PRINCETON, N.J. - For Deb Jastrebski's son Marc, who was born with Down syndrome, going to the doctor or dentist felt like torture. His fear of doctors-and the way health care providers were treating him-led to episodes of screaming and sometimes hitting to the point where the blood vessels in his face broke. Ultimately, his fear resulted in missed medical visits and health problems.

"Standard practice for working with fearful patients had been to subdue them or hold them down. I knew there had to be a better way," Jastrebski said. She was determined to help her son work through his fear of seeing doctors. Her approach led to Practice Without Pressure, which she founded to help people with special needs learn skills to handle routine dental exams, blood draws, women's health exams, and nail and hair care. Today the organization works with hundreds of individuals, families, and providers. In 2009, Jastrebski opened her center to provide both practice sessions and actual medical treatment for patients with disabilities.

For creating a strategy to help people with disabilities complete routine medical visits without fear, Jastrebski has been named one of 10 recipients of the Robert Wood Johnson Foundation Community Health Leaders Award. The award honors exceptional men and women who have overcome significant obstacles to tackle some of the most challenging health and health care problems facing their communities. Jastrebski will receive the award during a ceremony in Baltimore, Md., on November 9.

"Marc had problems with eye exams, dental visits, and also haircuts, which don't
hurt. But he was scared, and we had to make it less scary for him," Jastrebski said. She had worked as a physician's assistant after college, so she knew how to give shots and draw blood, and she'd worked as a computer specialist, so she was well versed in analyzing and solving problems. To help her son prepare for medical and dental treatment, she broke down each routine procedure into small steps. Over the course of two weeks, Jastrebski rehearsed these visits with Marc, enabling him to cooperate during routine medical and dental visits without her help and without sedation or restraints.

It wasn't long before other families with children with special needs started knocking on Jastrebski's door. "I would meet with them at my kitchen table, and we saw about 50 families in a two-year period," said Jastrebski. As founder and chief executive officer of the nonprofit Practice Without Pressure in Newark, Del., Jastrebski is now working to change how health care providers are taught to treat people with special needs in medical school.

For example, a patient with cerebral palsy might need five to 10 seconds just to turn her head. "If a dentist can understand that in advance, and prepare for it, it's no longer a problem," said Jastrebski, who often videotapes practice sessions with patients to help show health care providers what to expect during an appointment.

This approach saves money, according to Jastrebski. "It costs more to sedate or restrain patients during a medical or dental visit," said Jastrebski. In 2009, her approach helped the state of Delaware avoid paying $260,000 a year for sedation, since the majority of patients seen by Practice Without Pressure have previously been sedated for routine dental care. But after an average of just over two practice sessions, 80 percent of those patients were able to receive a dental exam or cleaning without sedation. And the savings don't end there. "If people are not able to take advantage of preventive care, we pay more for the medical complications later," Jastrebski said.

_Community Health Leaders_ National Program Director Janice Ford Griffin said the selection committee honored Jastrebski for her creativity and for her commitment to helping people with special needs receive health care. "Deb Jastrebski's personal experience has led to new practices that produce better health outcomes achieved by delivering more effective services through a unique marriage of skills and compassion," Griffin said.

Today, Jastrebski's son Marc supports other patients during medical visits in addition to working a part-time job. "When Marc comes in to help us, he will sometimes sit in the dental chair and have a simulated filling done to show other patients that it's okay," said Jastrebski. "It's a long way from that day when the allergist handed me a prescription for a blood test and told me, 'Good luck.' I don't want other families to face that anymore."

"Deb is a true inspiration to anyone who has the honor of knowing her," said Rita M.
Landgraf of Delaware Health & Social Services. "Her ability to take her vision and empower a vulnerable population by introducing them to a stress-free approach to preventive care and treatment is transformative. In addition, she has taught the medical community a new path to serving this population in a more humane manner."

The Robert Wood Johnson Foundation has honored more than 190 Community Health Leaders since 1993. The work of the nine other 2011 recipients includes a transportation and support program for families with children battling cancer in San Diego; a community initiative to ensure access to medical care in the Kansas farm belt; a campaign for early detection and treatment of breast cancer for uninsured and underserved women in Miami; a nurse training program for disadvantaged Hawaiian students; a home health aide service for elderly Asian Americans in suburban Philadelphia; a rural community health outreach program in the Delta region of Arkansas; an anti-hunger and nutrition program in New Brunswick, N.J.; health education for Mexican Americans in Brooklyn, N.Y.; and health care for the working poor in Altoona, Pa.

Nominations can be submitted for the 2012 Community Health Leaders Award through November 28, 2011. For details on how to submit a nomination, including eligibility requirements and selection criteria, visit www.communityhealthleaders.org.

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The Robert Wood Johnson Foundation established the Community Health Leaders Award to recognize individuals who overcome daunting obstacles to improve health and health care in their communities. Today, there are more than 190 outstanding Community Health Leaders from nearly all states, Puerto Rico, and the District of Columbia. For more information, visit www.communityhealthleaders.org.

The Robert Wood Johnson Foundation focuses on the pressing health and health care issues facing our country. As the nation’s largest philanthropy devoted exclusively to health and health care, the Foundation works with a diverse group of organizations and individuals to identify solutions and achieve comprehensive, measurable, and timely change. For nearly 40 years the Foundation has brought experience, commitment, and a rigorous, balanced approach to the problems that affect the health and health care of those it serves. When it comes to helping Americans lead healthier lives and get the care they need, the Foundation expects to make a difference in your lifetime. For more information, visit www.rwjf.org.