

# Deborah Spitalnik

by Jonathan Jaffe



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There are pivotal events in everyone’s life. For Deborah Spitalnik, that event was a 1977 Temple University conference that attracted pioneers and luminaries in the field of developmental disabilities.

Among them were psychologist Seymour B. Sarason, who helped establish the field of community psychology; and three prominent disability advocates: Gunnar and Rosemary Dybwad and Elizabeth Boggs.

While Spitalnik—coordinator for the event—said she saw herself “as merely staff for the conference,” its participants saw her as more.

“They were gracious and supportive,” she recalled. “The chance to meet and to interact with such people propelled me forward. Knowing these people made a difference in my life, a difference in the path I took and changed the course of my life.”

Today, Spitalnik—executive director of the Elizabeth M. Boggs Center on Developmental Disabilities in New Brunswick and professor of pediatrics at UMDNJ-Robert Wood Johnson Medical School—is well-known in the developmental disabilities community.

“She’s a little like E.F. Hutton; When Deborah speaks, people sit up and listen,” said family advocate Donna Icovino, who serves with Spitalnik on a state Department of Human Services’ task force that is creating a service and support plan for people with co-occurring developmental disabilities and mental health needs.

When the dual-diagnosis task force first met in January 2008, Icovino said, she was quick to notice “Deborah’s compassion and commitment. She’s a person with incredible knowledge, foresight and energy. She is a comprehensive thinker who comes up with creative solutions.”

Spitalnik, an author and lecturer, has distinguished herself in her field. She is the past chair

of the President’s Committee for People with Intellectual Disabilities and a past president of the Association of University Centers on Disabilities.

Spitalnik also serves on a host of committees and boards, including the New Jersey Council on Developmental Disabilities, The Governor’s Council for the Prevention of Mental Retardation and Developmental Disabilities, and the Governor’s Advisory Council on Traumatic Brain Injury.

Like those who encouraged her 30 years ago, Spitalnik now helps to advance young people in the developmental disabilities community.

“When I was younger, I sought her advice and counsel,” said Tom Baffuto, executive director of the Arc of New Jersey. “Now that I’ve been around awhile, I find myself still seeking her advice and counsel. We just had a difficult issue raised in our office. The first words out of my mouth were to get hold of Deborah and see what she thinks.”

Spitalnik is also known for contributing to and assisting New Jersey with the creation of policies and initiatives.

“In her role at the Boggs Center, Deborah has personally invested in the success of every single Director of Developmental Disabilities that New Jersey has had,” said Nancy Thaler, executive director of the National Association of State Directors of Developmental Disability Services. “No matter what the circumstance or issue, Deborah sees it as part of her mission to provide the tools and the resources they need for success.

“People in state government are often easy scapegoats for dissatisfaction and blame,” added Thaler, a former Pennsylvania director of developmental disabilities. “That’s not Deborah. She’s always positive, always supportive and helpful. She knows that people with disabilities can be better served if everyone works together.”

## FROM PRE-MED TO DISABILITY POLICIES

In the late 1960s, Spitalnik said, she was a pre-med student at Brandeis University, but was “drawn to social issues” and ended up majoring in sociology and psychology. While an undergraduate, she volunteered at an overcrowded Massachusetts institution and between her junior and senior years, she worked at Bellevue Hospital’s psychiatric facility in New York on a social work fellowship.

After graduating college in 1970, she taught kindergarten at an impoverished Boston elementary school while working toward a graduate degree in education and social policy at Harvard University. Spitalnik said her work experiences began to show her “how very little society valued the poor, minorities, and adults and children with disabilities.

“Through my initial introductions to people with disabilities, I saw that disability is not just a condition. Disability is related to social circumstances and to individual rights,” Spitalnik said. “So, a lot of disability policy are rights issues. Disability issues are tied to issues of class, poverty and race, which can make people feel and actually be more vulnerable.

“Those experiences made me curious about the intersection between people and policy,” she added. “I began to think about how policy and the settings where people receive services helped to shape their lives. I started to develop my interest in public policy and the possibility of social change.”

Spitalnik earned a graduate degree in 1973 and a child clinical psychology fellowship in 1975 at St. Christopher’s Hospital for Children in Philadelphia. Spitalnik then worked as a child development consultant while she pursued her doctorate in clinical psychology at Temple University.

It was at Temple in 1977 that Spitalnik said her career path changed at that conference on developmental disabilities. “The influence of the people at that conference was inspiring. It was like meeting your idols. These people were living legends,” said Spitalnik.

