



July 23, 2012

Dr. Mary Wakefield
5600 Fishers Lane
Rockville, MD 20857

Dear Dr. Wakefield:

On behalf of the HIV Health and Human Services Planning Council of New York (Planning Council) and its Consumers Committee, I write to support the extension of the Ryan White HIV/AIDS Treatment Extension Act (HATEA) when it expires on September 30th, 2013. Planning Council members collectively have decades of experience in delivering and/or receiving HIV/AIDS medical and social support services and recognize the crucial contribution of Ryan White to the health and well-being of People Living with HIV/AIDS (PLWHA). While Planning Council members support the extension of HATEA as a whole, these comments focus specifically on Part A.

The Planning Council is charged with examining needs, developing service models, and keeping abreast of federal, state, and local policy issues. The Council uses the information gleaned from this work to set priorities for and allocate approximately \$120 million in HRSA funding. In all of our work, our primary interest is the welfare of PLWHA. At a recent meeting, members of the Consumers Committee poignantly described the impact of Ryan White-funded treatment and care on their lives:

I was linked to food and nutrition, and that helped link me to care coordination and to taking my medication.

I was able to get mental health care. I receive counseling and see a psychiatrist once per month for medication. This helps me with my depression and helps me to stay sober.

I was homeless and a drug addict. Ryan White took me off the streets and gave me a second chance at life.

After diagnosis, I thought my life was over. Food and nutrition programs taught me how to cook the food that I need to take with my medication and gave me

mental health services. This was instrumental in giving me the confidence to move forward and not be overwhelmed by feelings of despair and uselessness.

When I first learned of my diagnosis in 1987, I felt terribly ashamed. I thought I had disappointed all the people who had ever invested time in me – my teachers, mentors, and friends. I thought my life was over. I was told I had a year and a half to live. I had thoughts of suicide and was fighting depression, staying at home with the covers pulled over my head. I was ashamed to admit that I needed help to survive. But I finally got enough courage to face my fears and the world and say “I am still alive and I plan to stay that way.” My CBO was essential in helping me. I went to them for legal help and the meals program when I wasn’t eating enough. I also started volunteering. Volunteering as a mentor has been empowering because, as I lead, I am reminded of the things that I need to do for myself.

When I was diagnosed with HIV, I was put in a wheelchair. With help, I got better, got out of hospice care, learned to take care of myself, and got mental health care. All of this helped me to get out of diapers and out of the wheelchair and helped me not to be crazy.

I have a college degree and am able to search for services, but the care coordination funded by Ryan White is very helpful for people who may not have the wherewithal to find services on their own.

Ryan White helped me to get my confidence back and meet my good friend, who is also living with HIV/AIDS. Mental health and nutrition services were helpful.

Ryan White helped me to get through the legal system. The people at my CBO helped me to get my kids back and to get support.

When I had nowhere else to go, Ryan White took care of me.

Planning Council and Consumers Committee members affirm the effectiveness of the current Ryan White care system. These funds enable us to preserve our current wraparound system of care and ensure that clients do not fall through the cracks. The flexibility to use Ryan White dollars both for core medical and non-core support services helps us to build a system that best fits local need. We support an extension of the Ryan White HIV/AIDS Treatment Extension Act while we plan for the full implementation of the Affordable Care Act in 2014 and of Medicaid redesign in New York State.

Along with the rest of the HIV/AIDS community, we are working to implement the goals of President Obama’s National HIV/AIDS Strategy: lowering the number of new

infections, facilitating entry to care and enhancing health outcomes for PLWHA, and decreasing health inequalities. With the extension of Ryan White, we will ensure that our advances to date will continue. My colleagues on the Planning Council and I endorse open entrance to excellent health care, stability of care, strengthening of resources, expanding client capability, and continuing and enhancing the flexibility and responsiveness of the system. Ryan White enables us to make progress on this vital work.

Thank you very much for this opportunity to comment.

Sincerely yours,



Dorella Walters
Community Co-Chair
HIV Health and Human Services Planning Council of New York

cc: Michael R. Bloomberg, Mayor
Thomas A. Farley, MD, MPH, Commissioner of Health
Christina Chang, Deputy Commissioner for Policy and External Affairs
Jan Carl Park, Governmental Co-Chair