

1 HIV Health & Human Services Planning

2 Council of New York

3 February 23, 2016

4
5 MR. LESIEUR: Despite the people in the
6 back room, we're going to start. Good morning
7 everybody. My name is Matthew Lesieur. I'm a
8 community co-chair of the Ryan White Planning
9 Council, so I want to welcome everyone here. Very
10 impressive showing. I'm glad that we have a
11 pretty good participation here.

12 So I just want to sort of provide this
13 meeting in the context of the bigger role of the
14 Planning Council and why are we here in the first
15 place.

16 So with the exception, I would say
17 [indecipherable]. The Ryan White Planning Council
18 is the only federally funded program that I know
19 of that is mandated by legislature that as a
20 condition of the city or jurisdiction getting its
21 funding, that the elected official must establish
22 an independent planning body made up of people
23 affected with HIV as well as community members and
24 that they have sole authority over how to allocate
25 and set priorities for this funding.

1 It is different from anything else.
2 Different from community development block grant;
3 different from [Indecipherable]; different from
4 defense department. Any other federal funding you
5 can think of, when the money gets into the
6 jurisdiction, it's left up to government
7 officials, bureaucrats, whatever you want to call
8 them to decide internally how to spend that money.
9 That's been that way since the bill was passed in
10 1990 and the City received its first award in 1991
11 if I think I have my years right.

12 So this has been a long history here and
13 this is something we very much cherish.

14 Carrie Fisher is going to talk for a
15 moment [indecipherable] the context of how this
16 actual meeting came into being. I just sort of
17 wanted everyone to be aware of the importance of
18 today in the context of making decisions over how
19 this planning body is going to proceed to set
20 priorities for its roughly a hundred million
21 dollars in federal funds it gets.

22 And the one thing that has sort of
23 become a constant I would say every since the
24 departure of Bill Clinton as president is that
25 we're not getting any new money. We're lucky if

1 we're going to receive relatively stable flat
2 funding and that is the new normal. If anything,
3 we received some cuts over the last couple of
4 years, so we're lucky if we get the same amount of
5 funding from year to year.

6 So the Planning Council has really,
7 really started to ask itself, is the current
8 allocation of resources that we currently have the
9 most effective and efficient usage of our money?
10 Are we doing right by the consumers who live in
11 the boroughs and three counties north of us? Are
12 the allocation of resources effective? And are
13 there in equities in the delivery of resources
14 between the City and State three counties north of
15 us? Is everybody getting their fair share? Is
16 everybody receiving the same quality of care
17 across the EMA?

18 And so, this -- you know, we come to a
19 point now where as Carrie is going to explain, we
20 really wanted to have a much larger dialogue with
21 the entire community about some key issues about
22 socioeconomic factors, around housing and trying
23 to think out of the box and where we can do better
24 delivering services and asking ourselves is our
25 priority setting process on the right track.

1 And with that, I'll leave it to Carrie
2 Fisher.

3 MS. DAVIS: Carrie Fisher, I like that.

4 MR. LESIEUR: I'm thinking Star Wars,
5 what can I say?

6 MS. DAVIS: Oh yes. Hi there. My name
7 is not Carrie Fisher and I don't play one on TV.
8 My name is Carrie Davis and I'm the Co-Chair of
9 the Needs Assessment Committee of the HIV Planning
10 Council and I also work at the Lesbian, Gay, Bi-
11 sexual and Transgender Community Center on
12 Thirteenth Street.

13 So, as Matt mentioned, in deciding on
14 about how we're going to spend our money, we need
15 to understand need. And the Needs Assessment
16 Committee is one of nine committees that are part
17 of the HIV Planning Council that look at different
18 issues. We focus on managing the need.

19 We work in strong concert with the New
20 York City Department of Health and we felt that
21 looking back on how things had changed over recent
22 years, in particular around HIV prevention and
23 treatment with the advent of the actually HIV and
24 Aids strategy back in 2010, that we wanted to look
25 at need a little differently. We had already

1 created a needs assessment, but it was time to
2 think more publicly about different issues that
3 were coming forth; looking at housing,
4 socioeconomic factors and co-factors and issues
5 like hepatitis C. So we thought we would look,
6 take a step back and do a public event to try to
7 share more with you all with what's going on in a
8 way that might be received and understood a little
9 differently.

10 So we've created today's event, again
11 with full work -- as part of the Needs Assessment
12 Committee, but also with the Consumer's Committee.
13 They gave us a lot of feedback about the questions
14 we should be asking, the issues and some of the
15 concerns they had about different aspects of
16 what's going -- what we're going to be talking
17 about today and we hope that we've captured all of
18 that as the day goes forward.

19 I want to talk about our format really
20 briefly. Each panel will open with a five to
21 eight presentation of data by a staff member from
22 the New York City Department of Health. These are
23 going to be the only formal presentations that are
24 going to be made today. The rest of it will be a
25 panel discussion that will be moderated. We're

1 going to try to keep to our time schedule. I've
2 already had a conversation with all the moderators
3 about moving us forward today.

4 The panelists and moderators were given
5 an opportunity to include information in your
6 packets, so some of the presentations have been
7 added to those packets and feel free to look at
8 those and use those as you need to.

9 And so finally, I just want to close by
10 acknowledging and thanking those people that work
11 so hard in this, of course, the Needs Assessment
12 Committee. My Needs Assessment Co-Chair, Daniel
13 Casionos [phonetic] is out of town right now,
14 could not be here, a long planned trip to the
15 Amazon. He's having a good time. His thoughts
16 are with us. As well as the Department of Health
17 Staff that really helped put this together; Nia
18 Rothschild [phonetic], Jan Carl Park and all the
19 other people we work with at the Department of
20 Health who really have given us tremendous support
21 in this.

22 So with that, I'm going to hand the
23 baton over to our moderator of the first panel,
24 Eric Rudy. Can the first panel take their seats
25 up here?

1 MR. RUDE: Hi. My name is Eric Rude. I
2 am the Director of Viral Hepatitis Policy and
3 Development at the New York City Department of
4 Health and Mental Hygiene and I'd like to --
5 actually before we get going with the panel and
6 before we even introduce everybody, we're going to
7 start with a data presentation on the co-infected
8 population in New York City. So I'm going to hand
9 it over first to Jacinthe Thomas at the Department
10 of Health.

11 MS. THOMAS: Good morning everyone.

12 SEVERAL: Morning.

13 MS. THOMAS: My name is Jacinthe Thomas.
14 I'm a Senior Research Analyst with the Caring
15 Treatment, Research and Evaluation Unit within the
16 New York [indecipherable] Aids and Prevention
17 Control.

18 Today, I'm going to share with you the
19 result of an analysis that we did looking at HIV
20 and HCV co-infection. So before I talk more about
21 the analysis that we did, I want to give a little
22 bit of background about HIV and HCV co-infection.

23 There was a study that was conducted for
24 which the data are shown on the left side where
25 they look at the advance events of anti-HIV drugs.

1 So they look at depths in a [indecipherable] of
2 patients who were treated with anti-HIV drug. And
3 what they found is that liver related disease,
4 liver related death was the most frequent cause of
5 non-AIDS related death.

6 They also look at among those who died
7 of liver disease. What they found is that the
8 risk of death, of dying from liver disease was
9 highest among patients co-infected with HCV and
10 Hepatitis B. So I should mention that throughout
11 the presentation, I'll use the acronym HCV when
12 referring to Hepatitis C.

13 So this graph, it show the HCV care
14 continuum. This is very similar to the HIV care
15 continuum, but what it does, it show -- sorry. It
16 shows the estimate of the number of HIV infected
17 -- HCV infected patient achieving each step along
18 the HCV care continuum from those who have
19 currently -- those who are currently infected with
20 HCV and then, as you can see, there is a
21 continuous drop throughout the, along the HCV care
22 continuum.

23 And if you look at on the last step of
24 the HCV care continuum, when we look at of all the
25 first person estimated to be infected with HCV in

1 New York City, less than ten percent achieve
2 sustained biological response, meaning that they
3 are clear of the HCV virus.

4 So now to get to the analysis, the PCSI
5 match that we use for this analysis was made
6 possible by the program collaboration and service
7 integration project at New York City DOHMH and
8 that what the project had allowed us to do is to
9 share data between programs and we were able to
10 share data across different diseases area, such as
11 TB, viral hepatitis, HIV and STDs.

12 And so using the PCSI match result, we
13 looked at three different data sources that were
14 included in the PCSI match. We looked at the ESHA
15 data where the ESHA stand for electronic system
16 for HIV/AIDS reporting and evaluation, which is
17 the main reporting system used for Ryan White part
18 A to report on Ryan White part A clients.

19 So clients were included in the PCSI
20 match where a client was served for any part of
21 2010 to 2014. And that were match through the HIV
22 registry.

23 Now the HIV registry includes all people
24 in New York City diagnosed with AIDS or HIV
25 infection and in the PCSI match, we included all

1 those from 2010 to 2013 -- 2000 to 2013. And then
2 in the PCSI match, we also included hepatitis C
3 registry data, which include all people diagnosed
4 in New York City for the same time period as the
5 HIV registry which is from 2000 to 2013.

6 We wanted to exclude a number of -- we
7 excluded all the deaths that occur and were
8 reported as of December, 2015 to us from this
9 analysis. We also, when we look at certain
10 information, which I'll be discussing shortly, we
11 -- in terms of looking at Ryan White information
12 for this analysis, we used the data which was most
13 recently reported in the HIV registry as of
14 September, 2015.

15 As of July, 2015, HIV, HCV or any result
16 has been reported, negative HCV or any result have
17 been reported to the Health Department and so we
18 use this information for the analysis using data
19 that was recently reported as of January, 2016.

20 In looking at the ESHA data, we looked
21 at the updated substance use information in ESHA
22 and insurance information for Ryan White clients
23 using data reported as of January, 2016.

24 Now onto the good part. Who is co-
25 infected with HCV and hepatitis -- HCV and HIV?

1 So using the data from the PCSI match result, we
2 look at all patient living in New York City who
3 are considered to be alive as of December, 2014
4 and for this, we use two definition when looking
5 at co-infection.

6 We use the ever chronically infected
7 with HCV, which is that the way we define
8 chronically infected with HCV is that they needed
9 to have a HCV antibody positive test in the HCV
10 registry.

11 In terms of currently, chronically
12 infected, we looked at those who were HCV -- that
13 had an HCV antibody positive or a flag in the
14 registry as -- that they were flagged in the
15 registry as chronically infected and they didn't
16 have a negative INE [phonetic] -- HCV INE result
17 at the Ryan White, meaning that they still had the
18 virus.

19 For this, we wanted to kind of get a
20 better sense of the patterns in terms of looking
21 at some of the criteria that are used when looking
22 at treatment, so we look at recent hard drug use.

23 For this, we look at the population
24 serve in 2014, so we look at all clients in the
25 PCSI match result which was 2014 was the most

1 recent result that was -- the most recent data
2 that were included in the PCSI match result for
3 Ryan White. And we look at -- so for the co-
4 infected, they needed to be serve in 2014. They
5 were flagged in the registry as being in the HCV
6 registry as being currently infected. And then we
7 also look at those, we could only look at those
8 that had none missing information for insurance.

9 So when we defined, we said hard drug
10 use, so for the ESHA data, we only looked at any
11 information that was in ESHA for this population
12 from 2013 to present. So we didn't look at any
13 information prior to 2014 when looking at the
14 recent hard drug use.

15 And then in terms of the
16 [indecipherable] information which we, which was
17 from the HIV registry, we looked at any
18 information that was reporting on [indecipherable]
19 in 2014 through 2015. So for the [indecipherable]
20 information, what we did is we look at the latest
21 information that they had in the registry and we
22 saved as an anchor and then we look at six months
23 prior to that anchor and look at whether or not
24 they had [indecipherable] and if they didn't have
25 any [indecipherable], we use that anchor as the

1 [indecipherable] information in order to look at
2 -- sorry -- in order to look at whether they had
3 detectable [indecipherable] in the last six months
4 or undetectable [indecipherable] which we define
5 as detectable [indecipherable] which is
6 [indecipherable] greater than fifty.

7 And then we look at those who had recent
8 hard drug use or detectable [indecipherable]. For
9 those that had neither -- so they didn't have
10 neither reported, neither recent hard drug use or
11 detectable [indecipherable] reported, so that's
12 the information.

13 When you look at the insurance
14 information with this information, the neither
15 reported, so they didn't report any hard drug use
16 or any detectable [indecipherable]. It was about
17 thirty-two percent for all the, we're looking at
18 all insurance information, none missing
19 information.

20 And then we had the unknown drug use and
21 no detectable [indecipherable] which is a little
22 bit lower.

23 One thing that I want to mention. When
24 we're looking at recent hard drug use, one thing
25 that we have not been able to do is that in Ryan

1 White -- in ESHA, the information on hard drug use
2 is not reported from all service categories, so we
3 have a lot of unknown, none reported is the
4 category that we mentioned above. So you see
5 there were like more than sixty percent for which
6 we don't have, we don't know anything about this
7 information. So we don't have any information on
8 this.

