A LESSON IN HUMANISM:
Educating Medical Students About Family-Centered Care and Developmental Disabilities

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Photo of Rachel Bryant and her mother, Ginny. Photo Credit: John Emerson
“It has opened my mind to seeing how people can learn to adapt and find joy in life, despite what may seem like a challenge.” These words from a medical student capture the essence of humanism that is at the core of a unique educational experience at University of Medicine and Dentistry of New Jersey (UMDNJ) Robert Wood Johnson Medical School (RWJMS). The Seminar on Family Centered Care and Developmental Disabilities, coordinated by The Boggs Center, New Jersey’s federally designated University Center for Excellence in Developmental Disabilities Education, Research, and Service, is embedded in the required third-year pediatrics rotation. Adapted from work originally done in Vermont, the seminar began at RWJMS in 1989.

In the first two years of medical school, students have opportunities for experiential learning through the course Patient Centered Medicine I. In the third year, which includes this pediatrics clerkship, medical students move from largely classroom-based learning to clinical practice-based learning. This juncture in the cycle of medical education has been described by Judah L. Goldberg as the period when the tension between humanism and professionalism is heightened.

The Seminar on Family Centered Care and Developmental Disabilities offers a variety of learning experiences. The seminar includes didactics and group discussion, a lecture by a family educator, values clarification exercises and, as the centerpiece educational experience, a visit to the home of a family with a child with a disability.

Disability and family-centered care are the focus of this seminar, but they also function as proxies for broader considerations inherent in humanism. Humanism emphasizes learning through human experience and addressing universal problems and responsibility to others and to society. Student evaluations of the seminar reflect gains in sensitivity and understanding through these experiences. (See “In Their Own Words” box.)

Seeing families in their homes, rather than in a clinical setting, is the hallmark of this seminar. Students are welcomed into the family’s environment, play with the child, have dinner and talk with the parents. These visits typically create a shift in the students’ perspectives. Seeing children and families in their day-to-day lives stands in stark contrast to the clinical setting, be it the hospital, physician office or outpatient clinic, where generally only the needs, problems and/or crises of these families are presented.

Spending time in the home within the family’s context, students gain insight into how families adapt and accommodate and also into the nature of resiliency. The power of the home visit as an educational tool is summed up by Ginny Bryant, who along with her husband Steve and their seven-year-old daughter Rachel [pictured], hosts students: “It’s amazing to see the transformation of the students during the short time they’re with us. Their expectations are blown away when Rachel makes eye contact and talks with them.”

The seminar helps students realize that the effectiveness of their efforts (including medical interventions, prescriptions, referrals and instructions) may be mediated by circumstances in patients’ lives, distinct from the healthcare encounter. The social and financial challenges of disability also become apparent to students as they gain an appreciation for the importance of connecting families to resources and for the physician’s responsibility to be an active agent in that process.

A basic tenant of family-centered care is the centrality of the family’s role and the family’s expertise about the child. A powerful message absorbed by the medical students is the fact that families are the most knowledgeable about their children. Having received this message, students come to understand the importance of listening, both to the parents and to the child. Listening, as an element of humanism and as a clinical tool, may be learned through the disability lens of the seminar but is a skill that has universal application in the physician role in all areas of medicine. Students often express a sense of relief when family members tell them that it is all right, and in fact preferable, to admit that they don’t know something. Families encourage the students to adopt a spirit of openness and a willingness to learn from the family and to seek out information.

The complexities inherent in disabilities and chronic health conditions highlight for students the importance of communication—not only communication with children and families but also with other providers. When families explain what they go through in negotiating the complexities of medical care and other services, students begin to appreciate that communication, coordination and collaboration are more than philosophical ideals, but rather are skills and practices.
that have direct impact on the lives of patients with complex conditions. As healthcare systems move to more collaborative, team-based approaches, these experiences with disabilities and family-centered care prepare students for these evolving roles.

Additionally, the seminar provides an opportunity for self-reflection. As a faculty, we continuously grapple with how to measure the impact of this experience on students. Students participate in a values clarification exercise that addresses their perceived level of comfort in parenting a child with a disability or serious health condition. This requires them to consider possibilities outside their own experience, especially as most of them do not yet have children.

HUMANISM: In Their Own Words

Self-reflection: “[I am] more aware about how to act as a physician, not just with patients with disabilities, but with all patients.”

Awareness: “I will always keep in mind that there are a million other things that happen before and after I see the patient and there’s more to know than can be elicited in 15 minutes.”

Sensitivity: “I still will never understand what it is like to raise a child with a developmental disability. But at least now I know enough to assess all cases on an individual basis and with increased sensitivity.”

Understanding: “I was very impressed and humbled to be allowed to view people’s private, everyday lives and to see how they handled disabilities.”

Shifting perspectives: “To parents, the child is still a child and needs to live a happy normal life as much as possible.”

Humility: “[I now see] the trials and tribulations families go through to get equipment and medications that physicians prescribe and that are necessary.”

Empathy: “I will see a child before I see the disability; I will listen to the parents first—they know their child best, I will ask questions; I will ask how the family is doing.

Insight: “Before yesterday, I saw kids in these big wheelchairs and didn’t know what to think or how to act. This really opened my eyes.”

We have begun to assess shifts in values as a result of this seminar, including the home visits. Preliminary results indicate a 57 percent shift in the students’ projection of their own comfort about parenting children with different disabilities, with 25 percent reporting feeling more comfortable about Down syndrome after these experiences.

We sense that through the generosity of our host families and these experiences in family-centered care and developmental disabilities, our students are moving closer to what Goldberg calls “an expansive spirit of humanism that transcends the specific realm of health and disease.”

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