

COLLEGIUM



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With the creation of the new Golisano Institute for Developmental Disability Nursing, the Wegmans School of Nursing will transform the way nurses treat the unique needs of individuals with developmental disabilities (DD).

Made possible through a \$5.8 million gift from Tom Golisano, founder and chairman of Paychex, and the Golisano Foundation, the Institute is the first of its kind in the United States.

Dr. Dianne Cooney Miner, founding dean of the School of Nursing, is leading the Institute. Leveraging Fisher's current partnerships with universities around the globe and carrying the Golisano name—which brings its own seal of excellence among those in the developmental disability care sector—the Institute intends to have an international impact on nursing education by creating an adoptable model of care focused on a population that, research shows, has experienced significant health disparities and a severe lack of access to both primary and specialized care.

Revealing a Need

Established in 1985, the Golisano Foundation works to create a better world for people with intellectual and developmental disabilities. Today, it is one of the largest private foundations in the nation devoted exclusively to ensuring those individuals experience an enhanced quality of life. Tom Golisano understands firsthand the gaps that exist in care and support for this population, as his son was born with a developmental disability.

“Tom’s commitment and passion for improving the lives of people with developmental disabilities stems from his own experiences, and he looks for experts in the field to deliver the right services and programs to do that,” said Ann Costello, executive director of the Golisano Foundation. “He wants these efforts to be as good as they can be because he knows how tremendous the need is for families.”

Golisano and the Foundation have worked in collaboration with Special Olympics, the world’s largest global public health organization serving people with intellectual and developmental disabilities. Golisano’s support of Special Olympics Health has expanded access to health care globally through Healthy Athletes health screening programs and Healthy Communities, which connects athletes to year-round medical and dental care, fitness, and wellness programs in the communities where they live.

& INCLUSIVE

\$5.8M Gift Reimagines Nursing Care

Ongoing research conducted by the Special Olympics has revealed the gaps in care that individuals with developmental disabilities face. Data shows that disproportionate numbers of individuals with developmental disabilities suffer from health issues including tooth decay, bone deformation, and obesity. These issues can often go untreated or undiagnosed due to the limited availability of health care services for this population, leading to more serious and sometimes life-threatening conditions. The research also indicated that many health care providers are inadequately trained or not trained at all to provide care and support to this population.

Costello said that while the Foundation has formed partnerships with doctors, dentists, medical centers, and medical and dental schools, there was a recognition that nurses play a vital role in fostering inclusive health. In terms of care



coordination and the way health will be administered and managed, she believes nurses and nurse practitioners can play an even greater role in addressing health disparities.

“We are honored to partner with the Golisano Foundation in advancing Tom’s vision for both the Rochester community and for individuals with developmental disabilities,” said President Gerard Rooney. “This vital work and education will have an impact far beyond Rochester, and we are proud to lead the Golisano Institute.”

Embracing a Call to Action

When the College approached the

Foundation with an initial concept, Costello saw the opportunity to work together and reimagine developmental disability nursing education. The largest enroller of nursing and mental health counseling students in the region, Fisher’s School of Nursing consistently achieves rankings as a top nursing program. The expertise of its faculty, strong partnerships within the local community, and a network of nursing colleagues across the globe made it an ideal partner in the Foundation’s efforts. In addition, creating thought leadership centers is a strong focus of the College’s Strategic Plan.

What followed was a yearlong conversation about establishing an institute that could create and promote a new model of care for



nurses around the world who treat patients with developmental disabilities.

“We had many discussions around the role that nurses play across the continuum of care for people with developmental disabilities, and we recognized that while we do exceptional work in this area, there was a gap,” said Cooney Miner. “I recognized that this call to action is in the bailiwick of nurses.”

Costello said the Institute is a deliberate attempt to address a deficiency in preparing health care providers to treat patients with developmental disabilities.

“Based on its reputation, its network, and its commitment to working with this underserved population, we know it is in Fisher’s DNA to serve those in need,” she explained.

To Cooney Miner, this work isn’t just in Fisher’s DNA, it’s the heart of the nursing profession. Historically, nurses have followed a deep commitment to underserved populations. At the turn of the century, it was nurses, led by Lillian Wall, a community health nurse from Rochester, who largely helped vast populations of immigrants in Manhattan receive the health care they desperately needed through the establishment of the Henry Street Settlement. Recently, Cooney Miner pointed to the work of the New York University Hartford Institute for Geriatric Nursing, which transformed the care of elders, and Columbia University’s work in meeting the needs of veterans through the Jonas Nursing and Veterans Healthcare organization.

“As I thought about the work of Hartford, Jonas, and Lillian Wald, I



thought that our School—with the support of the Golisano Foundation—could create a similar model of nursing care that could transform the patient experience for those living with developmental disabilities,” she said.

Developing a Model for Reliable Care

The Institute will focus on several initiatives, including curriculum development, advocacy leadership, specialized training through online and in-class microcredentialing, and a summer fellows program. All align with the goal that nursing educators across the country will adopt this new care model that ensures the delivery of high-quality, safe, highly effective, and reliable care.



To do this, Cooney Miner said the curriculum will teach nurses at both the undergraduate and graduate levels to better understand the unique needs of their patients.

“We understand that health professionals don’t trust that they have the best skills to provide care or manage the challenges individuals with developmental disabilities may face,” said Cooney Miner.