9 And also, I want to mention, when you're
10 looking at the neither reported, again to go back
11 to this neither reported, this is the category
12 that we think would benefit most from getting --
13 from treatment for the co-infection, for hepatitis
14 C.

15 And also, I want to mention that the
16 Medicaid begin to cover the new HCV treatment so
17 the data that we use here is from 2014, so we
18 weren't able to look, to take into consideration
19 the new treatment information in this analysis.

20 And so, also I want to mention about the
21 [indecipherable] and on insure. So those are our
22 clients in each year that reported as having
23 [indecipherable] or un-insure. However, we do not
24 have information from the [indecipherable] program
25 because this information is being held by the

1 state, so we don't have information on clients who
2 were [indecipherable] program.

3 So in talking about treatment
4 consideration, they are like multiple barriers to
5 care including treatment because before treatment
6 can be considered, the patient needs to be in care
7 and so there are things that need to be considered
8 such as lacking the patient to care and also
9 provider education to help the clients get the
10 help that they need.

11 Also, to give a brief summary because
12 the table that we just looked at had a lot of
13 information. When we look at co-infected clients
14 served in New York City in 2014, we see that in
15 terms of insurance, eighty-nine percent received
16 public health insurance. And with public
17 insurance, it's Medicare, Medicaid, military and
18 other public. While only nine percent were
19 uninsured or reliant only on [indecipherable].

20 And then when we -- to summarize about
21 the recent hard drug use, only twenty percent
22 reported recent hard drug use. However, as I
23 mentioned before, the information was only on a
24 number of clients, for seventeen percent.

25 In terms of [indecipherable] status, we

1 found out that fifty-three percent had at least
2 one detectable, which is greater than more than
3 fifty [indecipherable] in the last six months. So
4 there are a number of assistance that are
5 available for, in terms when considering treatment
6 for HCV, including drug company patient
7 assistance. Also helping the clients navigate to
8 help them receive the insurance coverage that they
9 need. There are a lot of partnerships between
10 providers and speciality companies and then also
11 as the supports for provider who has the
12 experience of treating patient with substance use.

13 To conclude, at the Department of
14 Health, we think that they are the help available
15 to -- that the majority of HCV patient could be,
16 should be able to, should be able to get treatment
17 from, through the healthcare system and we are
18 available to help and assist on a case by case
19 basis.

20 Thank you.

21 MR. LESIEUR: Thank you very much. You
22 can leave that up. Thanks. If you don't mind,
23 I'm going to refer to some of your slides. These
24 are excellent, excellent data. Thanks Jacinthe.

25 You know, this kind of data analysis is

1 vital to programs like Ryan White and
2 [indecipherable] and I know that this data
3 analysis is something that you're going to be
4 using -- oops, excuse me -- as you do your needs
5 assessment.

6 And I did want to just point out a
7 couple of things because we use things like this
8 treatment cascade. This is something that every
9 state in the country has, has created that is a
10 real good illustration of the critical gaps that
11 exist in treatment for hepatitis C, both in the
12 co-infected population and in the mono-infected
13 population. And you'll just see that, at the very
14 end here, there are very few people that are being
15 cured. This is very few people, both with HCV and
16 also co-infected HCV and HIV and what this says is
17 that we need help.

18 We need help with linkage to care
19 specifically because you see that huge drop in
20 people who are infected and aware of their
21 infection. So we need people tested and then we
22 need -- there's another huge drop in people who
23 are eligible to be treated, treated and then
24 there's, you know, right here, it's a little bit
25 stable. We can get people treated and cured once

1 they're in treatment. We have the drugs now. The
2 really good drugs that will cure people. So once
3 we get them into treatment, that's fine. We just
4 need to get them into treatment. That's the
5 problem.

6 So what this analysis is showing us is
7 that there are a lot of people who are co-infected
8 who can't access treatment and that's the purpose
9 of today's discussion. And a lot of the problem
10 exists in that access to care, so what I'd like to
11 do is, at that, is introduce our panelists, so
12 from left to right, I'd like to introduce Thad
13 Smith from AbbVie who is the Director of the
14 Patient Access Programs.

15 Then we have Dr. Shuchin Shukla who is
16 in charge of the Project Inspire Program at
17 Montefiore Medical Center.

18 Paul Bolter, the evaluation -- I'm sorry
19 -- the creator of the -- gosh, Paul, I'm not sure
20 what your --

21 MR. BOLTER: I haven't created much.

22 MR. LESIEUR: Paul, what is your, what
23 is your title?

24 MR. BOLTER: Community Allocation
25 Education [indecipherable].

1 MR. LESIEUR: Thank you very much. At
2 the American Liver Foundation.

3 And then we have Melvin who is a
4 community advocate. Excellent.

5 And then Tracey Griffith, the Hepatitis
6 C Program Manager at Suny Downstate.

7 I want to thank you all very much for
8 being here today. It's really important to hear
9 from community members like yourselves,
10 professionals and consumers. So let's get started
11 with some questions. What kind of barriers and
12 let's see, Melvin, I'd like to start with you.

13 First of all, before we even get to
14 barriers, would you like to tell us what your
15 story is with HIV co-infection?

16 MR. SHEPHERD: How long do I have?

17 MR. LESIEUR: Well, you know what, I'm
18 going to be generous. Why don't you start and
19 pick up one of those microphones and tell us all
20 about yourself.

21 MR. SHEPHERD: Oh. I'll try to do this
22 as briefly as I can.

23 MR. LESIEUR: All right. Excellent.

24 MR. SHEPHERD: My name is Melvin
25 Shepherd. I'm sixty-one years old. I'm co-

1 infected with HIV and Hepatitis C.

2 MR. LESIEUR: Would you put your
3 microphone up?

4 MR. SHEPHERD: All right. I've been
5 peer educated at ASC/NYC for fourteen years.
6 Today I stand here in good health thanks to my
7 doctors and my support at ASC/NYC.

8 For many different trainers and
9 workshops and events concerning HIV and hepatitis
10 C, today I am more informed about my situation and
11 the things I need to do for myself to make it
12 better.

13 I've learned the important facts that my
14 doctors are a very important part of my life. It
15 is important for me to take my medication and for
16 me to get my -- it's very important for me to get
17 my proper rest and keep my doctor's appointment.
18 Sometime I may feel, find things in my labs that I
19 don't understand. I'm so glad I have ASC to help
20 me understand them.

21 From the year 2006 to 2007, I was on --

22 MR. LESIEUR: You're going to have to
23 keep the mic up.

24 MR. SHEPHERD: -- oh. I've been doing
25 [indecipherable]. I was at [indecipherable] for

1 eighteen months. I went through the side affects
2 for one day. The longest day of my life. I had
3 hot flashes for three minutes. I had cold flashes
4 for another three minutes for three hours. I was
5 in my wellness room at ASC/NYC. The drug staff
6 member there, Mr. Mondo Blue talked me into,
7 talked me through it. He told me to relax and
8 reminded me that I was around friends and co-
9 workers and that I would be safe.

10 And for the next eighteen months, the
11 only challenge I think I faced was taking that
12 needle, the interferon, once a week. And I'm so
13 glad that, you know, I can walk from
14 [indecipherable] back to ASC and felt comfortable
15 because I was a peer there. I was still able to
16 work and everything and, you know, try to help
17 other people.

18 MR. LESIEUR: I'm sorry. Melvin, you
19 were on the interferon treatment, weekly
20 injections. Is that right?

21 MR. SHEPHERD: Yes, yes, yes.

22 MR. LESIEUR: And you're cured now?

23 MR. SHEPHERD: No, no. That's never
24 part of it. This was in 2006 to 2007. I stayed
25 on it for eighteen months because they gave me an

1 extra six months. The treatment was for twelve
2 months. They gave me an extra six months to make
3 sure it was gone because I was undetected.

4 Two years after being through that and
5 then nine months after all the treatment, it came
6 back in me. It came back. And I wasn't -- I
7 mean, I don't know how it got there. I practiced
8 safer sex. ASC taught me a lot of things and I
9 know to protect myself at all costs is one of
10 them.

11 Skip to let's say 2010. I went to
12 another hospital. I went to Sam's Clinic, Saint
13 Lukes, one hundred fifty-ninth Street and my
14 doctor, Abigail Zula [phonetic], she was very
15 good. She monitored my hep C. My HIV was still
16 undetectable. I was told in 2015 about a new
17 treatment that appeared to work in people of
18 color. My doctor put me on that list for people
19 that really needed it and by -- and this, in
20 October of 2015, I was able to get that drug,
21 Harvoni.

22 Let's say the first week, the first week
23 of it, I went through all the side affects;
24 dizziness, weakness, confused and at that time, I
25 believe I consulted one of our new drug staff at

1 ASC, Ms. Daniel Barnes and I told her about all my
2 symptoms and I told her when I took my medication.
3 And she said, "Well, take it at night." And I
4 couldn't believe it. It worked. I had no
5 symptoms after that.

6 And so today, let's say three months
7 later, I took the Harvoni from October to
8 December. Right now, I'm off it. I'm
9 undetectable and my HIV is undetectable and let's
10 say ASC helped me a great deal with the support
11 and the health information and referrals that I
12 received. I'm in good shape and I hope to remain
13 that way.

14 I would like to thank the panel. I
15 would like to thank Ms. Nan [phonetic] for having
16 me and I would definitely like to thank my staff
17 at ASC for coming here to support me and for, you
18 know, keeping me, keeping on.

19 MR. LESIEUR: Excellent Melvin. I
20 appreciate that.

21 I just have a follow-up question for
22 you. So you said you're undetectable now.

23 MR. SHEPHERD: Yes.

24 MR. LESIEUR: For how long.

25 MR. SHEPHERD: Three months now.

1 MR. LESIEUR: All right.

2 MR. SHEPHERD: Oh no, two months.

3 MR. LESIEUR: All right. Dr. Shukla,
4 how long is it -- do you mind picking up a
5 microphone? How long before Melvin would be
6 considered cured?

7 DR. SHUKLA: Three months after the last
8 pill.

9 MR. LESIEUR: Okay. So, I'd say Melvin,
10 you're well on your road to calling yourself a
11 cure, right?

12 MR. SHEPHERD: Maybe.

13 MR. LESIEUR: All right. Excellent.
14 That's a success story. So you were able to get
15 Harvoni which is the newest, one of the newest
16 directly acting anti-virals.

17 MR. SHEPHERD: Yes.

18 MR. LESIEUR: Many people, however,
19 can't. It's one of the newer drugs. We were very
20 fortunate to have these new, the new very high
21 priced drugs on the market in 2014, however access
22 to these drugs is very limited. And I wonder if
23 someone on the panel can describe what the
24 limitations are. Dr. Shukla, would you be able to
25 discuss some of the conditions that exist for

1 people?

2 DR. SHUKLA: Sure. So I think for co-
3 infected patients, it hasn't been the biggest
4 problem. There's a real long process in getting
5 medication from insurance companies. And as a
6 physician, usually we don't have time to spend,
7 you know, probably up to an hour or two of
8 paperwork and phone calls to get it done, but if
9 you get it done either with help or yourself,
10 usually it gets approved.

11 I think the harder situations are for
12 mono-infected, so people without HIV that have hep
13 C, they often get denied depending on the
14 insurance company.

15 However, it's still a pretty long
16 process and it's a barrier as a doctor. If I
17 didn't have help doing it, I probably wouldn't be
18 doing it.

19 MR. BOLTER: May I say something?

20 MR. LESIEUR: You may, Paul. Thank you.

21 MR. BOLTER: Hi. Good to hear you,
22 Melvin. Thank you.

23 I had hepatitis C for thirty years. I
24 got diagnosed in 2001 and I didn't get cured until
25 2014 and in that time, I was on treatment seven

1 different times and what happened was is that
2 there were so few hep C drugs for someone that was
3 mono-infected that if one drug didn't work after
4 six months, they took me off of it. Then I had to
5 wait two years and then I would go on another
6 study and it was like that through fifteen years.

7 Fortunately, my F1 score never went past
8 a zero one, but for many, many people with hep C,
9 that's not the case. So what happens is, is while
10 they're waiting to be approved for a new drug or
11 waiting for a drug that they can financially
12 afford based on their race, gender, HIV status and
13 what have you, disease does progress and sometimes
14 rapidly.

15 So that's like one of the biggest
16 barriers, especially if there are other co-
17 morbidities. If I had diabetes, if I had kidney
18 disease. All these other factors take place in
19 what treatment I'm going to get and then you have
20 certain providers that will only prescribe one
21 medication or one protocol. And that's not the
22 best protocol for everybody, so patients often
23 have to shop to find a doctor that will give them
24 the medication without these included barriers.

25 MR. LESIEUR: Often on their own without

1 assistance.

