

# F o c u s

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With the help of community leaders and parents of children with disabilities, School of Education professor Tracy Knight is teaching students about the problems faced by children with disabilities and their families.

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**–Tracy Knight**

## Creating Special Education Partnerships

**G**rowing up in an impoverished section of Jackson, Mississippi, School of Education professor Tracy Knight witnessed the problems her family experienced in negotiating the special education system to obtain help for her brother, who had a severe speech impediment. Her mother tried to work with the public school district but became frustrated with the system’s unfamiliar terminology, policies, and processes. Knight vowed to someday find a way to help families become effective advocates for their children.

Knight has developed a new course for special education majors in the School of Education that incorporates the experiences of parents of children with special needs and the expertise of urban community leaders. These parents and community leaders are co-facilitating the class with Knight so students receive firsthand knowledge of the struggles urban families face negotiating the special education system. The course is funded through SU’s Vision Fund, which was created to stimulate innovative approaches to teaching and learning. “Even though it’s a class, it’s also a community partnership,” Knight says. “The class is designed to enrich my students’ experiences and teach them to develop relationships with communities they will work with in the future.”

Knight actively recruited families, community leaders, and service providers to work with her on the class, which was offered for the first time this summer. She also works with Sharon Dunmore, a special education doctoral student, mother of four, and wife of the Rev. Sherman Dunmore of the People’s African Methodist Episcopal Zion Church in Syracuse. Despite her many family, church, and student responsibilities, Dunmore devotes time to the class because she believes it’s important for future educators to understand the social construction of the areas in which they may teach. She says students with disabilities are much the same as those who traditionally have been discriminated against because of race, class, or gender. “People with disabilities are often made invisible in society, and we need to acknowledge their needs,” she says.

A key issue for Knight’s class is learning about the cultural climate in urban communities. Knight says most urban school teachers and administrators don’t live in the communities where they teach, but she believes they must learn to understand the influence the communities have on the children. “You’re not just teaching children, you’re teaching their parents and your teaching colleagues,” Knight says. “What happens in the home happens in school and vice versa.”

Knight’s students also are learning about the social structure from which the children come. Sharon Dunmore says the role of the church and the extended family in a child’s development is crucial to understanding the social structure in urban environments. She

says clergy and grandparents are often the most prevalent role models for children. Frequently the grandparents or pastor attend school meetings because parents may be having trouble dealing with their child's disability. "Grandparents are often the safety net that keeps children from falling through the cracks of the special education system," Dunmore says. "They're a family's Rock of Gibraltar. And I know from my own family's experience that many look to their reverend for guidance when dealing with the school."

The Rev. Sherman Dunmore is among the community members co-facilitating the class. He feels that some of the most important work he does with the class is sharing with students an understanding of what parents of children with disabilities will need from them as teachers. "Sometimes teachers are misguided and think they have to rescue the kids," he says. "Many times, being a rescuer is detrimental in the long run. It is a lot more effective to help the kids and their families learn to help themselves."

Knight says it's important to keep interaction between community members and the University alive. "Syracuse University is a great resource to the community, but many parents I've met don't see it that way," Knight says. "This class is designed to create a partnership with community members that shows there are people on campus who really care about them."

—JONATHAN HAY

## Helping Women During Difficult Pregnancies

College of Nursing professor Denise Côté-Arsenault '76, G'85 knows how devastating an unsuccessful pregnancy can be for a woman. She experienced the loss of her own baby and endured a difficult subsequent pregnancy. Since 1983, she has reached out to others who've shared similar experiences.

Côté-Arsenault, who earned bachelor's and master's degrees from the College of Nursing and has taught there for 14 years, chose the topic of pregnant women who've previously suffered perinatal loss for her University of Rochester doctoral dissertation. "It has been my program of research ever since," says the former labor, delivery, and postpartum nurse. "It's been a much richer area of research than I ever dreamed."

When Côté-Arsenault began working on the dissertation in 1992, only about five studies had been done on women in pregnancies after perinatal loss. Today, some 35 studies have been conducted on the subject, and Côté-Arsenault is working on her fifth. "In my first study, I compared pregnant women who have experienced perinatal loss with those who haven't," she says. "I found that those with previous loss had more of what I call 'pregnancy anxiety'—more concerns about their pregnancy, their baby, and themselves."

Côté-Arsenault found that many of the women felt they had lost a baby, not just a pregnancy, even though the majority had first trimester losses, generally called miscarriages. Some women, however, had carried the babies to near full term, or lost them shortly after delivery. "I looked at the anxiety of women who thought they had lost a baby with more personhood—a baby who was given a name, or who would now be a certain age," she says. "Those who lost a baby who to them had become a person had greater pregnancy anxiety. The more they thought they had lost, the more anxious they were about the current pregnancy."

In subsequent studies, Côté-Arsenault asked these women why they called the doctor's office more frequently than other pregnant women, or why they changed doctors after the loss of a baby. She also did two focus group studies, including one with women who became pregnant again after a loss. "The metaphor I came up with to describe them is having one foot in the pregnancy and one foot out," she says. "They could not totally count on having the baby



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College of Nursing professor Denise Côté-Arsenault studies how women who've experienced perinatal loss deal with subsequent pregnancies.

because they knew that babies don't always survive. They were doing everything they could to be sure the pregnancy went well, but emotionally they were leaving room for the possibility of something happening to this baby."

Côté-Arsenault is now studying support groups for such women in Minneapolis and Seattle. In talking to group members, she has found that the women lack trust in the health care delivery system, they worry about their ability to carry a healthy child to term, and some feel like failures. The study also has revealed that such women often need more reassurance from their medical professionals that the pregnancy is going well—they request more monitoring or testing than do women who have not experienced a failed pregnancy. Côté-Arsenault believes medical professionals should be supportive of these women, accommodate their needs, and understand their anxiety. "There are no specific protocols for care given to these women," she says. "That's what I am working on. Ultimately, my goal is to change how we care for these women and their families. We need to provide more sensitive care and be aware of their concerns."

Côté-Arsenault includes students on her research teams, finding them a "tremendous asset." "They are especially helpful with qualitative work because they take a fresh look at what the women are saying," she says.

Nursing graduate Kate Foley '00, who worked with Côté-Arsenault, listened to interview tapes of women who had experienced a loss. She found hearing their words to be a moving experience. "Everyone thinks of pregnancy as a perfectly happy time, but the things these women said were heart wrenching," Foley says. "I hope that being part of this research will help me be more understanding of what these women go through."

—PAULA MESEROLL