



Moving Research into Doing

Susan Sullivan-Bolyai creates social support networks to empower families of children with chronic conditions

Nurse scientists are keen observers, driven to action by what they observe. What they see and experience as clinicians and community members informs their scholarship and inspires them to pursue research that results in direct benefit to patients and families. Many of them can identify events early in their career that have shaped their life's work. For former YSN doctoral student and postdoctoral fellow, Susan Sullivan-Bolyai, DNSc '99, such an event involved a 3-year old girl who was injured in a motor vehicle accident in Denver, Colorado three decades ago.

The vehicle, driven by the mother of the young girl, hit an icy patch of road, spun out of control and crashed into a tree. The child sustained a severe cervical fracture, her spinal cord cut in such a way that she could no longer breathe by herself. "She was basically dead at the scene of the accident," recalls Sullivan-Bolyai. Fortunately, a surgical resident driving several cars behind observed the accident and resuscitated the child at the scene. The young girl was delivered to the pediatric intensive care unit (Peds ICU) at University of Colorado Medical Center where Sullivan-Bolyai then worked as a registered nurse. Because she received emergency care so quickly after the accident, the child survived and sustained no brain damage. She did, however, become ventilator-dependent. At the time, due to the nature of her injuries, she was not able to live with her

family, and was instead, for several years following the accident, a resident of the Peds ICU where she was cared for by Sullivan-Bolyai and her colleagues. "She was delightful and she had a great sense of humor!" recalls Sullivan-Bolyai. "She became a part of our family."

At the Peds ICU, Sullivan-Bolyai cared for many children with chronic conditions.

"Nurses who work in this environment get to know the families of the kids on the unit extremely well," she says. "In getting to know them, I always wondered, what happens to the kids once they leave our unit and how do their families manage their child's chronic condition at home?"

These questions inspired Sullivan-Bolyai to seek out opportunities to get more directly involved with childhood chronic illness care. She received her master's degree from Emory University and a post-master's degree from the University of Washington. During this time, she began to focus on family dynamics at the transition between acute and chronic illness in young children. Later, in Seattle, WA, she worked as a Clinical Nurse Specialist and Case Manager for a large group of kids with multi-congenital chronic conditions. She recalls, "I began to see that, in learning to manage their child's condition, parents often developed successful coping strategies that could benefit other parents of newly diagnosed children." She also noticed that in cases where parents had few financial resources they often relied on other support mechanisms such as family, community and religion, which helped them to manage their child's condition.

Inspired by what she observed in her clinical work, Sullivan-Bolyai began to think seriously about enrolling in a doctoral program. While she was on faculty at Salve Regina School of

Building on YSN Research to Manage Overweight in Youth At-Risk for Diabetes Type 2

While finishing her doctoral degree at Boston College, a classmate of Diane Berry's introduced her to the diabetes work of YSN's Margaret Grey. Berry saw an instant match to her own research interest and soon found herself interviewing as a Trial Coordinator for Dr. Grey's core study, "Preventing Type 2 Diabetes in At-Risk Youth."

That college classmate was Robin Whittemore, PhD, APRN, who is now an Associate Research Scientist and Lecturer at YSN. It was at Dr. Whittemore's urging that Dr. Grey came to interview Dr. Berry for her initial job at YSN. And it is this aspect of personal link—and the network of researchers that results from such ever-expanding connections—that epitomizes the YSN approach to developing leadership in nursing. Drawing on the talents and work of several generations of dedicated nurse researchers and clinicians, YSN is training the next generation of nursing leaders.

After joining the YSN community, and once she had earned her PhD, Dr. Berry then made an even greater commitment to YSN when she applied and was accepted for a post-doctoral fellowship to conduct a two-year intervention pilot study of her own, known as the Parent Study (see article describing this program, entitled, "An Obesity Intervention for Multi-Ethnic Families," in the Summer 2004 issue of *Nursing Matters*).

With the research that resulted from the Parent Study in press, Dr. Berry has taken a position as Assistant Professor at the School of Nursing at UNC Chapel Hill and is a fellow in their Interdisciplinary Obesity Research Center, and is a co-investigator on two studies on diabetes and obesity. She is also preparing an R01 grant application to follow-up her Parent Study research.