2 MR. BOLTER: Without navigation.

3 MR. LESIEUR: Right.

4 MR. BOLTER: Because sometimes the
5 navigation isn't in place.

6 MR. LESIEUR: Right.

7 MR. BOLTER: So once the person is
8 diagnosed, linkage to care has to happen right
9 then and there within the same facility not refer
10 out to linkage to care because you'll lose the
11 patient.

12 MR. LESIEUR: Exactly. Tracey, you run
13 a program at Suny Downstate. What kind of
14 assistance do you provide for patients who are on
15 hepatitis C treatment?

16 MS. GRIFFITH: So, at Downstate, we have
17 a program funded through the Department of Health
18 where it's specifically to link people who are co-
19 infected to care.

20 So I, in my team, I have a peer and I
21 have a case manager, a navigator and there is
22 myself. So between the three of us, we're able to
23 kind of go out into the community in Brooklyn,
24 test people and get them into care.

25 So typically for my program, we -- I can

1 probably get someone on treatment within a month,
2 two months usually tops. All of my patients that
3 have been referred to me, I have gotten medication
4 for. It takes a little time, like the doctor
5 said, but I'm able to do it. And it's -- one of
6 the key things with hep C is that you do need
7 support. So if there's only a provider, it's
8 much, much harder for the patient to get treatment
9 versus at least having a nurse or a case manager
10 or someone in the team to help navigate the
11 system.

12 MR. LESIEUR: You said navigation is
13 key?

14 MS. GRIFFITH: It is key because if we
15 have -- I have encountered many people who, and
16 many doctors, who are trying to treat hep C and
17 they just don't know what to do, where to go or
18 where to send the patient and if you have someone
19 who can actually -- who's like a peer, a peer is
20 great especially since they've been through the
21 process, they know what it takes, they know what
22 they need to do. That peer is able to help other
23 patients kind of get through the system,
24 understand what to expect, what labs need to be
25 done so that they can get the treatment.

1 So it's really important to have at
2 least a nurse or a case manager around that can
3 help the person, the patient, figure out a plan
4 for them.

5 MR. LESIEUR: Creating a care plan.

6 MS. GRIFFITH: Right.

7 MR. LESIEUR: With a multi-disciplinary
8 medical team is appropriate.

9 MS. GRIFFITH: It's appropriate. It's
10 ideal.

11 MR. LESIEUR: Uh-huh.

12 MS. GRIFFITH: It's not always the
13 perfect set up for everyone. It's not something
14 that everyone is able to have, but having the
15 multi-disciplinary team is a hundred percent best.

16 MR. LESIEUR: Right.

17 MS. GRIFFITH: In my opinion.

18 MR. LESIEUR: And you also mentioned
19 peer navigation.

20 MS. GRIFFITH: Right. So we have -- a
21 lot of programs are now developing peers. The
22 Department of Health also has an HCV peer
23 navigation program and they're able to assist
24 patients or people who are hep C positive to find
25 them a provider that actually treats the virus, so

1 they're able -- so you're not really -- the
2 patient is just not left out by themselves trying
3 to figure out what to do. The Department of
4 Health does have help out there to help people
5 find where they can get care throughout the city.

6 MR. LESIEUR: And these are peers like
7 Melvin who would have gone through treatment and
8 then been able to help other folks.

9 MS. GRIFFITH: Right.

10 MR. LESIEUR: Melvin aids community
11 service center --

12 MR. SHEPHERD: Yes.

13 MR. LESIEUR: -- has programs like that.
14 Am I right?

15 MR. SHEPHERD: They have a lot of them.
16 A few program --

17 MR. LESIEUR: Would you mind picking up
18 a microphone?

19 MR. SHEPHERD: Yeah.

20 MR. LESIEUR: Thanks.

21 MR. SHEPHERD: Yeah, they have a lot of
22 support books and I think that's very important
23 because a person like me, myself, can sit with
24 other people and talk about our problems and feel
25 very open about sharing and that's a big deal.

1 You know, just to have that environment.

2 MR. LESIEUR: Exactly. Other kinds of
3 support are necessary. Dr. Shukla was discussing
4 how a lot of the paperwork that goes into
5 authorizing patients who need the treatment in
6 order to get the insurance approved, insurance
7 reimbursement improved.

8 Thad, you help patients with this -- you
9 have a patient assistance program with AbbVie, can
10 you describe the assistance you provide?

11 MR. SMITH: Sure. Good morning
12 everybody. Can I have like two minutes for a
13 quick aside?

14 MR. LESIEUR: Sure.

15 MR. SMITH: Okay. So at events like
16 this, I reflect back on my history with HIV and
17 about thirty years ago, as a then student at a
18 military college, I stumbled on this HIV event at
19 the Washington Mall. I don't know if -- I'm sort
20 of older than some of the people in the room, but
21 there's this thing called the quilt. I don't know
22 if any of you remember that, but that was my first
23 impression and my first learning about HIV and now
24 here I am about thirty years later working the
25 drug company that's helped advance treatment of

1 both HIV and HCV and as I'm sure everybody knows,
2 HCV is now killing more people than HIV. So made
3 a lot of progress, but there's still a lot of work
4 to be done.

5 So with that, my responsibilities at
6 AbbVie that I oversee are patient assistance
7 programs that serve people in the United States
8 across all of our different disease areas,
9 including both HIV and HCV.

10 We offer a whole set of services to help
11 people access their medicine which can include
12 helping people in doctor's offices with navigating
13 the insurance hurdles, like prior authorizations
14 and then appeal support.

15 And then we offer co-pay assistance for
16 people who have commercial insurance and still
17 need some help.

18 And then the area that I'm most focused
19 on is free medicine for people that can't afford
20 it most of whom don't have -- can't access it,
21 ideally because they don't have insurance, but
22 what we found in this disease in particular, there
23 are so many people that even with insurance,
24 they're just not able to access it because of
25 insurance restrictions primarily related to

1 [indecipherable] scores. Some also related to
2 drug and alcohol use as well, or preferences for
3 certain drugs by health plans.

4 So what we try to do is if people can't
5 access their medicine through insurance is they
6 most often qualify for free medicine and then they
7 can get their course of therapy delivered to their
8 house or to their doctor's office from our service
9 providers.

10 MR. LESIEUR: So I imagine that if
11 someone is uninsured and possibly not approved
12 through [indecipherable], they would be able to
13 get their medication through your patient
14 assistance program?

15 MR. SMITH: It's a case by case
16 situation, but if they're -- generally, if they're
17 not approved and they've gone, gotten the initial
18 -- the necessary denials, they would be approved.

19 MR. LESIEUR: Right. Okay. Excellent.
20 Yes, Paul?

21 MR. BOLTER: At the American Liver
22 Foundation, we have an affiliation with the PAN
23 [phonetic] Network, which is also a Patient
24 Assistant Network. We ask people to call our,
25 call into our call line. It's 1-800-Go-Liver and

1 we get over almost six thousand calls last year
2 alone just hep C related. People from Egypt, all
3 over the world, looking for assistance with
4 medication and services here because it's more
5 assessable here than it is in a lot of other
6 countries, so this project [indecipherable].

7 There's a lot of different programs out
8 there as well that help supplement you along the
9 way because some people with insurance still have
10 a three, four, five thousand dollar co-pay.

11 So there's a lot of different programs
12 outside of like what Abbie is doing and Abbie has
13 been one of the leaders in continuously supporting
14 patients with hep C. I just wanted to add that.

15 MR. LESIEUR: Thanks Paul. Paul, while
16 we have you, what other services for patients who
17 are having difficulty accessing treatment or
18 navigating the healthcare system can you provide
19 at the American Liver Foundation?

20 MR. BOLTER: At the American Liver
21 Valuation or Foundation?

22 MR. LESIEUR: Did I say valuation?
23 Sorry. The American Liver Foundation.

24 MR. BOLTER: My role is to provide
25 education and support and advocacy to many of the

1 agencies that are in this room today from Staten
2 Island to northern New Jersey.

3 So what we do is go around and we
4 educate staff, case managers, linkage to care
5 specialists, peer navigators, patient navigators,
6 doctors, admin on liver disease, liver wellness,
7 especially viral hepatitis and hepatitis C and
8 also co-infection.

9 We can't talk about HIV these days
10 without talking about hep C and visa versa.
11 They're like the new companion diseases that are
12 out there today.

13 So what we do is provide education on
14 what kind of medications are available. Not
15 everybody is going to get Harvoni. Not everybody
16 is going to go on these drugs that are available.
17 So when we see the commercials and we hear the
18 messages, we have to always remind people that
19 yes, this commercial comes on at eleven/twelve
20 o'clock at night and everybody looks sad in that
21 commercial, but that doesn't have to be you. So
22 we try to reduce some of the stigma within the hep
23 C community because there's a lot of stigma
24 attached to this disease, especially from patients
25 living with it.

1 So we just try to provide education and
2 support around understanding the virus, what the
3 virus can do to you and how to prevent it from
4 causing further disease and damage, so if that
5 means we go to Washington and we work with the
6 House and legislation on some bills that are out
7 there, then we do that.

8 And on a local level, we work with
9 companies like ADV and the LGBT Center, the
10 Department of Mental Health and Hygiene on trying
11 to provide patient navigator network, which we're
12 actually having a meeting today, which is also
13 folks that are in this line of work of education
14 and support, come together and talk about best
15 practices and how to support the challenges they
16 have within their agencies on helping people
17 navigate through the health system.

18 So a lot of different things like that.

19 MR. LESIEUR: Excellent. Thank you.

20 I'd like to return a little bit to the
21 restrictions on treatment and I wanted to ask Dr.
22 Shukla, if I could, we -- I don't know that we
23 addressed restriction on HIV viral load. Can you
24 describe or can you just discuss that briefly what
25 that restriction is?

1 DR. SHUKLA: So I'll start with saying
2 that this is a moving target for doctors and
3 agencies and everything in terms of every
4 insurance company has their own rules. They
5 change them constantly. They aren't informing you
6 necessarily. They might post on their website.
7 They might not. So it's -- it takes a lot of
8 legwork just from that perspective.

9 So on top of that, I would say my
10 experience as a treater has been that, yeah, if
11 someone has -- so I misspoke I guess in the
12 beginning saying that usually people with co-
13 infection, meaning HIV and hep C, usually get
14 approved. That's true, but I think one of the
15 barriers is if their HIV has been detectable maybe
16 in the last six months -- it depends on how much
17 data the insurance companies request when you send
18 in the prior authorization.

19 And other reason is if they have, you
20 know, some insurance companies actually ask for a
21 U-tox, a urine drug screen, which is absolutely
22 not in line with medical recommendations, but the
23 insurance companies make these rules and have
24 denied patients meds, lifesaving meds because of
25 that.

1 Those are the main reasons I see co-
2 infected patients being denied.

3 So a positive U-tox, I would say pretty
4 clearly has no reason for denial. There's some
5 evidence that you have a slightly reduced cure
6 rate if you're taking these really great meds and
7 you are abusing alcohol or maybe more specifically
8 alcohol, but you can still get cured with a
9 really, really good chance of curing your virus.

10 Positive viral load, I saw that on the
11 list of questions and I tried to do a little
12 research. I don't think there's much data on cure
13 rates on someone's HIV viral load is detectable,
14 meaning their HIV is not under control and they're
15 taking hep C meds. I would assume the concern is
16 that the patient is not adherent with their HIV
17 meds and that's their reason an insurance company
18 might not want them to have hep C meds. Which I
19 think is somewhat legitimate, but yeah I guess
20 I'll say it's somewhat legitimate, but I don't
21 have a strong feeling either way about it, I
22 guess.

23 MR. LESIEUR: Well, I think you're
24 right. It's a moving target. I -- this is
25 something that has been a constant concern of mine

1 since the drug utilization and review board of the
2 office of, the state office of health insurance
3 had instituted these restrictions in 2014 when
4 Harvoni came on the market.

5 It's been a constant state -- cause of
6 concern because there really is no medical
7 rationale for this.

8 But I do have good news. In my
9 discussions with the state, I'm constantly
10 speaking with the state office of health insurance
11 and my colleagues at the state department of
12 health and if you recall, and you may not be aware
13 of this, but in response to these really
14 restrictive guidelines and these exist not in New
15 York state only, but all across the country, the
16 Centers for Medicaid and Medicare Services, CMS,
17 wrote a letter to every state office of Medicaid
18 and Medicare. No, I'm sorry, Medicaid. And told
19 them that they need to be aware of what's going on
20 in their own regarding these restrictions. They
21 need to not be discriminatory. They need to be,
22 they need to make sure that they're -- not just
23 their own Medicaid fee for service program, but
24 also all of their Medicaid managed care programs
25 are not overcharging and their prices are all in

1 line.

2 So our office of Medicaid -- or our
3 Medicaid program in New York state is actually
4 surveying each one of their Medicaid programs
5 right now as we speak and they're going to have a
6 definitive list of what all of their restrictions
7 are.

