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Chair of City Council Health Committee and Women with Disabilities Describe an Inaccessible Healthcare System

June 9, 2015, New York City – Women with disabilities who have been unable to obtain breast and cervical cancer screening for years testified before the New York City Council Finance Committee today. While they have the same risk of getting breast cancer as other women, the mortality rate for women with disabilities is one-third higher than the general population, a situation that City Council Health Committee Chair Corey Johnson called “unacceptable.”

The disparity exists because it is difficult or impossible for women with disabilities that limit their mobility to get mammograms and other routine health care, despite the fact that federal, state and local laws all require health facilities to make their services accessible. Their cancer is generally diagnosed late and they receive less aggressive treatment, including less radiation therapy, fewer axillary lymph node dissections to remove invasive cancer cells, and fewer follow up mammograms.

Brooklyn resident Udean Murray, who testified this afternoon, had breast cancer when she was 24. Later in life she was diagnosed with Multiple Sclerosis and she now uses a wheelchair. Ms. Murray told the committee, “Having had cancer at such a young age I have always been very diligent about getting regular breast and gynecological exams, but when my MS progressed to the point where I could no longer control the movement of my legs, this became a terrible ordeal.

“The last time I went to the hospital and tried to hold myself up so I could get a mammogram, I fell down. I was supposed to go back in April but I didn’t keep my appointment. I just can’t do this anymore, especially when I really doubt that they are getting any kind of an accurate reading. The machine isn’t designed to get a reading from someone who is shaking and trying to hold on to it to keep themselves from falling down.”

Ms. Murray also described the common difficulty women with physical disabilities have getting access to gynecological care. “As bad as it has been trying to get a mammogram since I have been using a wheelchair, my experience going to the gynecologist was much, much worse. I have no control over my legs. When I went for a gynecological exam in March of 2011, I was not able to put my feet in the exam table stirrups. The doctor picked up my legs to try to force them in the stirrups. I was screaming in pain. She shoved an instrument into me and made me bleed. It was a horrible, terribly painful experience and at that time I said to myself, I’m never going for a gynecological exam again.”

Women with disabilities ranging from Multiple Sclerosis to Cerebral Palsy to paralysis resulting from childhood polio provided testimony to the Finance Committee in support of a funding proposal to make New York City’s public health facilities more accessible. The funds, \$15 million requested by New York’s Health and Hospitals Corporation (HHC), would be used to purchase accessible medical equipment and renovate examination rooms.

Addressing the women before the Finance Committee hearing, Council Health Committee Chair Corey Johnson said, “Even though we are celebrating the 25th Anniversary of the Americans with Disabilities

Act, New York City still has a long way to go. The number of women who die because they can't get care is staggering. We must spend the money to make sure women with disabilities have access to care." In addition to chairing the Health Committee, Council Member Johnson has a seat on the Finance Committee.

A report issued by Independence Care System (ICS) and New York Lawyers for the Public Interest in 2012 prompted a New York City Council oversight hearing on New York City's lack of accessible health care. Following that hearing, HHC received \$2.5 million from the Council to make a few of their women's health facilities more accessible. The funds HHC has requested for fiscal year 2016 would allow them to continue and expand that work to more facilities.

Marilyn Saviola, ICS Senior Vice President for Advocacy, oversees the ICS Women's Health Access Program. She said, "HHC was the only health care facility that responded after the oversight hearing to address the health disparities routinely experienced by women with physical disabilities. It is imperative that the City Council allocate the funds HHC has requested for 2016 in order to continue increasing accessibility."

As Independence Care System Chief Operating Officer Regina Estela notes, "This summer New York is hosting the nation's biggest celebration of the Americans with Disabilities Act 25th Anniversary. The administration has pledged to make New York a model of accessibility. That means we must do more to live up to the letter and spirit of the ADA, because after 25 years no one should have to worry about dying from cancer or some other treatable or preventable condition because medical facilities and medical equipment is inaccessible."

"It's really a shame that decades since the ADA was passed, women in New York City must fight for the right to accessible medical care," said Council Member Robert Cornegy in a written statement. "It would be even more of a shame for those of us who represent them not to raise our voices to demand the funds to create change in this area. This is about fundamental fairness, dignity, quality of life and in some cases, life or death. Let's fund HHC to adapt its facilities as quickly as possible and urge private healthcare providers to meet their ADA obligations as well." Council Member Cornegy sits on both the Health and Finance Committees.

Making health care widely accessible to people with disabilities is not only a legal and moral obligation; it has vast and growing financial implications. People with disabilities receive fewer x-rays, physicals, colonoscopies, vision screenings and preventive dental care appointments compared with the general population. They are commonly hospitalized for conditions that could have been prevented – diminishing their health and escalating health care costs.

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Independence Care System's Women's Health Access Program works to increase the availability of health services for women who have physical disabilities, in collaboration with New York City medical facilities. We believe that all medical facilities should be able to provide the best possible care to people with disabilities, as they need and are legally entitled to under the Americans with Disabilities Act and numerous state and local laws. Independence Care System is a nonprofit organization dedicated to supporting adults with physical disabilities and chronic conditions to live at home and participate fully in community life. We provide managed long-term care services, as well as a number of specialized services, to residents of the Bronx, Brooklyn, Manhattan and Queens.