

Game Changers

Nurses With Disabilities Work to Dispel Bias in Health Care

By Janet Edwards



As an avid climber, crawling high into trees didn't seem like such a risky proposition to Michelle Kephart, RN, MSN. However, midway through her nursing program, Kephart fell 25 feet from a tree, injuring her spinal cord. Returning to nursing school amid skepticism from the faculty, and with no idea how her quadriplegia would impact her education, Kephart found the support she needed in the National Organization of Nurses with Disabilities (NOND).

"I still wanted to be a nurse, but just didn't know how. I was looking for any kind of resources," Kephart says. "NOND really helped me in finding out what my rights were and what I could expect from the school—what sort of accommodations they could make and what was reasonable to ask from them in order for me to finish my program."

Kephart, who graduated from nursing school in 2010 and joined the NOND board of directors that same year, was happy to learn such a resource exists. "I don't think I would have been able to get through nursing school without their help," she says.

Many nurses who acquire disabilities after licensure don't

know they can continue working, says Karen McCulloh, RN, a longtime disability advocate that is both hearing and visually impaired. "The message many nurses with disabilities receive is they don't have a place," she says.

McCulloh co-founded NOND, an Illinois-based national organization. She served as its first president and continues to serve as a member of the board's executive committee. She also serves as the project director of the LEAD Center at the National Disability Institute in Washington, D.C., funded by the Dept. of Labor Office of Disability Employment Policy (ODEP). McCulloh also serves on the AbilityOne Commission as a President Obama appointee.

NOND evolved out of a 2003 national symposium directed to address nursing students with disabilities, McCulloh says. Among the attendees were nurses, nursing organizations, physicians, nurse educators, legal experts, disability rights advocates, and other health care professionals.

McCulloh recalls, "The whole topic of inclusion was controversial. It was an exciting but tense conversation in regard to both bias and acceptance." After hearing a nurse educator say,

“The courageous thing that nurses with disabilities can do is to retire,” she realized it was time for nurses with disabilities to step up and speak for themselves. McCulloh says she was excluded from nursing for nearly 13 years because of having multiple disabilities. In response, she says, McCulloh set up her own for-profit small business where she developed a new area of nursing, Community Health Disability Education.

Empowered by that discussion, McCulloh brought five nurses with disabilities together, without a mission or bylaws, and identified symposium attendees they wanted to recruit to the board of directors—15 members were recruited by the end of the day. “We were at the right place at the right time and with the right people,” McCulloh says.

The majority of board members are now nurses with disabilities, “proving the stereotype wrong,” says McCulloh. About 200 members are active in the organization’s advocacy, education and outreach efforts, which have broadened beyond nursing to include other careers in health care and underserved populations.

In an effort to enhance opportunities for people with disabilities to enter healthcare careers and become employed in healthcare industries, NOND was accepted by ODEP as an Alliance member in May 2011.

Nurses with disabilities face stiff challenges in their journey to become accepted and those objections often begin with misperceptions by nursing faculty, says Beth Marks, PhD, RN, president of NOND. Marks is a research associate professor and director of the HealthMatters Community Academic Partnership, and is co-producer of the film, *Open the Door, Get ‘Em a Locker: Educating Nursing Students with Disabilities*.

“Despite the potential for students with disabilities to enrich the nursing profession, nurse educators may be perpetuating historical attitudes, values, and practices that exclude students with disabilities from gaining admission or identifying themselves as people with disabilities,” Marks wrote in “Cultural Competence Revisited: Nursing Students with Disabilities,” a *Journal*

Parul Arora, RN, BSN, also a NOND board member, had nearly completed her nursing program when she first heard about the organization. It was exactly what she was looking for—a community that would inspire her to persevere. As a low-vision person, she had faced strong faculty resistance throughout her nursing education, a second-career path that followed six years in social work.

“I needed to see nurses with disabilities that were successful. You want to be inspired by people who have had obstacles who are successful,” she says. “In any program you have to prove yourself, but I had to prove myself more than my fellow students.”

It was dispiriting, but Arora says she learned a lot about herself, including how to be her own advocate “because no one else would do it.”

Kephart retains some function in her shoulders and arms, but no hand movement and no movement below her waist. After her injury, she resumed nursing school, but with some stipulations.

“I was allowed to return for one semester and take half a class load to see if I was capable of handling it,” she says. “I took two classes and did really well. Then we had to start talking about how I would get through my clinical experience. I’ve lost all my hand function so I don’t have any dexterity.”

During clinicals, she was provided an assistant who did everything under Kephart’s guidance. “If I had to use a stethoscope on somebody that was in a hospital bed and I couldn’t reach them, she would help me place it on his chest so I could listen. Or, if we were giving meds through IVs, she could set up the IV under my direction and I could watch what she was doing because I couldn’t reach it. We worked as a team, that was the accommodation I got.”

