

Overview and Summary: Addressing Disabilities in Healthcare

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Overview

Eleven years ago, after a monochorionic-diamniotic twin pregnancy that included twin-twin transfusion syndrome, selective intrauterine growth restriction, fetoscopic laser photocoagulation surgery, and finally preterm birth, I found myself mother to two very tiny and premature twin girls. Several years later I would further learn that one twin also has a previously unknown genetic difference which has caused additional health conditions and disabilities. Consequently, my introduction to motherhood also included a crash course in the navigation of the medical system in a space that is established for the “normate,” or the typical body ([Garland-Thomson, 1997](#)).

Persons with disabilities (PWD) face some of the greatest health disparities including decreased life expectancy ([Forman-Hoffman et al., 2015](#)); increased risk of chronic disease such as diabetes, cardiovascular disease and cancer ([Dixon-Ibarra & Horner-Johnson, 2014](#)); and are more likely to have health care needs unmet ([Casey, 2015](#); [Hwang et al., 2011](#)) and forgo necessary care ([Temple et al., 2020](#)). Existing gender ([Mulcahy et al., 2022](#)), racial/ethnic ([Akobirshoev et al., 2020](#)), and rural ([Iezzoni et al., 2006](#)) health disparities are exacerbated among PWD. Barriers to care for PWD are many and include inaccessible medical equipment ([Story et al., 2009](#)), inadequate health profession training/preparation related to caring for PWD ([Ankam et al., 2019](#); [Edwards & Hekel, 2021](#)), and underrepresentation of PWD among health care providers ([Rastogi, 2021](#)). Another fundamental obstacle to appropriate care includes communication challenges between providers and PWD ([Iezzoni, 2006](#); [National Council on Disability, 2022](#); [Sharby et al., 2015](#)), as well as negative attitudes among health care professionals towards PWD ([Edwards & Hekel, 2021](#)).

Fortunately, progress towards addressing these disparities and barriers to care is starting to be made. In the United States, federal agencies such as the National Council on Disabilities (NCD) have set forth policy frameworks outlining the critical steps to address disparities and barriers to care ([NCD, 2022](#)). The World Health Organization ([WHO, 2021](#)) and the United Nations Convention on the Rights of Persons with Disabilities ([United Nations, 2022](#)) work to address these challenges internationally. Within health professions education, core competencies for curricula related to training health care professionals to effectively care for PWD have been established ([Havercamp et al., 2021](#)) and disability-focused curricula have been implemented in some health professions programs ([Edwards & Hekel, 2021](#); [Santoro et al., 2017](#)).

As part of their critical roles as providers, educators, and scholars, there is much that nurses can do to assist these efforts to advance healthcare for PWD. The articles included in this OJIN topic add resources and provide examples of nurses working towards this endeavor. These articles provide practice guidance for working with multiple populations including adults and seniors with Autism Spectrum Disorder (ASD) ([Kartoz et al.](#)) and children with disabilities in educational settings ([Johnson](#)). Next, [Abbott](#) provides a primer to current standards regarding inclusive language, to help us ensure our language does not perpetuate discrimination and stigma. [Marks and Sisirak](#) provide a compelling explanation of what patients, colleagues, and the field of nursing can gain when education and employment for nurses with disabilities is truly inclusive and accessible. Finally, we focus on the power of scholarship ([Ailey](#)), specialized nursing ([Rees et al.](#)), and international collaboration ([Fisher et al.](#)) to affect changes for people with intellectual and developmental disabilities (PWIDD) and are inspired to adopt similar models across multiple settings and populations.

While much research concerns the increasing prevalence rate of ASD in children, [Connie Kartoz and co-authors provide critical information](#) on the often-understudied population of adults and seniors with ASDs. Few standards exist to guide providers on ways to consider the multiple intersecting elements that must be considered when caring for adults and seniors with ASD. For example, adults and seniors with ASD may differ in their ability to perform activities of daily living, which can have important implications for managing chronic medical or psychiatric conditions. Adults and seniors with ASD often have higher rates of such comorbidities, some of which may extend beyond childhood and others are associated with the aging process. Nurses should also consider the role of the family as well as the lived experience of adults and seniors with ASD when planning and providing care. [Kartoz et al.](#) provide practical guidance and considerations to promote individualized, patient-centered care for adults and seniors with ASD.

