

MARILYN E. SAVIOLA

Senior Vice President for Advocacy
and the ICS Health Access Program

Marilyn E. Saviola is a nationally recognized disability rights advocate with a 40-year history of fighting to improve the lives of people with disabilities in New York City, particularly by advocating for the rights of people with physical disabilities to live at home, in the community, as independently as possible.

Born and raised in the Bronx, Ms. Saviola contracted polio when she was 10. Subsequently, she lived in Goldwater Hospital, where she was part of a group of young people with disabilities who worked together to persuade the hospital administration to provide the services they needed to go out into the community and attend college.

Ms. Saviola began her professional career as a rehabilitation counselor at Goldwater, spending 11 years helping people with severe physical disabilities to meet the challenges of leaving the hospital and moving out into the community. She brought to that position not only her professional credentials—a master's degree in rehabilitation counseling from New York University—but also her personal experience.

In 1965, at the age of 20, Ms. Saviola fought her way into Long Island University in Brooklyn after initially being told by the New York State Vocational Rehabilitation Agency that her disability was too severe for her to be gainfully employed and that they would not pay for her education. As she became involved in the anti-Vietnam-war and the women's movements, she began thinking seriously about the civil rights of people with disabilities. Her Brooklyn apartment became a meeting place for the then-new organization Disabled in Action (DIA) and the DIA singers.

From 1983 to 1998, Ms. Saviola took up the reins as executive director of the Center for Independence of the Disabled in New York. Under her leadership, CIDNY became a premier independent living center, recognized for its expertise in advocacy, community-based long-term care and health care for people with disabilities. In 1998, Ms. Saviola brought her passion and deep knowledge of home- and community-based services to Independence Care System (ICS). As Senior Vice President for Advocacy, Ms. Saviola intervenes, often in crises, on behalf of ICS members struggling to negotiate the many systems that affect their lives.

For many years, Ms. Saviola has effectively brought the rights and concerns of people with physical disabilities to the attention of New York State government officials, New York City lawmakers and institutional health care providers. Most recently, she has testified at public hearings and health-related task forces about the ubiquitous barriers to health care that people with disabilities routinely encounter. Her advocacy has led to public hearings and to the New York State Department of Health notifying medical providers across the state of their obligation to make services accessible under federal, state and local laws. In addition, she has been a leading advocate in ensuring that people with disabilities who rely on the assistance of home care aides or personal care assistants receive the hours of care they require to remain independent, bringing the full force of the legal system to her advocacy when necessary.

In 2008, Ms. Saviola led the creation of the ICS Health Access Program for Women with Physical Disabilities, which works to ensure that women with physical disabilities get the preventive, gender-specific health services they need. The program's first initiative was the Breast Cancer Screening Project for Women with Physical



Disabilities. The project has been funded since its inception by the Greater NYC Affiliate of Susan G. Komen for the Cure, which chose it as its 2010 Grantee of the Year.

Through the Women's Health Access Program, which will add primary care services to its offerings this year, women with physical disabilities have received hundreds of breast cancer screenings and gynecological examinations, some for the first time ever. Without this program, routine gynecological services that most women in New York City take for granted, such as pelvic exams, cervical cancer screening, or dilatation and curettage, would be extremely difficult or impossible for women with physical disabilities to obtain.

In 2012, Ms. Saviola co-authored the report *Breaking Down Barriers, Breaking the Silence: Making Health Care Accessible for Women with Disabilities*, with New York Lawyers for the Public Interest. Publication of this report led the New York City Council to hold an oversight hearing regarding the inaccessibility of New York City health care facilities. It also resulted in the allocation of public funds to make select women's health care facilities more accessible; a partnership with New York City's Health and Hospitals Corporation (HHC), through which clinical and administrative staff are trained in disability awareness and competency; and the expansion of the ICS Women's Access to Healthcare Program into several HHC facilities.

As a community advocate, Ms. Saviola brings her unique and powerful voice to the work of many advisory committees, organizations and professional associations. She was a founding member of Concepts of Independence, the agency that first made consumer-directed services available to people with disabilities in New York State, allowing them to stay out of institutions and live at home in their communities. Ms. Saviola has served as chair of the Manhattan Borough Disability Advisory Group, board member of the Association of Independent Living Centers in New York, member of the New York City Medicaid Managed Care Task Force and board member of Disabled in Action.

Ms. Saviola lives an independent, very active life, working full time and using her skills and talents to make the world a better place for everyone. As she says, "Everyone benefits from accessible care and universal design. At some point in your life, you'll probably need something accessible."