Dr. Berry reflects on her time in New Haven, explaining that she chose YSN because of the opportunity she saw in the mentors who were available in a research-intensive environment. "The faculty and researchers at YSN really took me under their wing. My affiliation with Yale was a great experience for me," she remarks.

As she continues her work investigating and testing interventions that will benefit those managing overweight, Dr. Berry looks back on her experience at YSN to identify what she calls "the enduring impact" of the relationships that fostered her growth as a nurse scientist. My mentors were all so generous with their time and knowledge," she says. "They really had an impact on me and the research I go on to do will bear their influence."

Nursing, her Chairperson, Eileen Donnelly, let her know of Margaret Grey's groundbreaking research in helping families better manage childhood diabetes. Sullivan-Bolyai recalls, "Eileen sat me down and told me, 'You have to go to Yale and study with Margaret Grey!' That same day I made the call, spoke to Margaret, and it seemed from the beginning a perfect match."

Sullivan-Bolyai enrolled in YSN's doctoral program in 1995. "I had several superb educational experiences prior to Yale, but Yale was the most rewarding," she says. "It was the culmination of everything I had learned up until that point."

"Along with its rich history, at YSN there was a tremendous sense of what former Dean Donna Diers '64 calls, 'Moving Research into Doing.' I was surrounded by some of the most accomplished researchers in their field and their extremely able staff, who made themselves readily available to me for consultation and gave generously of their time," she says.

It was Dean Grey, according to Sullivan-Bolyai, who inspired her to be self-critical and to continuously strive to improve in her academic and research work. "Margaret leads by example. She never stops learning, never stops striving to become an even better researcher and she is incredibly generous in letting those she mentors see that side of her. She inspired us to approach our work with a similar passion. Whatever success I have now, is because of the excellent guidance that I received from her," she says.

Grey encouraged Sullivan-Bolyai to apply for an NIH-funded pre-doctoral training program and guided her through the application process. Later, upon completion of Sullivan-Bolyai's doctoral degree, Grey urged her to apply for post-doctoral training. During this time, Sullivan-Bolyai further developed her interests as a researcher. She began looking at child-parent interactions of young children (under 4 years old) who had been diagnosed with type 1 diabetes. "I started to think about how parents of young children who cannot yet communicate verbally figure out their child's symptoms and manage their condition. Do they develop different kinds of communication mechanisms from

parents of children without type 1 diabetes?" she asks.

She found that mothers of young children with type 1 diabetes had to be constantly vigilant in observing their child's behaviors and, as a result, became extremely good readers of their children's non-verbal cues. "They would be in a conversation with me and say 'see how his lip is turned up just a bit—he is starting to go low' and then they would intervene," Sullivan-Bolyai recalls.

Parents often obtain from informal interactions with other parents important information about managing a child's diabetes, such as what management behaviors work best, school issues, resources in the community and how to train a babysitter to care for your child. "So, I started asking mothers whether it would have been helpful to have other parents in their community whose children were also diagnosed with type 1 diabetes contact them to give them advice and social support," explains Sullivan-Bolyai. "I wanted to know if being part of a parent network would aid them in how they thought about and dealt with their family situation."

Since 2002, Sullivan-Bolyai has been an assistant professor at the UMass Graduate School of Nursing, where she works closely with former YSN postdoctoral fellow Carol Bova, Robin Klar, DNSc '02, and former YSN researcher and faculty member, Lynne Schilling. She teaches in the master's and doctoral programs and is furthering the research she began during her time at Yale. Her current, NIH-funded research project is "STEP: Social Support To Empower Parents," which looks at the experiences of both mothers and fathers in managing their children's type 1 diabetes. In the spring of 2005, she received the prestigious Junior Faculty Research Award from the Eastern Nursing Research Society.

"Only upon leaving Yale did I realize how much I had learned and how much more there is left to learn," observes Sullivan-Bolyai. "What really helped me in getting my arms around my own research was watching Margaret Grey at work. It is as my life-long mentor always says: 'I am still learning.' This is a crucial component of being a successful researcher and this is something that I am now trying to instill in my students."