Most notable among those who Spitalnik met was the late Elizabeth Boggs. “Elizabeth was very gracious to young people. She was delighted to offer her support and guidance,” said Spitalnik. “Over time, we came to develop a strong professional and personal relationship.”

When Spitalnik and her husband, John Weingart—now associate director of the Eagleton Institute for Politics at Rutgers University—moved to New Jersey in the early 1980s, they lived a short drive from Elizabeth Boggs’ home.

“Elizabeth introduced us to other young people, as she called us, and she helped me make professional contacts,” she recalled, fondly.

After finishing her graduate studies at Temple, Spitalnik worked at the university’s Developmental Disabilities Center where her research helped to shape the litigation that ultimately closed the Pennhurst State School in Montgomery County, Pa.

In the 1981 landmark de-institutionalization case, *Pennhurst State School v. Halderman*, the U.S. Supreme Court affirmed the rights of children with developmental disabilities to receive appropriate treatment and education.

Spitalnik said her previous work experiences at the Massachusetts institutions and at Bellevue made her “very troubled” that children and adults with disabilities were segregated in special schools and institutions. “At that time, we as a society did not address their issues or their needs; society denied them their basic rights,” she said.

Spitalnik later used her experience in the Pennhurst case to help close the Laconia (N.H.) State School and Training Center in 1991 and the Mansfield (Conn.) Training School in 1993.

While Spitalnik praised the Supreme Court’s 1999 *Olmstead* decision which affirmed the right of people with disabilities to live in the community, she also stressed “it’s not just about de-institutionalization. It must also be about building community capacity and providing the appropriate services and supports people need to have real quality of life in the community. There is still so much more to do.”

## ON BOARD WITH BOGGS

Spitalnik explained that New Jersey's precursor to the current Boggs Center was a small program at Kean University in Union.

Elizabeth Boggs enlisted Spitalnik to write the initial grant to expand that program into a University Affiliated Program (UAP) and move it from Kean College to Robert Wood Johnson Medical School.

Boggs also introduced Spitalnik to Lawrence Taft, chairman of pediatrics at the New Brunswick medical school. After that initial federal grant was secured, Spitalnik became executive director of the UAP.

"I've been here ever since," she said. "I traveled a different route to where I am today and never regretted the journey."

Colleagues are quick to recall a number of successes over the years.

Almost 20 years ago, Spitalnik initiated a seminar in developmental disabilities and family-centered care for third-year UMDNJ medical school students. The seminar includes course work that allows students to interact with parents of people with developmentally disabilities and make home visits to families.

"Deborah's idea was and is for medical students to begin to see a person with disabilities as a whole person—a person with a family and with challenges—not just as a diagnosis," said Michael Knox, deputy director of The Boggs Center.

"These students may not become developmental pediatricians, but will have a better awareness. Deborah is always looking down the road and she manages to see further than most other people."

In the mid-1980s, Knox noted, the University Centers for Excellence had an opportunity to obtain federal training grants. Spitalnik devised a strategy to help a group of provider agencies obtain funds by taking a person-centered approach to services.

"This was at a time when providers had programs and people (with disabilities) either fit in or

they didn't," Knox said. "The notion of taking an individualized approach to support people with disabilities was not done as it is today. Because of Deborah, some of those agencies ended up making a complete shift in the way they provide services."

## LOOKING AHEAD

Spitalnik said New Jersey needs to embark on reforms and service enhancements to continue to improve the quality of life and care for people with disabilities.

Spitalnik identified some of her top priorities as health care, community-based living, supported employment and insurance reforms. Future state initiatives should, she said, include: the creation of patient-centered, medical homes for adults with disabilities; and an increased commitment to supported employment opportunities for people with disabilities.

Also needed are more community supports to help the rising number of aging caregivers for children or family members with disabilities; and health care reforms so people with disabilities are not barred from insurance coverage by what insurance companies consider pre-existing conditions.

"Deborah has the most fertile mind for problem-solving and program development that I have ever seen," said Michael Knox. "When presented with a new project or an issue, Deborah doesn't just come up with one idea."

He said Spitalnik often comes up with a dozen or so concepts and then works through the pros and cons of each one, adding "it's amazing" to watch her mind work.

"Deborah is certainly known as a leader in the field, but she's more than that," Bafuto said. "She's made herself a friend, mentor and adviser to young people coming up. She's generous with her time and her guidance. No young person who comes to her is ever turned away." **P&F**