8 So you were saying it's a moving target
9 and you're right. Each one has their own list of
10 what their restrictions are. They may on Monday
11 do one thing and on Tuesday, do something entirely
12 different. So we will finally know what they are,
13 what the restrictions are once the survey is
14 completed.

15 But I think too that because the market
16 is changing, because now we do have more drugs on
17 the market and the price may be reduced that the
18 restrictions may not be so important any more
19 either. So we'll see.

20 Let me just take a quick look at the
21 time. We may be ready for our Q&A period. A
22 couple more minutes?

23 So, Melvin.

24 MR. SHEPHERD: Yes.

25 MR. LESIEUR: Let's talk about your life

1 post cure. You are now a man who has the freedom
2 to do whatever you want. What is it like being,
3 you're a peer navigator for Aids Service Center.

4 MR. SHEPHERD: Yes.

5 MR. LESIEUR: And how is it, how does it
6 feel after having hepatitis C for how many years
7 you had it with your HIV? What is -- how does it
8 feel different to you?

9 MR. SHEPHERD: First of all, I've been
10 diagnosed with HIV since 1986 and I think I found
11 out about my hep C in 2005 and upon learning these
12 things that's happening in my life, it was game
13 changers. I listen to people. I took advice.
14 And I got with the program, ASC/NYC that really
15 helped me stay on track and so I try to be a role
16 model, you know? I don't think I'm better than
17 nobody. I just listen now, you know? You bump
18 your head enough, you learn.

19 MR. LESIEUR: Excellent. Tracey, what
20 -- do you feel that some of the programs that
21 you've instituted at the -- are you -- by the way,
22 is it the STAR program that you work in?

23 MS. GRIFFITH: Right. The STAR program.

24 MR. LESIEUR: The STAR program at Suny
25 Downstate. Are some of the programs that you have

1 that are successful, are they scaleable [sic] to
2 the rest of the city and state, do you feel? Or
3 is it too financial -- is there -- is money and
4 finances and funding an issue?

5 MS. GRIFFITH: Funding is definitely an
6 issue. Without the funding, we wouldn't be -- I
7 wouldn't be able to have a team. I would be doing
8 the prior [indecipherable], education, the
9 counseling. I would be doing everything.

10 MR. LESIEUR: Uh-huh.

11 MS. GRIFFITH: So definitely having the
12 funding to bring on people to help you get the
13 prior authorization or to support the doctors is
14 important.

15 It's also important to -- it helps us go
16 out into the community and test people for hep C.
17 We weren't -- I was not able to do that post a
18 year ago before my grant.

19 So it's -- funding is a hundred percent
20 a necessity in a lot of -- especially in the STAR
21 program, but a lot of other programs within the
22 state to help go into the community and get the
23 patients to come into care because we cannot
24 expect that the patient will just come to us. We
25 have to go find them, basically. And it's hard.

1 It's very difficult to try to find the patients.
2 We, we -- I've encountered more mono-infected
3 patients than co-infected recently, but we're
4 still able to treat everybody.

5 MR. LESIEUR: That's excellent.

6 MS. GRIFFITH: Right. So you know, I've
7 done a lot. I've done pretty much all of the PAs
8 for my patients, so it takes me a long time to do
9 it, but I'm able to do it. You know, I do get --
10 I'm in I think seven or eight appeals right now,
11 doing two state appeals. You know, there are a
12 lot more insurance companies that are easier to
13 deal with versus others.

14 With the viral load, I've encountered,
15 with the hep C viral load, if they're under eight
16 hundred thousand that the insurance company has
17 actually denied it saying that they were not sick
18 enough. So I've encountered that and I've had to
19 write letters to get them approved.

20 Yeah, it just makes my, it makes it
21 longer to do, but I'm still at it. I still do it.

22 MR. LESIEUR: It's a burden.

23 MS. GRIFFITH: Right.

24 MR. LESIEUR: And it costs money. And
25 in summary, I just wanted to point out there are

1 two, two real barriers and one is the funding,
2 obviously, to find patients and to navigate them.
3 Again, that will alleviate this barrier, this huge
4 gap here between knowing that you're positive for
5 hepatitis C and not knowing that you're positive
6 for hep C.

7 The other barrier is once they're in
8 treatment or rather getting them into treatment is
9 that other barrier. People who are not able to
10 get into treatment because they are denied
11 treatment is the next barrier. So that's
12 something to consider here during this panel.
13 Those two barriers.

14 And you know, I've been doing hepatitis
15 work for fifteen years and we had no treatments
16 for a very, very long time and once those new
17 wonderful treatments came out, we in the business
18 thought it was all over. Everyone was going to be
19 cured. Once you do, you cure a majority of people
20 in the population, you have that ability to then
21 realize that you can -- if you cure everybody or
22 cure the majority, the virus will eventually you
23 know, leave the population.

24 But because then the price was -- most
25 people were priced out of it, then on top of that

1 have the insurance barrier added to that where
2 people couldn't access the treatment. That was
3 the, that you know, that prevented us from that
4 dream, realizing that dream.

5 So here we are back in ten years ago
6 where we're seeing it off in the distance again.
7 Seeing the end of this epidemic off in the
8 distance, but you know, we may be on the road
9 again. As the prices drop, as the treatments
10 become better and continue to get better and
11 insurance companies realize that people need the
12 drug, money becomes available, we'll hopefully see
13 the end of this.

14 So right now, I'd like to thank the
15 panel. Can we give everyone a real big hand?

16 And we have plenty of time for
17 questions. I have several microphones.

18 FEMALE: Hi, I have a question. Are
19 there any data at this point on reinfection rates
20 of co-infection or just hepatitis C?

21 MR. LESIEUR: Dr. Shukla, would you like
22 to answer that?

23 DR. SHUKLA: Okay. I should have
24 studied before I came. There is data. I'm not
25 incredibly familiar with it. The rate is quite

1 low and so some people use this as an argument of
2 why a person who injects drugs should not be given
3 meds, but my argument would be treating that
4 person prevents that person from infecting others,
5 so you know, in the HIV world, we treat as
6 prevention. I think that's sort of the mantra
7 moving into the hep C world. But I don't have the
8 exact number off the top of my head.

9 MR. LESIEUR: Yes, sorry.

10 MALE: If I could just give a little
11 insight on that. A lot of information I'm hearing
12 about reinfection is due to lack of education, so
13 when someone is finished with the twelve weeks of
14 treatment and then another twelve weeks, they're
15 given the cured diagnosis, they're given a message
16 hopefully from their doctor that after two weeks
17 of stopping medication to dispose of your personal
18 hygiene products; nail clippers, fingernail files,
19 toothbrush, razors. I shave my head. Any of that
20 stuff that may contaminated blood, that you may
21 have used prior to clearing the virus.

22 And watching out for nail salons and
23 pedicures and certain things like that where other
24 implements may have been contaminated and that's
25 like a standard message that's given out from a

1 lot of providers, so a lot of people miss that
2 message, but that has impact on some reinfection.

3 MR. LESIEUR: There's a question here.

4 FEMALE: I guess it's a comment and a
5 question. One thing that I didn't hear come up
6 was the utilization of syringe exchange programs?
7 And the fourteen of those across the city and in
8 treating active drug users, that that's a really
9 important step to make sure that you're linking
10 people back to syringe exchange program so even if
11 they are using while they're on treatment or they
12 continue using even when they're done treatment to
13 make sure that the providers are having that kind
14 of conversation with them to know where they
15 should go, know what they need, know how to stay
16 safe, know how to prevent reinfection.

17 And I heard a lot about patient
18 navigation, but not necessarily linkage to syringe
19 exchange programs.

20 MALE: I think that's part of it at the
21 patient navigator network, many of the people that
22 come to the meeting work for SEPs.

23 FEMALE: Uh-huh.

24 MALE: So they do have a really active
25 role and they're very visible in the community.

1 Thank you.

2 MR. LESIEUR: Over here.

3 MALE: Yeah, hello. Good morning. Up
4 to ninety-seven percent cure rate is formidable
5 and it's very promising and encouraging, however,
6 a cure is not a vaccine and it highlights what
7 Melvin mentioned. It highlights [Indecipherable]
8 reduction and educating. One serves an education
9 about how to prevent transmission of HIV -- HCV as
10 well.

11 Thank you for bringing that up in front
12 of us.

13 I would like to ask a question to Dr.
14 Shukla. If a patient is unable to access
15 treatment, how would you feel about referring this
16 patient to a clinical trial?

17 DR. SHUKLA: I don't know. Do you have
18 an answer to that? I mean, clinical -- so the
19 meds that exist all work really well, so in terms
20 of a clinical trial, I don't know if that would be
21 my best solution for a patient who's unable to
22 access medication. I, you know, the few patients
23 who can't access medication whether it's because
24 of their U-tox or their viral load or under
25 insurance, in some cases I would refer to like a

1 program like [indecipherable], a patient
2 assistance program.

3 But yeah, I don't know much about
4 clinical trials. Sorry.

5 MALE: I have another one here.

6 MALE: Yes. This is for Mr. Smith. You
7 have an acronym behind your name, AbbVie. I'd
8 like to know what that stands for.

9 MR. SMITH: Oh yeah. No, that's the a
10 reference to my employer, AbbVie, the drug
11 company. I don't have any acronyms after my name.
12 I want one, but I don't have one.

13 MR. LESIEUR: Anybody else?

14 MR. JOSEPH: My name is Howard Joseph
15 from Exponents. I think maybe more Melvin, I want
16 to share. I had hepatitis C for fifty years. I
17 stood on the sidelines with the interferon because
18 I distrusted what the pharmaceutical companies
19 were claiming and what the department of health
20 was claiming that they were having cures of sixty
21 to seventy percent with the interferon treatment.
22 I didn't see that in my friends who were being
23 treated. It was like one out of ten were reaching
24 what we call the cure.

25 Last year at this time, I went on the

1 Harvoni -- I wanted to go on the Harvoni treatment
2 and I'm on Medicaid and I'm working full-time, I'm
3 on Medicare. And they were hitting me with a co-
4 payment of fifteen thousand dollars for the three
5 month treatment and I just said, "Hold on. Hold
6 on." But one of the foundations that Gilliad
7 [phonetic] I think, put together, at some point
8 they had these foundations that will pick up the
9 co-payment and this foundation picked up my co-
10 payment and I went forward with the treatment and
11 I got to say, it was a piece of cake. I won't to
12 put that out here. Harvoni made the cure a piece
13 of cake. I took my medications for three months
14 and at the end of ninety days or sixty days
15 afterwards, I did another blood test. They told
16 me I was cured and that foundation sent me a
17 medal.

18 FEMALE: Hi. Good morning. Thank you
19 all for your presentations.

20 There's a practice that insurance
21 companies do that's called adverse tiering where
22 they automatically put certain drugs for certain
23 diseases in particular tiers that have more
24 expensive co-pays, etcetera. And I just, I'm
25 trying to -- I just want to clarify in my own mind

1 that the insurance barriers that you all spoke
2 about in terms of hep C, that is not adverse
3 tiering. Correct? The insurance barriers that
4 patients face who are hep C infected are because
5 of eligibility and because of lack of insurance to
6 begin with.

7 MS. GRIFFITH: It varies. It kind of
8 varies. It's a little bit of what you're saying.
9 It's a little bit of what we're saying. It really
10 depends on the insurance company. They -- I've
11 encountered in the last, I think, three weeks
12 where we've written for one prescription, one
13 particular medicine and the insurance company has
14 come back and said, "No, we cannot give that
15 medication. We have to give something else." But
16 the medication that was written was because there
17 was a particular issue, medical issue, that
18 warranted that medication and so a lot of
19 insurance companies are now trying to force us to
20 write for one versus the other because one is a
21 little bit cheaper than the other one.

22 So it, it does happen. It can and it
23 happened -- it just happened to me last week
24 twice, so right now, currently, I'm appealing it.
25 Right.

1 FEMALE: It's against the law.

2 MS. GRIFFITH: Right. It is, but the
3 insurance company doesn't really care. So, --

4 MR. LESIEUR: This is what, this is what
5 that letter that I was describing to you was
6 about.

7 MS. GRIFFITH: Right.

8 MR. LESIEUR: They are trying to get
9 away with something and it's up to the state
10 office of insurance to not let them do that.

11 MS. GRIFFITH: Right. It's hard, but
12 you know, it takes a long time. I know probably
13 in your practice it takes a long time. It just,
14 it's just all about being diligent and keeping at
15 it. I feel, I really do feel sorry for doctors
16 who are in a practice by themselves and don't have
17 at least one other person to help because that
18 doctor -- the insurance company will always deny
19 the prescription and the doctor will say, "Well,
20 you can't get it." And I've encountered a ton of
21 patients in that category.

22 So it's really, it's very difficult.
23 It's really important to have a team or at least
24 external support.

25 DR. SHUKLA: And just to piggy back on

1 what Tracey was saying and your question. So
2 there's -- at this point, let's say about five or
3 six different regimens depending on the genotype.

