rights Movement drawing on in the aftermath of the Civil Rights, Women's and Gay Liberation movements
Medical model	Expert/professional model/ rehabilitation model	Institutionalization pre-19th century, medical experts needed to intervene to care for disabled patients rather than fostering self-determination
Moral model	Religious model	Disability as embodiment of sin
Tragedy model	Charity model	Dickens' Tiny Tim, March of Dimes
Empowerment/ rights-based model	Interactional social-political model, independent living model	Independent Living Movement
Intersectional disability justice framework	Intersectional disability lens on racial, economic, queer, social justice models	Antioppression movements, including an intersectional lens on immigration, mass incarceration, and the environment

stigmatizing.³⁸ In this model, medical professionals are expected and encouraged to intervene and provide rehabilitative and curative services to minimize or lessen the disability.

The US government, medical practitioners, and psychologists have a long history of categorizing and classifying disability governed by the medical model. For example, from 1850 to 1920, the US census asked both free and enslaved adults questions related to disability including: "If this person was over 20 years of age, could they not read and write? Is the person 'deaf, dumb, blind, insane, idiotic, pauper, or convict?'"³⁹ In the medical model, PWD are classified as a stigmatizing other.

Some scholars posit that the medical model has led to low self-esteem, low self-worth, undeveloped life skills, poor education, and consequently high unemployment levels. It has also resulted in the segregation of PWD, thus breaking natural relationships with their families, communities, and society as a whole. PWD are seen as passive recipients of help.³⁹

Disability rights activists further posit that a focus on a cure and those with disabilities who have "overcome" their disabilities is harmful for PWD. Disability rights activists often reject the supremacy of medical professionals in decision-making and advocate

for the right to self-determination. The underlying assumption is that PWD, in order to be included in mainstream society, must manage to eliminate, minimize, or overcome their disability in order to be accepted.³⁸ Yet, while the medical model is the underlying framework for nursing education, practice, and policy, we recognize that there are nursing practitioners who partner with PWD in an empowering manner. Furthermore, there are PWD who welcome medical interventions to improve their quality of life.

Other PWD advocate for an emphasis on improving accessibility and inclusion rather than medical treatment or cures.³⁸ For example, a wheelchair user might prefer prioritizing removing physical and societal barriers to the inclusion of PWD rather than pursuing medical treatments, physical therapy, or funding curative research.³⁸

Tragedy model

In the tragedy model of disability, PWD are depicted as victims of circumstance who are deserving of pity, such as Charles Dickens' Tiny Tim character. A submodel, the charity model, sees PWD as victims of their "impairment" or deficit. In this framework, PWD are unable to lead an independent life or help

themselves and others, and are suffering. Consequently, they need special services, special institutions, such as special schools or homes rather than being integrated into society. In addition, PWD need sympathy, charity, welfare, and help and are not independent agents. Many PWD often internalize this concept and have a low self-esteem as a result of being treated according to this model.³⁹

Religious model

From a religious perspective, PWD may be seen as possible recipients of divine intervention curing them of their disability, or in need of charity or salvation. On the other hand, they might be perceived as sinners from the perspective of the moral model. In religious traditions that subscribe to reincarnation, disability is also seen as punishment from sins incurred from a previous life.⁴⁰

Strength-based models for nursing education

In contrast to the medical and tragedy models, there are a variety of proposed models for nursing education that can be further incorporated in the nursing curriculum.³⁸ However, even strength-based models can limit our understanding of inequities experienced by PWD.

Social model/minority model

The social model, also known as the minority model, sees disability as a socially constructed phenomenon.³⁸ This model states although a person's disability poses some limitations in an able-bodied society, oftentimes the surrounding society and environment is more limiting than the disability itself, which has particular applications to provider-patient interactions. Since the Disability Rights Movement in the 1960s was inspired by the civil rights and women's liberation movements, there was a recognition that PWD could draw strength from the experiences of people of color, people of low socioeconomic status, and linguistic minorities. The minority model recognizes that, as a group and individually,

PWD face prejudice, discrimination, segregation, or persecution.³⁸

The minority model recognizes the concept of ableism, in which people of disabilities are perceived as having traits that are viewed negatively by the dominant group. In addition, in this model, PWD are unable to benefit from able-bodied privilege and have involuntary membership usually from birth. The person with a disability may not be born into a family that can share that experience.³⁸

Empowerment/rights-based model

The empowerment-based model or interactional socio-political model sees disability not a tragedy or dependency but as a natural part of everyday life. In this model, disability is not considered a loss of potential, productivity, social contribution, value, or capability.^{41,42}

Independent living model of disability

As a part of the empowerment model, in the independent living model, a person with a disability is perceived as a responsible decision-maker with a fundamental right to choose. The independent living model allows for the person with a disability and loved ones to decide the course of treatment and what services they wish to benefit from. Most importantly, the independent living model advocates for the deinstitutionalization and mainstreaming of PWD as opposed to segregation.³⁹ This model stands in marked contrast to the institutionalization of PWD that was once favored by the medical model.