The assistant stayed with Kephart for the first three weeks of her clinical rotation, “but then we realized there wasn’t much she needed to do. I was able to do everything I needed to do, but we didn’t know that until we got out there and tried,” she says.

What people perceive as the role of nursing paints too narrow a picture, Kephart says.

“There are a lot of types of nurses. People only think about being a bedside nurse and them giving shots or drawing blood, but I think if people start to realize that there are so many more ways to be a nurse they’ll be more accepting of nurses with disabilities in general.”

Marks says the emphasis is misplaced when considering a student’s potential success in a nursing program. “As we accept and accommodate people with disabilities as nursing students and professional nurses, we will

discover that a student’s success is highly dependent on the availability of accommodations, not the type or severity of disability,” she wrote in the *Journal* article.

Arora did her clinical rotations with a pocket full of magni-

“When you have people that are very successful ... people who can say ‘this is wrong’—that’s a game changer.”

Parul Arora, RN, BSN



of Nursing article. “Educators in nursing schools continue to ask whether people with disabilities have a place in the nursing profession, while the more salient question is, ‘When will people with disabilities have a place in the nursing profession?’”

fiers and attachments that she bought on her own. She used one magnifier that fits on syringes so she could fill them properly, another for reading lab value reports and other small print, and a hands-free magnifier for miscellaneous tasks. She also found a computer screen device that reduced glare and offered some magnification.

Software that provides better onscreen enlargement capability is available. When Arora asked about having the software installed on the hospital's computer, she was told her faculty would need to request it. "When I asked the faculty, they never pursued it," she says.

"I purchased all these things because I wanted to be successful and I didn't want to make any errors," she says. "It's not rocket science, but there are so many different tasks it can be difficult to figure out which device works best with this syringe or what works best with that task." Learning how to accommodate on her own, while trying to master the practice

this person *not* do?' as opposed to 'What are the strengths this person brings to the situation?'

That's because "safety" is a major buzzword, Smeltzer says, and while health care providers and faculty assume safety issues are a concern when it comes to nurses with disabilities, that's simply not the case.

"There's no research to suggest that they're any less safe than health care providers without disabilities. But nevertheless that's what people go to, it's a safety issue – well, no, it's not. It's an attitude issue."

As a student, Arora frequently questioned her decision to pursue nursing. "I love the field. I have the qualities for it, but I thought, 'Maybe they're right, maybe I shouldn't be a nurse because ... it's more difficult for me.' You need others to believe in you, for you to believe in yourself," she says. "It was a constant advocacy in my head: 'You can do this. I'm smart enough. I have good qualities and I can go forward.'"

Kephart, who lives in Georgia, is now an adjunct faculty member in the medical assistant program at South University teaching classes in medical terminology and clinical competency, among others. She is also an educator in disease management and wellness at Community Health Mission.

When she first began teaching, Kephart wasn't sure what to expect. "I was a little nervous, but the students have been wonderful," she says. "It probably startles them when they first see me, but once we start talking about what they're learning and the reason that they're there, they

forget that I'm talking to them from a wheelchair."

Arora is completing her master's program in nursing, while working at NorthPointe Resources in Zion, Ill. As part of her job, she works on a diabetes prevention project for children and adolescents with intellectual and development disabilities, often giving presentations. "In my new job, there's no resistance, it's amazing. I don't drive. The job requires it but my colleagues have bent over backwards. Two others on my team do the driving and they're very willing," she says.

Her experience with NOND during her own struggle to become a nurse has impassioned Arora to reach out to young people with disabilities as a mentor and a resource. "I hate to say this, but my story is not unique. However, when you have people that are very successful and have tons of experience ... people who can say 'this is wrong' – that's a game changer. Sometimes you don't know the treatment you're getting or the obstacles in your way are wrong."

McCulloh agrees: "Often, we do not realize the power of experience and how that experience can make such a difference for opening opportunities for others." ●

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Janet Edwards is the editor of INSIGHT Into Diversity magazine.

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Michelle Kephart,
RN, MSN (*front row, left*)



of nursing, was a hardship, she says.

While Arora anticipated the clinical faculty might not know how to accommodate her disability, the level of resistance she encountered surprised her. "They had this attitude, 'How is this girl going to be a nurse?' and not so much, 'How can we help her be successful?'"

McCulloh acknowledges that relinquishing the traditional model of nursing is a challenge for schools, but is quick to point out that "Some faculty have been quite supportive of connecting students with student disability services to obtain accommodations for their success in a nursing program."

Existing faculty resistance results in part from weak enforcement of the American Disabilities Act, says Suzanne Smeltzer, EdD, RN, FAAN, professor and director of the Center for Nursing Research at Villanova University.

"The law is not enforced very rigorously. As a consequence, unless someone with a disability is really committed and willing to take it to the next level, if he or she is stopped at the schoolroom door the individual may turn around and try someplace else, or they may say, 'Well, I guess I can't do nursing.'"

Fellow health care providers perpetuate an additional obstacle, Smeltzer says. "Health care professionals think about, 'What can