4 MS. GRIFFITH: Uh-huh.

5 DR. SHUKLA: So and all of these meds
6 work really well with cure rates let's say above
7 ninety, ninety-five percent depending on a few
8 things.

9 MS. GRIFFITH: Right.

10 DR. SHUKLA: But these meds are not
11 equal specifically, just from a medical standpoint
12 in terms of drug interactions.

13 MS. GRIFFITH: Uh-huh.

14 DR. SHUKLA: So this, I would say, is
15 sort of a barrier that's specific to co-infected
16 patients in that the HIV medicines often interact
17 in pretty significant ways with hep C medicines
18 and if someone has lived with HIV for decades,
19 they might have been through a couple of different
20 regimens where they can't really switch from this
21 medicine to that medicine and so with all due
22 respect to AbbVie, AbbVie is actually one of the
23 medications that has some more side affects,
24 outside of its drug interactions.

25 So the problem becomes, you know, these

1 insurance companies will make a deal with this
2 drug company or that drug company to say this is
3 the one we prefer, this is the one that only
4 doctors can get --

5 MS. GRIFFITH: Uh-huh.

6 DR. SHUKLA: -- when it's not really in
7 the patient's interest.

8 MS. GRIFFITH: Right.

9 DR. SHUKLA: It's really in some maybe
10 stock holder's interest or financial person's
11 interest.

12 MS. GRIFFITH: Uh-huh.

13 DR. SHUKLA: And also folks that are
14 non-responders to treatment will fall into another
15 category, but usually sometimes the rule on the
16 street is you get one prescription a lifetime for
17 your hep C because it's such a challenge. You
18 know, people advocate to get referrals processed
19 and you get the drugs, but then if you fall out of
20 care, non-compliance, adherence or the drugs don't
21 work, what do you do then with this patient that
22 you spent eight months trying to get on care?

23 So sometimes the insurance companies
24 create that challenge as well. It's not maybe the
25 patient's fault the drugs didn't work, but how do

1 we get them another prescription after the first
2 one was so hard to get?

3 MR. LESIEUR: We have time for one more
4 question.

5 MR. OCEANS: Thank you. Jeff Oceans
6 from the Department of Health. What legal or
7 political actions are actually being taken right
8 now to make these drugs more assessable or
9 actually to make them cheaper?

10 MR. LESIEUR: Wow. That's a very good
11 question.

12 MALE: There's a lot of answers to that.

13 MS. GRIFFITH: Who will take that one?

14 MALE: No hope.

15 MR. LESIEUR: Right now, the latest news
16 is that Washington State just filed a lawsuit
17 against its State Medicaid program. Indiana is
18 about to sue their state Medicaid program.
19 Connecticut last year threatened to sue their
20 state Medicaid program. You know, that might
21 work.

22 So those are, you know, large actions.
23 On the ground though, I think there's also actions
24 that, that we can do at the grass roots level and
25 in New York State, there is a group called the New

1 York State Hepatitis C Coalition that's actively
2 working on this issue. You know, there are things
3 you can do to lobby your legislators or lobby the
4 Medicaid office or lobby the Drug Utilization
5 Review Board. They have meetings quarterly and
6 you can, you can apply, you can actually -- you
7 can voice your concerns with the Drug Utilization
8 Review Board. Now whether they listen to you or
9 not is, you know, it depends. But if there are
10 enough of us, they might hear you.

11 So those kinds of things can happen. I
12 think, unfortunately, however, time is really our
13 best, our best -- fortunately or unfortunately,
14 it's our best friend because I think, again, the
15 market is really starting to change because of
16 competition so that might be the best answer.

17 MALE: Just one more question I have if
18 I may? I'd appreciate it.

19 Harvoni is a fairly new drug. I know
20 the patent would last for X amount of years, so
21 how long before the patent will expire so you can
22 start doing some generics?

23 MALE: I think it's seven to ten years
24 for a patent. Ten years, right?

25 MS. GRIFFITH: It's about ten years for

1 a patent.

2 MALE: In ten years, like maybe a third
3 of people with hep C will be dead. I mean, it's
4 -- I just want to point something out about this,
5 the drug cost conversations.

6 So you know, I've seen studies, you
7 know, if we estimate there's two point six million
8 people in America with hep C. If we treated all
9 of them in one year, it would wipe out pretty much
10 the entire healthcare budget. So we can't really
11 just make this accountable to state Medicaid
12 offices. Really, the drug companies are holding a
13 gun to the American taxpayers' head. There's not
14 too many treatments we can do as doctors that are
15 as life saving and have such a mortality benefit
16 as treating and curing hep C and if we had maybe a
17 different patient population that weren't maybe
18 more minority and more drug users, I'm sure the
19 conversation would be different. But really, this
20 is a conversation about social justice and
21 patients aren't getting access to care for
22 absolutely non-medical reasons.

23 So I mean, I run a program that has a
24 pretty decent budget, but we've joked that maybe
25 it's worth using that money to buy a cruise ship

1 and bring all these patients to a third world
2 country where these drugs are tremendously cheaper
3 from the same drug companies. I mean, why is
4 America paying so much for these meds?

5 There's a hundred million dollars in the
6 Ryan White fund. That's like a thousand patients
7 to cure. I mean, that money wouldn't go very far
8 considering how expensive these meds are, so I
9 think that's a conversation that also needs to be
10 had.

11 MR. LESIEUR: Excellent, excellent way
12 to end. Thank you.

13 MANY: [Many talking at once as it
14 sounds as if meeting was adjourned].

15 MS. BARRETT: Hello everyone. Can we
16 get back to our seats please, so we can begin?
17 Okay. So as we get started, that was a great
18 presentation that we had before on hep C. And we
19 have more to present, so if we could just all get
20 situated so we can begin. It's a lot of
21 information that we're trying to crunch in a very
22 short time.

23 Okay. So we're going to begin our
24 second panel, but before we begin, so this panel
25 is on socioeconomic vulnerability with an emphasis

1 on employment and economic well being. It's a big
2 title and a lot of information, right?

3 Okay. So we're going to -- so as we did
4 before, we're going to have a very short data
5 presentation and a lot of information I must say
6 that's in your packet as well about this topic
7 that we're going to present. So we're going to
8 have Mary Irvine. She was here before. Okay,
9 here we go. That's going to do a quick data
10 presentation that we can use to start our panel
11 presentation.

12 Thank you.

13 MS. IRVINE: To make this shorter. All
14 right. How's that? My boots? Maybe it's my
15 boots.

16 So I'm just going to try to give you a
17 little local context in terms of the Ryan White
18 part A data that our providers diligently report
19 to us through E-share.

20 In the background, you pretty much
21 already I'm sure are aware of employment. We're
22 thinking about partly because it's a key resource
23 for becoming financially stable and insuring
24 housing stability and just economic self
25 sufficiency and as the sort of packet indicates,

1 the current treatments for HIV are effective
2 enough that more and more people are in a position
3 to go to work, go back to work while continuing to
4 manage their health.

5 And the research that's out there about
6 employment among people with HIV suggests that
7 there are health advantages, as well as sort of
8 quality of life benefits to employment. And then
9 thinking about it in terms of part A, our program
10 -- the program, of course, addresses all kinds of
11 social services and health services needs for low
12 income people living with HIV, but at this time,
13 it does not fund any kind of job placement, job
14 training or other assistance related to
15 employment.

16 That said, while we can't use Ryan White
17 funds specifically to support employment services
18 among our contractors, there are ways in which our
19 providers may be able to support employment goals
20 of their clients through referrals and linkages to
21 other programs that are funded for that.

22 And then in terms of the data, in the
23 summer of 2013, a couple of people in my unit were
24 working on looking at E-share employment
25 information which is limited. You'll see what we

1 have on it. But just, we were particularly
2 interested in seeing, you know, as a first look,
3 what's associated with being employed among our
4 Ryan White part A clients and what's associated
5 with becoming employed if you started out not
6 employed. And that's just because some of those
7 associations, there's factors that we can find
8 that are related to employment are one sort of
9 weigh-in to thinking about what are interventions
10 that we might do. Where might be intervene to
11 sort of increase these things that currently seem
12 to be associated with employment.

13 So looking at the data overall for HIV
14 positive adult Ryan White clients at that time,
15 this was just really a year and a half of E-share
16 data at the time, so 2012 and half of 2013,
17 fifteen percent of the Ryan White part A
18 population was employed either part-time or full-
19 time. We consider either part-time or full-time
20 the same. And then in terms of those -- we're
21 really interested in paid employment, so among
22 those who were not reported to be either out of
23 the work force, which could be because they
24 retired, they're a student or a full-time care
25 giver or not reported to be doing unpaid work,

1 only unpaid work.

2 We found higher odds of being currently
3 employed for pay among clients who were educated
4 at or above high school level, enrolled longer in
5 Ryan White services, which is interested, stably
6 housed, not surprising, younger, male, foreign
7 born and showing a higher CD-4 count. So CD-4 at
8 or above three fifty or for some of these people
9 not having CD-4 count which could just be that you
10 were newly diagnosed or not recently in care. I
11 think we had like a six month look back for that
12 CD-4.

13 And this is adjusting for several
14 demographic and clinical characteristics, so when
15 you hold those equal, these are the things that
16 are independently associated with being employed
17 currently.

18 And then we wanted to look specifically
19 at people who started out not employed when they
20 were enrolled in the Ryan White part-A program on
21 which we had data and see what was associated with
22 becoming employed. Now, just to reiterate, we
23 only had a year and a half of data, so this was
24 not a long stretch of time during which people
25 might sort of transition into employment. It's a

1 very short window of time for people to become
2 employed.

3 With that said, there were seven percent
4 who did become employed in that period and so
5 between their baseline assessment and a later
6 assessment in Ryan White.

7 And we found higher odds of becoming
8 employed among clients who were educated at or
9 above high school level, enrolled longer in Ryan
10 White, stably housed, younger, male and foreign
11 born. So all the same characteristics that were
12 associated with being employed currently in Ryan
13 White were associated with becoming employed if
14 you started out unemployment.

15 And however, CD-4 was the one thing that
16 wasn't significant in this smaller sub-group
17 analysis and that may have just been because of
18 the smaller end.

19 So just to sum up, any kind of
20 employment, part-time or full-time, for pay was
21 rare at fifteen percent. The odds of employment,
22 you can think of the odds as the likelihood or the
23 probability of something divided by the
24 probability of it not happening, so the chance of
25 being employed divided by the chances of not being

1 employed.

2 The odds increased with each level of
3 increased education or enrollment duration, so
4 there's this sort of gradient effect, like the
5 more education you had, the more likely you were
6 to be employed. The younger you were, the more
7 likely you were to be employed. And also true for
8 the longer you were enrolled in Ryan White, the
9 more likely you were to be employed, so there's
10 sort of gradient effect.

11 And then among those who were not
12 working at baseline and they were reassessed for
13 employment, seven percent gained employment and
14 the factors associated with gaining employment
15 were pretty much the same as those that were
16 associated with being employed in the first place.

17 So kind of when we're thinking of these
18 factors that are associated, one of the critical
19 distinctions to make is factors that we can
20 impact. What are the things that we actually
21 might be able to change or that a person might be
22 able to change over the course of their lives?

23 So demographics, often not that
24 changeable, but education, housing and enrollment
25 duration, all things that can change for an

1 individual and that we might be able to do
2 something about. Particularly in Ryan White, we
3 should be thinking about the housing association
4 because housing assistance is something that Ryan
5 White does pay for. And the retention of clients
6 in Ryan White services since clients who were in
7 services longer seem to be more likely to be able
8 to be employed and become employed.

9 And then finally just to reiterate, this
10 analysis is limited by a short time frame, so we
11 didn't get a lot of data on those transitions into
12 employment. At this point, we can go back and
13 revisit that and see how that looks.

14 We also didn't have information at the
15 time on sort of ability to work, so disability or
16 ability to work and that's something that some of
17 you may know we've been collecting in Ryan White
18 just since the start of 2014. So ESHA now has a
19 couple of years of data on sort of key
20 disabilities and that we can look at in relation
21 to employment and think about people who we would
22 particularly target to become employed.

23 So I think that really sums up what
24 we've seen so far in Ryan White. There's
25 obviously much more to look at in the future.

1 Thank you.

2 FEMALE: Wow. Thank you, Mary. That
3 was a lot of information in a very quick time. I
4 do appreciate it.

5 But with our panelists, they're going to
6 talk more about what's happening right now in our
7 current situation and go back to some of the
8 information that we see on our slides, so as our
9 panelists come up, I'll ask Carrie, Cathy, Aron
10 and David and Mark. You guys know who you are.
11 Don't be shy to come up. I'm on a first name
12 basis with all of you all.

