



## **CONSUMERS' COMMITTEE**

Tuesday, December 20, 2016, 1:00 – 3:00 PM  
LGBT Center, 208 West 13th Street, Rm 101, NY, NY

**Planning Council Members Present:** Billy Fields (Co-Chair), Randall Bruce (Consumer At Large), Lisa Best, Maria Diaz, John Schoepp

**Planning Council Members Absent:** Katrina Balovlenkov (Co-Chair), Altirik Harper, Harry Jackson, Jesus Maldonado, Antonio Munoz, Saul Reyes, Carlos Rosario, Kim Watson

**Appointed Community Members:** Ron Joyner, Mark Brown

**Guests:** Paul Carr

**NYCDOHMH:** Jose Colon-Berdecia, Jan Carl Park, Darryl Wong

### **MEETING MATERIALS DISTRIBUTED:**

- Meeting Agenda & Rules for Respectful Engagement;
- November 15, 2016 Meeting Minutes;
- Gina Quattrochi, Who Helped Provide Housing for AIDS Patients, Dies at 63, 12/19/16, NY Times;
- AIDS Service Center (ASCNYC) Remembers Bailey House CEO Gina Quattrochi;
- National AIDS Housing Coalition (NAHC) Tribute to Gina Quattrochi;
- All the King's Men: The Trump Presidency and the Deconstruction of Social Safety Net Programs, Presentation by Jan Carl Park, 12/12/16;
- Ryan White HIV/AIDS Program by the Numbers, HRSA;
- 1.1 Million New York Residents Would Lose Coverage in 2019 Under ACA Repeal, 12/16, Center on Budget and Policy Priorities,
- New York City Medical Monitoring Project (2009-2014) Fact Sheet, HIV Epidemiology & Field Services Program, 9/16, NYCDOHMH;
- Ballot for Planning Council Consumer At Large, 2016;
- Health Department Releases Data on Substance Use Among PLWHAs Receiving Care in NYC, 12/12/16, NYCDOHMH;
- Week of Action to Protect Our Care, Families USA, 12/16;
- Hepatitis B and C in New York City (2015) Annual Report, 10/16, NYCDOHMH;
- HIV/AIDS Annual Surveillance Report 2015, NYCDOHMH;
- NY HIV Planning Council January 2017 calendar;
- Consumers' Committee November 2016 Meeting Evaluation Results; and
- Consumers' Committee December 2016 Meeting Evaluation.

### **WELCOME/INTRODUCTIONS/REVIEW OF MINUTES**

*Billy Fields*, Committee Co-Chairs, opened the meeting. *Ms. Balovlenkov* was unable to attend due to illness. *Darryl Wong*, Planning Council Staff to the Consumers Committee announced the passing of former Planning Council and Integration of Care Committee member *Gina Quattrochi*, CEO of Bailey House. Gina was a pioneer in advocating for the housing needs of PLWHAs nationally and in NYC; a moment of silence was observed in her memory. The Rules of Respectful Engagement and meeting materials were reviewed and the November 2016 meeting minutes were accepted as presented.

Notable highlights in HIV Epidemiology from the 2015 HIV Annual Surveillance were cited – 83% of those included were virally suppressed, new HIV infections decreased by 8.3% from 2014, new HIV infections among MSM decreased by 10.5% in 2015, new infections among those 20-29 reached a new low since 1991 and there were no mother to child HIV transmissions in 2015.

### **PUBLIC COMMENT**

*Mark Brown* asked about the availability of Hep C DAAs through Medicaid, given the recent inclusion of most new generation Hep C medications in the NYS ADAP formulary as of November 28, 2016. It was noted that this change affects only those who are HIV+ and who qualify for ADAP. *Maria Diaz* from VOCAL commented on Gilead's resistance to price negotiations. *Paul Carr* commented that in Upstate New York, many HIV-related events and health fairs are possible only due to private sector & pharmaceutical manufacturer support and that he and others are establishing a blog talk radio station. *Ron Joyner* commented that there is a growing movement of collective depression/anxiety centered around the incoming administration and that we must resist the temptation to be pessimistic at this fragile time and must re-group to begin our advocacy efforts. *Lisa Best* re-iterated that consumers must be our own advocates and pro-active in preparation for changes in the safety net landscape. She reported to the group that in Rockland County, the Legislature met early to convene a vote on defunding the HIV program in that County, which passed.

### **PRESENTATION: THE POST-ELECTION HIV/AIDS FUNDING PICTURE: The Presidential Transition and the Future of Safety Net Programs**

*Jan Carl Park*, Governmental Co-Chair of the HIV Planning Council began by noting that President-Elect Trump said nothing about HIV during his campaign. The Trump administration has about 4,000 positions to fill in the Executive Branch and has announced a number of cabinet choices. Key choices include Rep. Tom Price for Health and Human Services (HHS), Ben Carson for Housing and Urban Development (HUD), and Seema Verma as Director of the Center for Medicare and Medicaid Services (CMS).

