Special Committee on Aging
United States Senate
113th Congress, 1st Session

Hearing:
Older Americans: The Changing Face of HIV/AIDS in America
September 18, 2013, 2:00 p.m., Dirksen 562

ORAL TESTIMONY
of
CAROLYN L. MASSEY

Chairman Nelson, Senator Collins and the distinguished Members of the Committee, thank you for the opportunity to address the very important subject of HIV and aging.

I am here to issue a clarion call, to give you the "inside story" on HIV and aging, and the real cost of continuing to minimize the impact that HIV, left unchecked in aging adults, will have on our country and aging citizens. My prayer is that by sharing some of my personal experiences and those of people who have died from HIV and AIDS, or are currently living with the disease, you might consider them as you determine how best to meet the needs of more than 1.2M persons who are known to be living with HIV in our country today. I say "known to be" because estimates are that approximately 25% of the people who are HIV-positive in the United States right now do not know their HIV status. We are fast approaching the point where truly 50% of the people who are living with this disease are at last 50 years of age. The pivotal study, *Research on Older Adults with HIV*, conducted by the AIDS Community Research Initiative of America, told us years ago that HIV/AIDS has a major impact on the quality of life for older adults living with the disease. I challenge you to consider the economic impact, the loss of life, loss of productivity, loss of tax revenues, trauma to families and loved ones that will only grow if HIV in aging adults is left unchecked.

I was initially diagnosed with HIV in the fall of 1994, the same year that my only brother died as a result of complications associated with AIDS. His name was Theodore Anthony Jackson, a budding young businessman, having just opened his third in what was to be a franchise of barbershops, called Tony's. He would be 55 years old today; our country lost the benefit of his gifts and the contributions that he would have made over the past 19 years. Only months after his death, I was diagnosed – I was 38 years old. During that time, the only drug widely available and prescribed was AZT – and in Anthony's case, we believe that it did him more harm than

good. As our family struggled emotionally with Anthony's rapid decline in his physical health and mental state, we were traumatized yet further by my diagnosis.

I am convinced that only because I moved my family to Philadelphia in 1996 and vigorously pursued medical treatment there (and ever since!) that I am alive today. The sad fact is that many of the people who are aging with HIV today did not know that less stigmatized environments and more knowledgeable physicians were available then. In fact, many of the people who are living with HIV today STILL do not know that there are life-saving treatments and care available to them. This is especially true of people known as 'Baby Boomers', those of us who are over 50 years of age. The older a person is, the less likely they are to be health literate about HIV, their HIV risk levels, how to establish healthy relationships, how to self-advocate and how to access the life-saving services that they need.

One of the things for which I am immensely grateful is that, with your support, health information technology will be used more. I believe that as that technology matures, you will see that HIV is truly not particular about infecting a particular group of people, but that there are more people already infected than we think and that each of us is at higher risk for infection than we ever imagined. In fact, if any of us has had unprotected sex we are at risk for HIV infection.

As you are aware, the field of geriatrics and gerontology is a relatively new one; still emerging within the larger medical community. I urge you and your Senate and House colleagues to provide increased resources to study, better understand, establish and widely implement the best care and treatment practices to address the needs of people who are aging with HIV. Support people who want to study medicine and work on these complex, difficult and intersecting problems of aging and HIV. The aging adults being diagnosed with and living with HIV, if left unattended, is one of the next big health challenges that we will face as a nation.

We have learned a lot over this 30-year journey with HIV in the United States. Among the things we have learned is that the most successful prevention interventions and approaches to care are those that begin with and continue to meaningfully involve the affected communities. The Ryan White CARE Act has provided a tremendous gift through lessons learned and the creation of a continuum of care that works. That continuum should be informing our work going forward in order to undergird the healthcare reform that is now underway.

Another lesson we have learned is that the approach to ending HIV must involve many sectors and various disciplines; this must be an interwoven and integrated effort that involves academic, scientific, political, at-risk populations, and other community stakeholders. We must find ways to effectively improve and measure the change in the quality of life for persons who

are living longer with HIV and begin to connect them, to the extent that they are able, to more productive lives. Too often in our zeal to solve one problem, we create other challenges. With improving care and services, and wider access for ALL people with HIV, we can expect that some will be able and want to return to work. Therefore, we need to develop ways to help support them as they do so and ensure that those supports and approaches are realistic and age and culturally appropriate. This involves working with employers and industries to develop new ways to work and developing more thoughtful, outcomes-driven benefit structures that don't perpetuate poverty, but support progress and hope.

Finally, I strongly urge you to not let our mothers, fathers, and elders die simply because we refuse to sensibly and effectively act. We have the means and wherewithal to better serve older adults with and at risk for HIV and to end this terrible epidemic; but only if we learn the lessons of the past and commit the resources to get there. Please, dear Senators, do not forget us.

Thank you for this opportunity to share some of my story. I welcome your thoughts and questions.