13 You know, as our panelists get settled
14 and we're thinking about employment and income,
15 you know, it just goes back to an Aretha Franklin
16 song, No Romance Without My Finance. Okay.
17 Because I got my mind on my money and my money on
18 my mind. Okay. It goes hand in hand. Right?
19 Okay.

20 So I could have -- so we can start from
21 my right going over to my left. If we can have
22 the panelists introduce themselves please.

23 MR. MISROCK: Hi. I am Mark Misrok
24 [phonetic] and I am with the National Working
25 Positive Coalition.

1 MR. PIERSANTE: Good morning everybody.
2 My name is David Piersante. I'm the Director of
3 Eligibility for the New York City HIV/AIDS
4 Services Administration.

5 MS. DAVIS: Hi there. I introduced
6 myself earlier, but I'm Carrie Davis. I'm the
7 Chief Programs and Policy Officer at New York
8 State's LGBT Community Center and also co-chair of
9 the Needs Assessment Committee.

10 MR. COBBS: Hi, my name is Aron Cobbs.
11 I'm a Community Educator at Lambda Legal.

12 MS. BOWMAN: I'm Cathy Bowman and I am
13 the Director of the LGBT and HIV Unit at South
14 Brooklyn Legal Services.

15 MS. BARRETT: Thank you guys. And for
16 those of you guys who don't know who I am, my name
17 is Fay Barrett. I'm the Director of Support
18 Services at the Ryan Center. So welcome and thank
19 you again to my panelists.

20 All right. So I have a bunch of
21 questions and we want you to be respectful to
22 answer our questions precise enough and also to
23 leave enough time for our audience to ask some
24 questions because this is really a big hot topic
25 when we're talking about income and employment and

1 getting back into the work force and we know that
2 there's a lot of factors that prevent individuals
3 from going back into the workforce.

4 So Carrie, I'm going to pose this
5 question to you. What are some of the biggest
6 fears of HIV positive clients and HIV positive
7 transgenders who are thinking about going back to
8 the work and who have no work experience?

9 MS. DAVIS: So, I'm going to re-frame
10 this question because I think there's, there's the
11 issue of people going back into the workforce, but
12 with the transgender community, a lot of people
13 have never really been in the workforce. And so
14 for that community, it's often looked at very
15 differently.

16 I think -- I've been working in the area
17 of HIV and with trans services for seventeen years
18 now and ever since I started this work, the focus
19 was on HIV with a minor focus on other health
20 issues. But, and we now have this magnificent
21 national strategy playing out in the way we fund
22 services, biomedical prevention model that really
23 should be successful if adequately funded and
24 resourced, but the most recent research on
25 transgender people and HIV -- and prep, shows that

1 basically states that prep is not effective with
2 transgender people compared to placebo.

3 So what -- they're not saying that the
4 biology of prep doesn't work with transgender
5 people. What they're saying is that there are
6 other factors that prevent transgender people from
7 adequately staying in a course of care that allows
8 prep to work.

9 So in a sense, certain communities --
10 and this is not unusual and it's not exclusive
11 just to transgender people. We often see a
12 similar issue with young [indecipherable] of
13 color, for example, in New York City. What we're
14 seeing is the relationship of factors that place
15 people at risk keeping them from engaging in care.

16 So from my perspective, it's not an
17 issue of return to the workforce, but actually
18 preparing people to be in the workforce at a very
19 foundational level.

20 MS. BARRETT: Okay. Mark, do you want
21 to piggy back from what Carrie was saying about
22 placing people back into work and the barriers
23 that people face when going back to work?

24 MR. MISROK: Sure. I want to just sort
25 of follow up on Carrie's comments. You know, I

1 think that the -- you know, I worked for fifteen
2 years as an employment specialist for the
3 population that included a number of people who
4 were transgender who I observed experiencing some
5 of the worst discrimination in the work place of
6 any workers in communities that were more
7 progressive than the average in this country.

8 And so I think that just in terms of
9 understanding the implications when people can't
10 access living wage, healthy, protected mainstream
11 employment, the options that are left to people
12 include some of the most risky and dangerous of
13 ways to get by financially and so I do think that
14 it's important that we really zero in on the fact
15 that not just, but certainly for the transgender
16 community, we need to understand that really
17 scaling up efforts to address employment needs is
18 essential to both HIV prevention and HIV care, so
19 I appreciate that focus.

20 In terms of other needs of people who
21 have worked and are looking to go back to work or
22 those who have not. You know, the fears include,
23 huge fears about losing benefits or even the
24 ability to understand what in the world happens to
25 my benefits. We live in one of the better

1 developed service systems in this country and it's
2 very difficult for people living with HIV to
3 understand exactly what would happen if they
4 started to get work earnings to any of their
5 benefits. The information is not made clear and
6 available and public to people living with HIV and
7 I think if you check around the room, few of us
8 who are service providers or policy makers
9 actually feel like we've been, had the opportunity
10 to become well equipped to understand the
11 implications related to these important safety
12 nets for our clients. So little wonder that we as
13 a system have done very little to really support
14 and encourage people to consider and pursue
15 employment.

16 MS. BARRETT: True.

17 MR. COBBS: If I can -- I'm sorry. If I
18 can just piggy back a little bit off of what --

19 MS. BARRETT: All right. Go ahead.

20 MR. COBBS: -- Mark and Carrie said.

21 And this appreciation for understanding
22 a reentry into the workforce for in particular
23 trans people of color, as Carrie mentioned, I
24 think that we have to understand sort of
25 nontraditional sort of forms of employment or

1 work, in particular when it comes to trans people
2 of color. And so understanding that people are
3 sort of operating and navigating survival
4 economies and you know, engaged in work and are
5 being paid for certain services and -- or not
6 paid. There's certain things that people, in
7 particular trans people of color that I work with
8 in community are doing all sorts of amazing
9 things, but within a volunteer capacity.

10 And so when it comes to applying for
11 jobs, we need to understand that a lot of people
12 who are working in community, especially for
13 larger or smaller non-profits have a number of
14 transferrable skills and a number of things you
15 can gain from traditional employment, but because
16 they don't have the respectability of being able
17 to list that on a resume per say, it's not
18 appreciated.

19 So I just wanted to say that work is,
20 expand the definition of work a little bit. Thank
21 you.

22 MS. BOWMAN: And I would just also add
23 from the legal perspective, it really is hard to
24 overstate the level of discrimination that trans
25 people experience in particularly in the

1 employment realm, but I think interacting with all
2 the systems that we all have to interact with all
3 the time. And so you know, we actually do have
4 very good laws in New York City and they do cover
5 gender identity, but I think making sure that
6 those laws are really enforced is important.

7 I think, as you were saying, it's like
8 even in these communities that we think of as
9 being among the more progressive I the country,
10 they're horrible. Like people are treating
11 horribly everyday and I think really making sure
12 that we are enforcing the discrimination laws that
13 we do have and really making these systems work
14 for the people that they're designed to work for
15 is incredibly important.

16 MS. BARRETT: Okay. So, we know that as
17 you guys mentioned the lack of availability of
18 work, especially you were talking about for
19 transgenders and people who they're mostly
20 volunteering. So what are some of the vocational
21 gaps that we see? What are some of the resources
22 that we need in our society to mend those gaps?
23 Go ahead Aron.

24 MR. COBBS: Well, I'll speak from, I
25 guess my perspective. At Lambda Legal, we work to

1 -- and it's a constant effort to, you know, make
2 sure that our staff, our volunteers, our interns
3 reflect our values and you know, the issues that
4 we represent. So hire, interview. There's very
5 pragmatic things that you can do. Actually take a
6 look at the resumes or, you know, take a chance
7 and have an interview and a conversation with
8 people. Provide opportunities for leadership
9 development, you know, for internships.

10 I'm working within a coalition here in
11 New York City called the Kiki Coalition that does
12 very intentional direct outreach to youth who may
13 be housing insecure or homeless or transient, but
14 who are involved in the ballroom community and
15 that's a community that certainly knows a lot
16 about, you know, resilience and supporting itself.

17 So there are lessons to be learned from
18 the community. We just have to listen about what
19 their needs are.

20 I also just say that, to put it more
21 concretely, I think that in terms of achieving or
22 sort of closing those gaps, we have to be very
23 mindful of the discrimination that Mark mentioned
24 and just be intentional, you know. Some of the
25 organizations that, you know, represent these

1 causes aren't necessarily employing trans women of
2 color and putting them in leadership positions or
3 allowing them to lead movements that they've
4 already been -- or efforts that they've already
5 been, you know, sort of under [indecipherable],
6 but haven't been necessarily given credit for.

7 So I think that visibility, opportunity
8 and all of those things.

9 MS. BARRETT: Okay. Go ahead.

10 MS. DAVIS: So right now, our strategy
11 for HIV is to make people less infectious. But I
12 don't believe when you speak to the people that
13 we're serving that less infectious is good enough.

14 So when we think about holistically
15 addressing HIV from a structural level, we can't
16 expect Department of Health biomedical prevention
17 to carry a load that's far beyond its capacity to
18 handle. We need to think of addressing poverty as
19 a primary intervention for dealing with HIV. So
20 as long as we make HIV just a medical issue and
21 ignore the -- we knew this back in the nineties
22 and eighties when we were doing organizing that
23 HIV was not just about pills, but it's become
24 that.

25 And I'm impressed by how effective prep

1 is, but when I talk to people about what they're
2 seeking to accomplish in their lives, prep isn't
3 what they're seeking to accomplish in their lives.
4 They have much larger goals and their ability to
5 stay on prep is predicated for their ability to
6 successfully accomplish those other goals and I
7 think if we -- if there's anything we can do as a
8 movement it's to focus on increasing resources in
9 other areas, not just around biomedical
10 prevention.

11 MS. BARRETT: Okay. Mark, you wanted to
12 say something?

13 MR. MISROK: Just I do think that that's
14 critically important to understand.

15 I also think that we need to today
16 understand that there has been a shift very
17 recently out of HRSA. The HIV/Aids Bureau
18 released a policy clarification notice earlier
19 this month. It's PCN1602. That actually is an
20 update of the articulation of what is or is not an
21 allowable use of Ryan White HIV/Aids program
22 dollars and together, alongside that PCN was a set
23 of FAQs for the PCN1602 that was a set of
24 questions that HRSA decided were the important
25 questions to ask. One of which actually was, Is

1 vocational therapy an allowable use of funds under
2 the Ryan White HIV/Aids program?' And it says,
3 Yes. Vocational therapy is allowable use of
4 funds under the rehabilitation services category.'

5 So we've lived for a long time under
6 this cloud of understanding that Ryan White can't
7 go there when it comes to employment and that's
8 why we've got a system that's so dramatically
9 under developed in terms of even assessing, much
10 less beginning to address employment needs.

11 MS. BARRETT: Exactly.

12 MR. MISROK: And so we need to make the
13 shift to looking at what we can do.

14 MS. BARRETT: Thank you. So true. You
15 know, we all know what the governor said that we
16 want to reduce or eliminate HIV by 2020.
17 Everybody knows this, right? We hear about 2020.

18 However, we all know also that if I
19 can't afford to eat or to live somewhere or to pay
20 my bills, I'm going to do whatever is necessary to
21 get my income to do that. Right? And we all know
22 the correlation if what I'm going to do if I'm
23 doing risky behaviors, what that's going to lead
24 to. It's not going to end the epidemic in 2020.

25 So David, what is the financial impact

1 if I am going back to work and it's going to
2 affect my benefits?

3 MR. MISROK: Okay. First let me just
4 give a quick little kind of data summary. And
5 keep in mind, everything that I'm going to say now
6 is HASA specific, which means that the benefits
7 that I'm going to speak of require that someone
8 become a HASA client and by that I mean somebody
9 as of today has to be CDC defined AIDS and/or HIV
10 symptomatic. We're hoping that's going to change
11 sooner than later. I'm sure many of you already
12 know about the, about the HASA for
13 [indecipherable] and you know, where we're looking
14 to open up HASA for individuals that are low
15 income and just HIV positive alone, which would
16 include a much larger group of the City's
17 population right now, which unfortunately are
18 excluded.

19 So right now, we're servicing about
20 thirty-one thousand cases, a little over thirty-
21 one thousand. Of that thirty-one thousand, about
22 half of them are on some type of federal income,
23 be it either SSI or SSD and we have, as of January
24 of 2016, we have approximately nineteen hundred
25 clients who have earned income, either through

1 part or full time employment.

2 So what I do when I educate HASA clients
3 again because one must be a HASA client to benefit
4 from this earned income disregard is that I let an
5 individual know that we have through the
6 assistance of New York State OTDA, which is Office
7 of Temporary and Disability Assistance, we have
8 the ability to discount ninety dollars of their
9 gross monthly income and then fifty percent of
10 that and that's a pretty big, that's a pretty big
11 chunk. That income is completely discounted and
12 not present on their budget and the New York State
13 OTDA allows us to do that for a twelve month
14 period for an individual who is single and if
15 we're talking about a family case where there's a
16 child under the age of eighteen, there is no time
17 limit. So that's a huge benefit.