Vice President-Elect Pence was governor of Indiana during that state's worst outbreak of HIV among IV drug users, which was exacerbated by his refusal (based on unscientific and religious-based views) to fund needle exchange, as well as his previous efforts to slash funding for HIV testing facilities in the state. He is also has a long anti-gay record and tried to divert Ryan White funding for conversion therapy.

Dr. Tom Price, nominee for Health and Human Services Secretary is a strong opponent of the Affordable Care Act (ACA, aka Obamacare) and was a lead sponsor in Congress of the "Empowering Patients First Act", which would repeal ACA and replace it with age-adjusted tax credits for individual purchase of insurance, a greater emphasis on health savings accounts (HAS) and high-risk subsidized insurance and cross-state insurance policies. In addition, Price also wants to slash funding to Medicaid and to privatize Medicare, which could drive many PLWHA who have gained coverage under ACA back into ADAP. Repeal without replacing the ACA would double the number of uninsured people and leave the nation with an even higher uninsured rate than before the ACA.

The Ryan White Program provides health care to 533,000 low-income people living with HIV and has a long history of bi-partisan support. It is too early to say the effect on FY 2017 funding levels (Continuing Funding Resolution through April 2017), and there are no signs of RW being specifically targeted by the incoming administration or Congress, but cuts in ACA, Medicare and Medicaid would result in a large number of people falling back on RW programs. Medicaid covers more than 73 million Americans, nearly one-quarter of the American population. It is currently the largest source of insurance coverage for people living with HIV, covering more than 40% of PLWHA who are in care. Rep. Price's plan proposes to restructure Medicaid by converting it to a block grant and cutting funding steeply (\$1.8 trillion over 10 years). The federal government would no longer pay a fixed share of states' Medicaid costs, causing funding to fall behind states' needs each year. 14-20 million

individuals could lose Medicaid coverage or no longer gain coverage in future. Seema Verma has worked for VP-elect Mike Pence on Medicaid and consulted with other states to require “work-fare” requirements and lockout periods for Medicaid recipients.

The number of Medicare beneficiaries with HIV has tripled since the 1990s, rising from 42,520 in 1997 to 120,000 in 2014. Approximately one quarter of people with HIV in care get their health insurance coverage through Medicare. Price supports shifting Medicare from open-ended commitment to pay for medical services toward a fixed governmental contribution for each beneficiary (“voucherization”). Opponents fear “skimpy coupon care”, higher premiums.

Ben Carson, who would run HUD, responsible for HOPWA, has a long history of opposing government safety net programs and admits that he has no experience running a federal agency. HOPWA makes grants to local communities, States and non-profit organizations for projects benefitting low income persons living with HIV/AIDS.

The Federal AIDS Policy Partnership (FAPP) and other advocacy groups are meeting to strategize how to meet the challenges of the next few years, focusing on preventing any disruptions in health coverage, maintaining critical reforms that address unfair or discriminatory insurer practices, maintaining the current funding structure, including the entitlement of the Medicaid program, ensuring access to a minimum essential benefits package, keeping health coverage, health services and prescription drugs affordable and sustaining strong non-discrimination protections.

#### **PLANNING COUNCIL UPDATES**

*Darryl Wong* reported that:

- It was announced that the Planning Council New Member Orientation is scheduled for Friday, January 6, to which all committee members are invited. As of December 20, there have been no notifications from the Mayor’s Office regarding new Planning Council member appointments.
- The HIV Community Planning Workgroup continues to meet monthly, where the focus is on exploring the feasibility of the structural integration of the Planning Council and the HIV Planning Group community planning bodies. The leadership of the Consumers Committee has been invited to participate and does so on an ongoing basis.
- With respect to consumer involvement in Quality Management, it was reported that the history of Community/Consumer Advisory Boards (CABs) in NYC represents a large investment in ASO agency time and staffing and that to date, the benefits have been marginal.
- Nominations are open for the 2027 Consumer At Large position and will be accepted until the day of the election, which will be on January 17, 2017 at the next Consumers Committee meeting.
- The Communications Division of DOHMH has received the Consumers Committee revised narrative for the outreach brochure and will begin working on modifications and re-design immediately. It is projected that a final narrative will be available for consumer review at the January meeting; it has also been projected that the prototype, upon approval from the Committee, will be ready to be reproduced by mid to late February.

#### **PUBLIC COMMENT/NEW BUSINESS/BOROUGH UPDATES**

#### **ADJOURNMENT**

There being no further business, the meeting was adjourned at 3:30PM.