Intersectional justice framework

The social and structural barriers that PWD grapple with and navigate are not random. They embody the legacy and ongoing reproduction of oppression, privilege, and conceptualizations of personhood. We propose a social justice framework to center our gaze on socially, economically, politically, and legally constructed, and therefore changeable, dynamics. This lens is consistent with the value of social justice put forth by the latest edition of the American Nurses Association's *Code of*

Ethics. Utilizing a social justice framework includes the acknowledgement that the legacy of scientific racism, deployed to justify slavery and all manner of structural and interpersonal violence, remains across multiple systems of society, establishing social institutions as mechanisms for injustice. A number of scholars are examining disability with an intersectional lens, including de Beco,⁴² who proposes an intersectional perspective within the context of international human rights laws. Annamma et al⁴³ highlights the importance of an intersectional approach by proposing a theoretical framework through which both race and ability can be examined. Puar⁴⁴ invites and challenges us to reconsider the biopolitical dimensions of disability as a binary construct and to connect disability studies scholarship with critical race theory and postcolonial theory in “The Right to Maim.” This work examines the intersections of biopolitical, sexual, and economic factors that influence how disability is often categorized and describes the social control through concepts such as debility, disability, and capacity. Disability, asserts Puar, exists in relation to race, gender, war, labor, and governance. She also cautions against the reduction of disability through “neoliberal biomedical circuits” and human rights discourses focusing on empowerment.

An underlying premise of a justice-oriented approach is the centrality of the medicalization of disability, which serves both as a gatekeeper for resources, legal protections, and accommodations, but also constructs disability as a binary. Mia Mingus,⁴⁵ a disability justice activist, calls for an approach to disability that welcomes difference and seeks to dismantle the systems that hold firm to specific views of what is “normal.” Her examination of the “Medical Industrial Complex” seeks to map out the many moving parts that comprise and uphold the machinations of profit, exploitation, ableism, violence, trauma, and oppression. According to Puar, “Her analysis suggests that access to the identity of disability in this regard is a function, result, and reclamation of white privilege.”⁴⁴

Historically, leaders of disability movements have been white men with language, educational, and socioeconomic privilege. There is a growing movement to center the diverse voices of low-income PWD of color who identify as having multiple marginalized identities, including diverse immigration and language backgrounds, religious minority status, and lesbian, gay, bisexual, transgender, and queer (LGBTQ+) status.

Looking expansively, it is our aim to acknowledge not only multiple critical perspectives but also the intersectionality of disability in order to enrich the professional development of emerging and future generations of nurses and their capacity to contribute to future dialogues focusing on the various dimensions of theory, practice, education, and policy.

INTEGRATING NEW METHODS TO EDUCATE NURSES TO SERVE PATIENTS WITH DISABILITIES

One recommendation to improve the quality of care for PWD is to design educational modules and curriculum tools as well as competency standards for these programs. The Alliance for Disability in Health Care Education utilized the Delphi process to develop a set of nationwide competencies in consultation with 150 disability organizations, educators, and advocates. Additional pedagogical approaches include interdisciplinary efforts with disability studies scholars as well as including reading assignments where the voices, worldviews, and experiences of PWD are front and center, which is consistent with transformative social justice pedagogy. Competencies include professionalism and patient-centered care, conceptual frameworks on disability, awareness of the ADA, principles of team and systems-based practice, and assessment and clinical care over the lifespan.³ A collaborative effort between nurses and nurse educators with and without disabilities, as well as PWD, will significantly strengthen the nursing profession.

RELEVANCE AND URGENCY—HEALTH CARE FOR ALL

The ACA (2010) enabled hundreds of thousands of PWD, categorized as having pre-existing conditions, to become newly eligible and obtain insurance coverage. Insurers could no longer deny coverage to people with pre-existing conditions, charge higher premiums, or withhold care relating to preexisting conditions. In addition, insurers were no longer allowed to impose lifetime or annual dollar limits, which had a significant impact on PWD who need 24/7 care or who have complicated medical equipment, treatments, or surgical procedures. The Money Follows the Person (MFP) demonstration program, which allowed PWD to leave institutions and enter the community, was reauthorized and expanded. In addition, the Community First Choice option was established, which increased the amount of funds for states that provided or expanded home and community-based services. This allowed PWD requiring in-home care and outpatient or community-based services access to these essential services.

However, the ACA is at risk of being dismantled, which has disastrous implications for PWD. These implications include losing coverage due to preexisting conditions, losing coverage due to the unaffordability of premiums and the lack of subsidies, and losing the ability to live in their homes if the MFP program is defunded. According to Hall et al,⁴⁷ PWD are more likely to be employed if they have Medicaid coverage. Given the current instability and lack of certainty of the health care market in the United States and its deleterious impact on PWD, it is imperative that the disability community and their allies and colleagues in the medical and nursing professions embrace an intersectional approach.

CONCLUSION/CALL TO ACTION

A social justice framework that includes centering PWD as an essential part of the

medical process can advance health care for all patients. Including a disability justice framework as a standard part of nursing education will increase the capacity of the nursing workforce. In order to improve the quality of care for PWD, given the health inequalities faced by PWD, we support designing educational modules and curriculum tools as well as competency standards for nursing programs, which both prepare the nursing workforce to accommodate PWD and foster inclusion of nurses with disabilities. Nurse educators can follow the lead of the Alliance for Disability in Health Care Education by responding to 2 critical gaps: the need for strengthened health and human services workforce capacity and the need for educating health care providers to serve PWD. In addition, we advocate for ongoing discussion of the care of PWD from the social justice lens and intersectional model, and intentional concerted efforts to dismantle the paternalistic approach among nursing students, faculty, administrators, and researchers. Toward this end, we propose incorporating an intersectional justice framework in nursing training, including updating curriculum materials such as textbooks, presentations, lectures, and classroom activities. An intersectional disability justice framework could include the development or improvement of existing modules including PWD in standard nursing practice or education and tying it with an experiential rotation at a site serving children and adults with disabilities. Such an approach could foster enthusiasm among potential nurses to specialize and seek out work with specific populations of PWD as well as foster support for nursing peers with disabilities. In addition to changing theoretical approaches, we acknowledge further work needs to be done to address issues regarding inequities in care for PWD. This includes ensuring the representation and participation of people with disabilities and addressing the need for strengthened health and human services workforce capacity.

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