18 When I'm educating clients about also
19 going back to work, I also want to mention about
20 social security disability. As employed
21 individuals, we're all paying into social
22 security. It's very important that somebody who
23 was physically able to and has the skills to get
24 back to work understand that part of, part of
25 becoming an employee and a working individual and

1 all that entails, the benefits are that you're
2 paying into a system which can then return your
3 money to you an increase in social security.

4 And social security disability, of
5 course, will travel with you from state to state.

6 We also have the thirty percent rent cap
7 which was passed in 2014 where as individuals are
8 not required to pay more than thirty percent of
9 their income, regardless of their income, towards
10 their rent share and that's huge. So many times
11 clients prior to the implementation of this new
12 law, you know, there might not be an incentive.
13 Yes, we had the earned income disregard, but then
14 still a large chunk of that budgeted income that
15 we have to put on their budget would have to go
16 towards rent. Now that's capped at thirty percent
17 and that's huge.

18 So it's a whole series of things that we
19 try to educate our HASA clients that's out there
20 and we also have a demonstration project called
21 the rise program. I don't know if anyone has
22 heard of that. That's under gay men's health
23 crisis and they work with individuals who are HASA
24 clients currently and we partner with them to get
25 clients into the workforce, to get them the skills

1 necessary to enter the workforce through computer
2 skills, interviewing skills, job training.

3 And we also have an internal vocational
4 rehabilitation unit which we've had for many years
5 at HASA.

6 MS. BARRETT: Thank you. But you know,
7 I'm coming -- I'm going directly to you, Cathy,
8 but for some individuals who are HIV positive and
9 they have all the challenges, but may not be
10 eligible for HASA. What, what do we do? What do
11 they do then or what services are be available for
12 them for income and needing to go back to work?
13 Where's the gap? And how can legally that we can
14 prevent these gaps that they can still get their
15 income, some of their benefits and still work?

16 MS. BOWMAN: There's a huge gap. So --
17 and I think what David was saying is at the
18 beginning, was this really reiterates the need for
19 HASA for all. That everyone who's positive needs
20 to be getting HASA benefits because there is a
21 huge gap now between people who have ever been
22 symptomatic with their HIV and people who have not
23 and so for the people who have not, you're not
24 eligible for HASA, so essentially you're eligible
25 for regular public assistance and that's it.

1 And the only --

2 MS. BARRETT: Doesn't really pay for
3 much.

4 MS. BOWMAN: It doesn't pay for much.
5 As people might know, the rent for a single person
6 on public assistance is two hundred and fifteen
7 dollars a month, so you know all those --

8 MS. BARRETT: And I can get a shoe box.

9 MS. BOWMAN: Maybe. I don't know.

10 MS. BARRETT: Maybe not.

11 MS. BOWMAN: Maybe you can't get a shoe
12 box. So it is two hundred and fifteen dollars a
13 month. That is, I really don't know how many
14 times you can think about that.

15 So for that population, there's only a
16 ninety dollar work income disregard and that's it.
17 The only people who get the fifty percent
18 disregard on regular public assistance are people
19 with minor children in the household.

20 So essentially, it's a ninety dollar
21 difference a month for people. So there's no real
22 incentive for people on public assistance to be
23 working except that you actually really cannot
24 live on public assistance. I mean there's that
25 negative incentive, but there's no positive

1 incentive.

2 And the other thing that's hard is all
3 of the different benefit systems have earned
4 income very differently and it's really
5 complicated, so HASA treats all of your earned
6 income one way. SSI treats it a completely
7 different way and social security disability
8 treats it yet another way and a lot of people are
9 getting all three of those benefits.

10 You know, it can make your head hurt
11 thinking about it and I think it is complicated
12 even for providers to understand all those issues
13 and I think trying to then educate all the people
14 who are living on those benefits about how it
15 works is very difficult and I think a lot of
16 people are afraid to go back to work. I think a
17 lot of people, you know, I hear a fair bit like I
18 don't really have enough money to live on. Things
19 have definitely improved since the thirty percent
20 cap on people's income going towards rent has
21 happened. That was a huge shift for people, so
22 that was fantastic, but people are afraid to go
23 back because you know, they're getting their
24 disability and they're really anxious about the
25 impact that working will have on that and it is

1 complicated and I mean, I won't even get into the
2 rules because you would just -- everyone would
3 fall asleep.

4 But it's -- they're very complicated and
5 they have lifetime caps on them and all sorts of
6 things and so I think one thing we need is for all
7 of us to be educated about those rules and how
8 they work, but maybe in the bigger picture
9 thinking about whether or not those rules really
10 all make sense, how they're structured. And maybe
11 they need to be simplified in the way that we're
12 discouraging people from going back to work who
13 has all different kinds of disabilities.

14 Because we also see a lot of folks who
15 aren't HASA eligible, but are getting disability
16 benefits because they have another kind of
17 disability. So all those people also. It's just
18 incredibly discouraging. I think we've created a
19 discouraging system for people and we need to
20 rethink that in the big picture.

21 MS. BARRETT: Mark, I want you to follow
22 up on the question because I know that you do a
23 lot of work around this, around this issue.

24 MR. MISROK: And it's tremendously
25 complicated. The complexity of it for many people

1 has been, is explanation enough for why they have
2 not worked in years and are not planning to
3 because it's so -- you know, there are some people
4 who simply miss out on the possibility of moving
5 to work for months and years on end and there are
6 other people who say, you know what, I just have
7 to -- I can't understand what's going to happen.
8 I'm just going to take a risk and go and are
9 unable to make well-informed decisions and plans
10 for a transition that might better take care of
11 themselves and their own economic stability.

12 I want to encourage, in terms of needs
13 assessment in this area, because it is so
14 difficult to just go online and find information.
15 Service providers can't do this. People living
16 with HIV or other disabilities.

17 In other states, there's a set of states
18 that have invested in a project called Disability
19 Benefits 101 dot org. DB101.org. If you go to
20 DB101.org, you will see especially in the
21 California state site of this project, you will
22 see an extraordinarily comprehensive and
23 assessable access to information about the entire,
24 virtually the entire range of benefits that are
25 available to both health, financial related to all

1 -- including HIV benefits. And in addition, they
2 have an online calculator so that you can actually
3 plug in what the benefits an individual receives
4 and the amount and take a look at various
5 scenarios of what will happen and what will or
6 won't change based on changes related to work.

7 MS. BARRETT: Okay.

8 MR. MISROK: So this is one thing we
9 need.

10 MS. BARRETT: All right.

11 MR. MISROK: Is to make the information
12 accessible.

13 MS. BARRETT: So, it's a lot of
14 information and one of the things that you guys
15 touch on and I just wanted to ask Aron really
16 quickly. When we talk about discrimination, and
17 I'm going to ask you to do this really quickly
18 because I really want to give our community a
19 chance to ask questions since it's really such a
20 good topic that we're talking about.

21 When we talk about discrimination of
22 people going back into the workforce, they really
23 want to work and their benefits area going to be
24 interrupted and they have other things that's
25 going on and they're back to where how can they

1 handle or what do they do to if they're being
2 discriminated against when they are going back to
3 work? Or they are at work and they are employed.

4 MR. COBBS: So hopefully they're calling
5 Lambda Legal when they're being discriminated
6 against and hopefully if we're not able to
7 represent them in any sort of impact litigation
8 case, we're at least able to refer them to other
9 resource referrals.

10 But are you -- is the question, what are
11 people actually doing who are encountering this
12 discrimination?

13 MS. BARRETT: Yes. What can they do?
14 Uh-huh.

15 MR. COBBS: What can they do? Yes.
16 Call, call Lambda Legal. Access, I would probably
17 defer to a number of my esteemed panelists here in
18 terms of accessing resources and, you know,
19 reentry programs to secure more traditional forms
20 of work.

21 But yes, definitely report those
22 incidents. There's a number of laws and
23 protections that exist, but when it comes to an
24 actual robust reenforcement or enforcement of
25 those laws, they're just -- it's not enough. You

1 know, if you want to be able to access family
2 medical leave, that requires disclosure.

3 MS. BARRETT: Right.

4 MR. COBBS: And disclosure is a very
5 difficult thing to do with the stigma that still,
6 you know, is very pervasive throughout this
7 country, let alone in New York City even still.

8 So it's one thing when we tell people,
9 these are your rights, but you know, closing that
10 gab between legal and lived reality is very
11 difficult because of the stigma.

12 MS. BARRETT: Cathy, can you just really
13 quickly, just sum that up?

14 MS. BOWMAN: Well, I would, I would just
15 really encourage people. Lambda does do a lot of
16 big litigation, but to see a lawyer if you're
17 having discrimination issues no matter what, to
18 talk to someone.

19 And they're also a lot of things that
20 people can do pro se on their own, so you know,
21 the AAOC handles discrimination that violates any
22 of the federal laws, but in New York State, the
23 Division of Human Rights handles things that
24 violate state law and the New York City Commission
25 on human rights handles things that violate the

1 New York City human rights laws. And you can go
2 file by yourself in those places. You don't have
3 to have a lawyer to do that.

4 I really encourage people to talk to
5 lawyers. I think we do a better job when we help
6 you file, but if you can't get to us, if that
7 access is a problem, I would really be sending
8 people directly there because in addition to
9 people complaining about their own issues, it
10 starts to gather data for people about what kind
11 of problems that they're seeing.

12 For example, right now, you know people
13 in the New York City Human Rights Commission are
14 seeing a lot of complaints about how transgender
15 people are treated in shelters. And you know, for
16 them to be gathering that data is extremely
17 important because other people are saying, Well,
18 I'm not hearing it. I'm not seeing it. Where,
19 you know, what are we talking about?' And so if
20 people are actually really going and making those
21 complaints.

22 And look, two years ago, I wouldn't have
23 told you to do this because the Commission was
24 terrible and did nothing for anybody, but they're
25 really trying to improve the commission right now.

1 They've hired a lot of new people and with the new
2 administration. It's like a lot of things.
3 There's new administration. People are really
4 trying to put some effort into this.

5 And hopefully it is no longer a waste of
6 our time to be filing things at the commission.
7 We're starting to really do it a lot and I really
8 encourage people to tell. People who are
9 experiencing these problems, if you can't get a
10 lawyer to help you for free or you know, if you
11 really need to go out there and do it, go do it
12 yourself. You know, people are very capable of
13 explaining their own experience and now that they
14 have better people working there, I think they're
15 able to record that experience.

16 MS. BARRETT: Thank you.

17 MS. BOWMAN: So it should be reported.

18 MS. BARRETT: Thank you. Carrie, I know
19 you have a question, a statement. I'm going to
20 give you [indecipherable] --

21 MS. DAVIS: So the Commission of Human
22 Rights as Cathy mentioned is under new ownership.
23 Let's put it that way. They have an amazing new
24 commissioner, Commissioner Malalis, and they have
25 a tremendous focus right now on transgender

1 issues.

2 They're rolling out a whole training
3 curriculum that's going to go out to all city
4 agencies. They are working with community members
5 to deliver that curriculum. It's all hush/hush,
6 I'm not going to formally announce that.

7 But I would also say they also have
8 trans staff there. So that when it comes to
9 transgender issues, the Commission rolled out
10 guidelines in 2004. They reissued revised
11 guidelines this year and they're moving forward in
12 many different ways, so I think that's a
13 tremendous opportunity that we have right now.

14 MS. BARRETT: Okay. Thank you. So now
15 I want to open up to questions from our audience
16 and I'm sure you guys have a lot of questions, so
17 if I could get everyone with our mic to come
18 around. Yeah?

19 MR. BOLTER: Hi. Thank you. My name is
20 Paul Bolter with the American Liver Foundation and
21 when you talk about discrimination in employment,
22 there's -- especially returning back to work,
23 there's often perceived discrimination and flat
24 out discrimination.

25 So if somebody is returning back to the

1 workforce after five, ten, fifteen years either
2 due to their HIV status, housing, whatever
3 prevented them from going, returning to work, that
4 has to be an identifiable reason, an acceptable
5 reason for not getting the job. It's not
6 necessarily discriminatory. It is if you don't
7 have skills, but also there's -- so that might be
8 like a perceived discrimination.

9 But what are the actual examples of
10 discrimination? I think a lot of people think oh
11 it's because I have the virus. But what about it?
12 You mentioned FMLA, but FMLA is to protect you
13 from losing your job due to your health. So what
14 is the actual discrimination? I'm not sure that
15 was very clear. Like what are some examples of
16 the discrimination people are faced?

17 MS. BOWMAN: During the hiring process
18 do you mean?

19 MR. BOLTER: Sure. [Indecipherable] me
20 trying to work. Why -- what is the actual
21 discriminatory event [indecipherable] get the job?

22 MS. BOWMAN: Well, I mean I, I think
23 part of the point here is that when you have a big
24 gap in employment that people can say I just don't
25 want to hire you because you have a big gap in

1 employment. And that's why employment services
2 and all that can be very important.

