7 Common Concerns Brought Up by People Aging With HIV

We held listening sessions across the country, and this is what we heard.

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The following is a guest post by Ronald Johnson, Policy Fellow at AIDS United.

Right now, we stand at a unique moment in the course of the HIV epidemic in the United States, one where we can actually see the end in sight even if it's only a speck on the horizon. However, it is important to acknowledge and appreciate, just days after National HIV/AIDS & Aging Awareness Day, how remarkable this truly is. There are those of us who remember when such a moment was scarcely conceivable, a time when an HIV diagnosis was a death sentence and palliative care was all that could be offered to us as our CD4 counts were decimated by this disease.

Today, we no longer have to live with the ever-present threat of opportunistic infection taking us before our time even though, thanks to HIV stigma and inequities in the way we receive care, many of us still do. There are those of us who, with the gift of restored health, face new challenges—ones that we never anticipated during the height of the epidemic in the late '80s and early '90s. They are the challenges of aging with HIV, and hundreds of thousands of us confront them every day.

Today in the United States, 50% of people living with HIV are over 50 years old, and that number is expected to climb to more than 70% by 2030. And yet, our investment in resources, care and research for those of us aging with HIV has not kept pace with the demand demonstrated by the hundreds of thousands of older Americans currently living with HIV. In response to the disparity between the needs of people aging with HIV and the services available to them, AIDS United's Policy Department & I have engaged in a series of listening sessions that aimed to give a voice to older adults living with HIV.

Clear, and at many times poignant, examples that reveal the gaps between current policies, programs and research and the real needs and concerns of older adults living with HIV were seen and heard in these HIV & aging listening sessions, which were conducted this summer in cities across the country, including San Juan, Puerto Rico. The sessions, in which older adults living with HIV participated, were a part of AIDS United's HIV & Aging project. The project's focus is protecting the lives of people living with HIV who are 50 years and older. The goal of the listening sessions was to hear personal stories, information, observations, and comments from the participants to

inform the development of a policy paper and legislative agenda on HIV & aging and to inform federal and state advocacy on HIV & aging issues.

The participants reflected the diversity of the HIV and aging population. Emerging from the diversity of people were common themes:

- Concern over threats to continuity of care resulting from shifting health coverage to Medicare and or Medicaid or changing private health insurance plans. The concern frequently rises to fear and anxiety.

- Experiencing co-morbidity with several non-HIV related health conditions and dealing with the challenges of managing care with multiple doctors and other health providers. The challenges raise the need for case management services that can help to facilitate medical care.

- Questions about the impact of HIV on aging, the impact of HIV on non-HIV conditions, notably cardiovascular disease and diabetes, and the impact of aging on HIV.

- Polypharmacy issues, including the interaction between HIV medications and medications for non-HIV related conditions.

- Concerns over the lack of safe, adequate, and affordable housing; lack of transportation options, and the increased need for supportive services.

- Persistence of loneliness and social isolation.

- Heightened concerns about stigma and discrimination, with many participants experiencing stigma and discrimination.

While facilitating these sessions, I also was hearing many of my own concerns as an older adult living with HIV. Many times, I thought of my challenges in taking 10+ pills a day, only one of which is an HIV medication. I also worry about how I'll get long-term care if (or when) I need it. The sessions gave me a heightened sense of purpose for the HIV & Aging project and for the

importance of the project calling out the need for new policies and describing those policies and laying out a legislative agenda to achieve the needed policies.

The listening sessions, and more to the point the dozens of older adults living with HIV who participated and told their stories, reminded me of the importance of National HIV/AIDS & Aging Awareness Day. You can appreciate the progress that is enabling people living with HIV age into our 50s, 60s, 70s, and beyond. You can be aware of the continuing and new challenges that older adults living with HIV are experiencing every day. You can re-affirm your commitment to making sure older adults with HIV are thriving and living our lives with dignity and respect.

Watch for more to come from AIDS United's focus on HIV and aging because the real importance of HIV/AIDS and Aging Awareness Day is that we stay aware throughout the year.

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