Next, [Kathleen Johnson demonstrates the importance of an interdisciplinary approach to healthcare and education](#) to ensure an accessible and successful educational experience for children with disabilities. Johnson describes through a case study the essential role that school nurses play in the interdisciplinary team, often acting as a linchpin between the child,

parents, healthcare providers, and educators. School nurses can explore issues related to absences, provide referrals, ensure a safe environment, and help manage health conditions at school for children with disabilities. Johnson provides resources and guidance to assist school nurses and other team members in their efforts to ensure that children with disabilities have equitable access to education.

Nurses' awareness of and use of inclusive language is crucial given the extent of communication challenges between providers and PWD. [Miriam Abbott provides an invaluable resource comparing six current inclusive language standards](#) across three different guidelines from the Centers for Disease Control and Prevention (CDC), the American Psychological Association (APA), and the American Medical Association (AMA). Abbott compares recommendations regarding current topics such as person versus identity first language, pronouns, disability, and specific disabilities such as visual impairment. While some differences exist across the guidelines, Abbott explains that all recognize that language changes and these resources should be used as a guide rather than a mandate. Ultimately, Abbott reassures us that, while mistakes will be made despite best intentions, the goal is to be open, ask when you are unsure of preferences, and be willing to learn and adapt as new speech patterns evolve.

As we work to shift our language regarding disability, so too must the field of nursing modify attitudes and practices to make education and employment for nurses with disabilities inclusive and accessible. [Beth Marks and Jasmina Sisirak describe the many benefits of appreciating disability](#) as natural variation and a value-added attribute that contributes to diversity of a workforce rather than something that needs to be fixed or ignored. Educating and employing nurses with disability will create better concordance between PWD and their health providers, increase visibility of disability, and expose ableism. Appreciating and valuing the lived experience of nurses with disability includes recognizing these individuals as colleagues who have important insights to share, working towards cultural humility, reducing barriers in education and the work environment through the principles of universal design, and actively recruiting, hiring, and retaining nurses with disabilities.

The next series of articles in this topic focus on the work that has been done to address some of the long-standing health disparities faced by persons with intellectual and developmental disabilities (PWIDD). [Sarah Ailey and Tanya Friese demonstrate the power of scholarship](#) that engages with the disability community to affect changes. Ailey and Friese describe how they have used the Boyer Model of Scholarship, which includes discovery, teaching, application, and integration, at a graduate school of nursing to improve clinical care for PWIDD. They describe how graduate student projects and engagement of partners from the disability community have been able to address health disparities for PWIDD at a micro, meso, and macro level; indeed, their medical center's work to provide individualized care now serves as a gold standard in acute care for PWIDD.

The United Kingdom has developed another approach, specialist community learning (intellectual) disabilities nurses (CLDNs) to address health disparities for individuals with PWIDD. CLDN is a nurse specialization that focuses on ensuring adequate care is provided for PWIDD, especially in hospital settings. To better understand their role in Wales, [Stacey Rees and Ruth Northway conducted a qualitative study with 14 CLDNs](#). Using a critical incident technique, Rees and Northway's work reveals four themes related to the work of CLDNs: proactive/preparatory work, therapeutic relationships, coordination, and influencing healthcare/outcomes. The work they perform facilitates appropriate care while addressing the many barriers to treatment for PWIDD. This incorporation of CLDN as a nurse specialization can serve as an example for other countries to improve care for PWIDD and other populations.

Finally, [Kathleen Fisher and colleagues describe how, spurred by the alarming outcomes for PWIDD during COVID-19](#), they joined forces to address longstanding health disparities experienced by PWIDD. They created the Global IDD Nursing Collaboration, an international nurse research collaboration focused on improving health disparities for PWIDD. The collaboration spans multiple countries and provides a mechanism for nurses to share, learn about, and advocate for practices and policies that differ across locations. For example, nurse navigators in Australia and nurse liaisons in several countries provide services to facilitate care for PWIDD, yet no similar role exists in the United States or Canada. Similarly, the United Kingdom and Ireland are more advanced than most countries in their provider education related to PWIDD, providing IDD-related pathways and specialties. The Global IDD Nursing Collaboration can serve as a model for promoting person-centered care for PWIDD by sharing research, education, practices, and policies.

The journal editors invite you to share your response to this OJIN topic addressing Disabilities in Healthcare either by writing a Letter to the Editor or by submitting a manuscript which will further the discussion of this topic which has been initiated by these introductory articles.

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