Many primary care settings can create anxiety or fearfulness among individuals with developmental disabilities. Also, a lack of understanding on the part of health care staff can create barriers to communication with patients, leading some providers to shy away from those relationships. This is particularly true for young adults, as they transition out of pediatric care and into adult primary care settings, Cooney Miner added.

“Based on questions nurses ask about mobility, communication patterns, social and emotional health, and issues that may cause stress or trigger anxiety or fear, nurses can design and implement quality

models of care that are highly reliable and patient centered,” she explained.

For example, Cooney Miner said nurses can foster an environment where young adults won’t experience anxiety, have an easier time communicating their concerns, and become active partners in managing their health.

“It’s recognizing that in many cases, people with developmental disabilities are able to be agents of their own care, and we should not make the assumption that a family member or attendant will answer all the questions,” she explained. “As nurses, we need to show respect for the person as a partner in care and gather the accurate information we need from the right people.”

Dr. Elizabeth Kiss, an assistant professor in the School of Nursing, has focused some of her research on nursing education surrounding the care of patients with developmental disabilities. A critical care nurse in medical surgical units, Kiss said nurses will benefit greatly from these curriculum enhancements.

“Many of our patients have developmental disabilities, and often, I saw that we were so focused on their acute issues and delivering life-saving interventions that we were not attuned to what they might have needed because of their disability,” she said. “This is an area where we can really make a difference, and change the way nurses care for these patients.”

The Institute will also implement cutting-edge technology in nursing education, using high-fidelity mannequins, avatars, and standardized patients in its curriculum. Cooney Miner said simulation exercises specific to the care of individuals with developmental disabilities will allow students to gain new knowledge, skills, and competencies that they will transition into the clinical practice environment. The Institute plans to make this same technology available globally in an effort to reach all nurses who wish to enhance their own practice knowledge and skills in developmental disability patient care.

Sharing Good Practice

To develop and implement the

curriculum, the Institute will draw upon relationships with professional nursing associations and partnerships with international nursing schools such as the Waterford Institute of Technology (WIT) in Waterford, Ireland.

WIT's nursing school has offered a specialized degree in developmental disability nursing since 2002. There, the curriculum addresses challenges in effective communication, early intervention strategies, and applied behavioral analysis and positive behavioral change techniques, among other training. The College plans to host faculty members from Ireland on campus to offer guidance in curriculum development.

"I have colleagues who have wonderful knowledge, skills, and academic experiential qualifications that we can call upon to be partners in this work," Cooney Miner said.

One such colleague, Dr. John Wells, head of WIT's School of Health Sciences, sees potential in this new partnership with Fisher. He said the Institute is breaking new ground in the United States at a particularly innovative time in relation to the social integration and support of people with developmental disabilities.

"Our partnership comes just at the moment when the next iteration of support for people with developmental disabilities is in progress," Wells said. "It provides opportunities for the Institute to explore with us innovative approaches to care and develop new thinking as to how we can best support people with developmental disabilities to achieve their life potential by assisting in the planning and implementation of a groundbreaking curriculum within the American context."

Wells pointed to advances in health care that have created longer life expectancies for individuals with developmental disabilities, as well as the new range of

services and skills needed to respond to this population as it ages as just one area where the two institutions can create a mutual learning experience.

"The establishment of the Institute is history-making in terms of the development of nursing education, not only because it foregrounds a significant area of care in the United States that has, perhaps, been a 'Cinderella' of nursing education in the past, but also because, through its partnership with WIT, establishes the education of nurses specializing in the support of people with developmental disabilities within an international context of learning and sharing good practice," he said.

Creating Champions for Health

Through the Institute, health systems, health centers, schools, advocacy groups, and families will also have access to a strong network of community clinical nurse specialists who will advise them on providing care for individuals with developmental disabilities. In addition, the Institute will leverage the network of Golisano Children's Hospitals and community health centers, as well as the Foundation's collaboration with Special Olympics Health, to extend its reach.

"There is a real need to develop advocacy leaders in developmental disability health care to encourage dialogue and promote positive change to ensure that this population receives the quality of life that they deserve," Cooney Miner said.

To that end, the Golisano Summer Fellows Program, slated to launch in 2021, will offer specialty training in developmental disability health care and policy to develop the next generation of thought leaders who will care and advocate for this unique population. The Institute hopes to attract fellows from across the globe, who will then return to their home institutions and practice sites to implement and encourage the adoption of an inclusive health model for developmental disability

populations.

Current health care professionals also will be exposed to best practices through a biannual national symposium that will serve to pool expertise from health systems and health practitioners, as well as other Golisano-supported institutions such as the Special Olympics.

"The beauty of the program is it's trying to embed experience into the curriculum as well as offer further advanced training at the graduate level," said Costello. "Success to us is to see this move beyond Rochester, and New York, to around the country and world."

The Institute will be guided by an advisory board of health care providers, patients and families, and other stakeholders. Cooney Miner is already fostering partnerships with organizations and agencies including the Developmental Disabilities Nursing Association; the American Association of Developmental Medicine and Dentistry; the Child, Adolescent & Family Expert Panel of the American Academy of Nursing; Mary Cariola Children's Center; and Easterseals New York, among others.

For Cooney Miner, each of these efforts aims to ensure that current and future nursing professionals across the globe will have the experience and knowledge to practice inclusive care.

"The Institute will help nurses—the largest population of health care providers in the country, if not the world—be champions for delivering high-quality, reliable health care for this special population," she said.