3 Some of this isn't very subtle. I mean,
4 you know, especially when anyone who is gender
5 non-conforming is interviewing for jobs, they get
6 questions like you know, what are you? You know,
7 what's your name really? Who are you? You know,
8 it's sort of the last frontier where people have
9 no boundaries whatsoever in terms of what they'll
10 ask, you know, down to like what bathroom are you
11 going to use, all of those sorts of things.

12 So, and you know, a lot of times people
13 -- sometimes these things are hard to prove.
14 People meet people. They interview them and then
15 you know, you just don't get the job. You know,
16 sometimes it's hard to prove.

17 But sometimes, they're incredibly
18 blatant things. We see particularly horrible
19 treatment when people are actually transitioning
20 at work. Some very intense time that people who
21 already have jobs experience a lot of violence and
22 really, you know, I just met with someone last
23 week who was describing not being able to use
24 either bathroom and having to go to the bathroom
25 in a bucket where he was working.

1 So, it's not subtle. So that, and with
2 HIV, I think a lot of times, it's like people
3 smell that people are sick. Like you know, what's
4 going on with you? And, and they're trying to
5 figure out, you know, why have you been out of the
6 workplace. And it's actually not legal to ask
7 people why they've been out of the workplace, but
8 people do ask people why they've been out of the
9 workplace. So there are a lot of things like
10 that.

11 So there are very subtle ways to
12 discriminate against people and some people are
13 very expert at it and it's very hard to prove.
14 And you know, some people are not even bothering.
15 I mean, people think they have a right to do all
16 of this stuff. I mean we certainly see that in
17 housing, the people are like, 'You can't tell me
18 who I can live in my housing.' And we're like,
19 'As a matter-of-fact, we can tell you.'

20 You know, but so I think -- you know,
21 and sometimes employers have that same attitude
22 like you can't tell me that I have to, you know,
23 treat this person like I treat everybody else and
24 the truth is yes we can tell them that.

25 So it's a whole range, but.

1 MS. BARRETT: Let's take another
2 question for the other panelists.

3 MALE: Hi. Good morning everyone.
4 Thank you for talking a little bit about the
5 issues that trans populations are facing.

6 In the work that I do, we have a coming
7 home program at Mount Sinai for those patients who
8 are coming out of prison or may have had some
9 criminal background history.

10 If you could talk a little bit about
11 what services are for people who have been out of
12 the workforce particularly because of their
13 involvement with the criminal justice system. I
14 think that's a whole other ball game.

15 MS. BARRETT: Anybody want to take that
16 question? What about [indecipherable]? Mark.

17 MR. MISROK: That -- excuse me, we have
18 a response over here.

19 MS. WELLBE: [Indecipherable].

20 MR. MISROK: Sure.

21 MS. WELLBE: Okay. Great. Hi. I'm
22 Monica Wellbe. I'm an attorney with the Legal
23 Action Center. I do think when you're facing
24 multiple issues, whether you have HIV and other
25 issues that you might be dealing with, criminal

1 justice involvement is, is really daunting when
2 you're going back into the workforce. We work
3 with people with criminal histories on reentry
4 issues and discrimination issues and sort of
5 having a good understanding of what your
6 conviction history is prior to entering the
7 workforce is the best thing that anybody can do.

8 So getting an official rap sheet is a
9 good starting point because a lot of employers are
10 now doing commercial background checks on folks,
11 even though the fair chance act did pass, it
12 usually ends up later on in the process after a
13 conditional offer in New York City now under the
14 law, but still commercial background checks I
15 think about ninety percent of employers are
16 conducting them.

17 So for people to be empowered to
18 understand their criminal conviction history is
19 really, really important.

20 I don't know if that answers your
21 question.

22 MR. MISROK: We've got two over here.

23 MALE: I have a question. I think it is
24 very important that when someone seeks services
25 that the face they meet in the organizations, the

1 helping organizations be a face that is someone
2 that they can be comfortable with.

3 When this whole thing started, the
4 response to Aids in the eighties came from the
5 affected communities and when that response, when
6 those initiatives became community based
7 organizations, the staff in the organization
8 looked very much like the affected populations.
9 In my own organization, we always had formerly
10 incarcerated, formerly addicted transgender
11 individuals working in the community based
12 organization.

13 And then the blessing happened. In 1997
14 when the new drugs came through and the treatment
15 and the response became more medicalized [sic] and
16 that as it became more medicalized [sic], the
17 people who were now providing the services were
18 not so much the people from the community, but
19 people from the medical establishment.

20 And now when we have prep and pep and my
21 question is to you, Carrie, is that we seem to
22 have some kind of -- it seems to me, that we're
23 going to end Aids through pep and prep and I'm a
24 little skeptical about that because while we're
25 trying to get everybody onto pep or prep, there

1 are other activities that in our programs that we
2 were helping people with. Activities that build
3 self management skills. Activities that build
4 self esteem. And it seems to me, we're
5 emphasizing less on these, this kind of skill
6 building while we think we've got a technological
7 and pharmaceutical cure for this epidemic. And
8 Carrie, I think you touched on it and I would like
9 to know if you have more thoughts on this.

10 Is the direction we're going in
11 medicalizing [sic] the treatment, are we losing
12 something?

13 MS. DAVIS: So we've all seen the
14 continuum of care, right? The HIV continuum of
15 care. How do we -- if we look at that continuum,
16 between each pillar, there's a gap and then it
17 steps down. How do we address the gap? It's the
18 gap where the solutions are or need to be found.

19 So why would a young, a transgender
20 woman of color who's an undocumented immigrant why
21 would she not -- who's doing sex work, why would
22 she not have an HIV test? That's the first thing,
23 right? Because we need to identify.

24 The solution is to moving her if she's
25 positive and this is an actual person that we work

1 with, moving her to a point where she's in care
2 and she's undetectable, requires more than medical
3 solutions. So it's the gaps where we have the
4 solution to the continuum of care. It's the same
5 with hepatitis C.

6 So the solutions, when you make a map of
7 that and I do an exercise where I just, I put up a
8 power point and I ask people to fill out what the
9 solutions are to each individual case, we realize
10 that they're not about giving people medication.
11 That's part of it. But it's about everything in
12 between. It's about language issues. It's about
13 immigration issues. It's about legal issues.
14 It's about self efficacy, believing that you can
15 do something. That's not something you can give a
16 pill to somebody for.

17 So if you want, if someone wants -- if
18 you can get someone to believe they can do
19 something, you've taken a huge step towards
20 accomplishing your goal. These things require
21 more holistic interventions that we have moved
22 away from since the 1990's.

23 So the solution is to see our, that HIV
24 should be in our Department of Labor budget. HIV
25 should be in our Department of Education budget.

1 And so forth.

2 DAVID: Hi, it's David. David, this is
3 for you, David and it pertains to I'm going back
4 to work having been a HASA client. A lot of the
5 clients that I've been speaking with are fearful
6 of going back to work because they don't have the
7 information readily available to determine what
8 the impact it would have on them.

9 Is that information readily available
10 without actually having to go to disclose to your
11 case worker?

12 And you mentioned something about the
13 ninety dollar disregard and then the fifty percent
14 off the rest over a twelve month period. Is that
15 -- because sometimes people don't work every month
16 or have a regular job, so it's work here, a month
17 here and maybe not at all. So how is that
18 calculated? Thank you.

19 MR. PIERSANTE: Okay. So thank you for
20 the question.

21 So to answer the first part. Our
22 budgeting, as Cathy can attest to, is a little bit
23 on the complicated side and so we do not want to
24 rely on our twelve hundred line staff, well we're
25 twelve hundred in total, vast majority of line

1 staff, to tell a client this is exactly what your
2 budget is going to be. So we have a specialized
3 unit of which I'm in charge of. That's one of my
4 areas that I oversee, where we do just that.

5 So as I mentioned before, we have that
6 demonstration project with the gay man's health
7 crisis. So a lot of times, they'll, you know, one
8 of the staff there will shoot me an email and say,
9 "David, this is an individual. He may want, you
10 know, he's been offered this job, twenty thousand
11 a year. Give me a snapshot of what his benefits
12 are going to be." And then I can do that.

13 I would much rather do that and keep it
14 within me and my staff than have the information
15 disseminated amongst so many people because it is
16 a complicated process.

17 So that's the first part. The second
18 part regarding sporadic employment. We are able
19 to apply the rules of the income disregard both
20 for part-time and for full-time employment. And
21 at any point in time when one's income changes,
22 especially if there is a decrease, we need to know
23 that because then that -- you know, that
24 individual's budget is going to have to be changed
25 to reflect a lower income amount and if somebody

1 works periodically like for example we have some
2 individuals who teach and then they have the
3 summers off. So during that summer months, of
4 course, we're going to remove that income and then
5 apply it back.

6 And that twelve months need not to be
7 consecutive, so if you are in -- let's say you
8 have a job for six months. You lose that job.
9 Three months later, you get another job. If
10 you're a single individual, you still -- you have
11 not exhausted your twelve months of that benefit,
12 so we would turn that back on for you.

13 MALE: Okay. Another one.

14 MALE: Can I just follow up? A quick
15 follow up. Folks may or may not know that for
16 anyone who is getting SSI or SSDI that the social
17 security administration has posted, published and
18 posted online what's called the red book which has
19 all of the rules and regulations that you can take
20 a look at and understand to assess what would or
21 would not change in terms of beginning to make
22 work earnings and change to your income.

23 So social security does allow us as
24 adults to have access to that information and make
25 the policies transparent. So both beneficiaries

1 and service providers and policy makers can see
2 that and understand that. And I do think we need
3 to encourage our friends at HRA to empower us to
4 also as adults have access to the policies being
5 transparent so that we can actually take a look at
6 them. We can go online and see them and have the
7 empowerment to understand and make decisions and
8 be equipped to make well informed choices about
9 work and work earnings.

10 FEMALE: Yes. Good afternoon. The more
11 that I'm listening to the panelists and the voices
12 in the room, the more it's becoming clear to me
13 that this really has to be a broader and ongoing
14 conversation because we're dealing with changing
15 some policies and adding some things maybe
16 legislatively.

17 If you're going back to work, you're
18 probably going to have a better chance of working
19 in an area that is supportive of serving of your
20 HIV or your disability.

21 I'm returning back to work twelve hours
22 a week and I'm struggling. And I'm struggling
23 because I got health issues. I'm struggling
24 because the sticker shock of SSI, DSS. I'm from
25 Tri County. DSS is Department of Social Services.

1 I nicknamed them Department of Satan Services, but
2 the issue I'm bringing up is that they're all
3 going to deal with you differently financially and
4 if you're not prepared for the sticker shock of
5 your rent going up, food stamps going down, now I
6 got to add in transportation money and all of
7 these other issues that will come up, I would
8 really like to see a discussion and a development
9 in the agencies that serve and otherwise of
10 employment support system. A peer support system
11 within agencies. An employment support system
12 because you might be ready to go back to work and
13 three months later you get a health issue and now
14 you're out.

15 DSS oftentimes will sanction you because
16 you got sick and they didn't think it was enough
17 reason for you to leave a job. You voluntarily
18 left a job, now I'm going to sanction you for
19 three months.

20 We need to have a broader conversation
21 and maybe start a bank where information can go in
22 related to different employment challenges and
23 issues.

24 So I'm hoping that that might be
25 something that can be helpful in addressing the

1 larger conversation. Thank you.

2 MALE: I have another one here.

3 MS. BARRETT: We have time for one more
4 question because we need to stick to the time.
5 This is a really a big hot topic. I can only take
6 one more question so that we stay on track. You
7 can speak to the panelist if you have questions
8 afterwards. Go ahead.

9 MALE: So I'm one of those persons who
10 is transitioning to job after ten years of not
11 working. And because this is about, you know, the
12 experience, so recently I had my -- I get hassled
13 and I went to re-certification and I been speaking
14 with my case manager. So both of them have
15 different answers to my transition questions, so I
16 find that, you know, as a consumer, it is
17 difficult to get a balanced answer as to how do
18 you transition.

19 HASA had two meetings and they both had
20 different answers. So one of the things that one
21 experiences -- the one on one builds confidence,
22 but if the other person who you are asking for
23 information doesn't have a clear sense of what,
24 you know, what you need, you feel lost. So then
25 it becomes a moment of fear, so am I ready to do

1 this? You may feel it, but again we're talking
2 about support.

3 It's, I think a lot of the focus should
4 be, at least from my experience, in how to do
5 support the individual who is transitioning, who
6 wants to go back to the workforce. Not that they
7 are not available resources out there. I mean, we
8 have here a list of places we could go. But it's
9 the relationship that empowers you to say yes,
10 this is possible.

11 And the challenges, and I've heard also
12 other people who are in the same transitioning
13 mode, is that everywhere you go and ask the
14 question to perhaps lead you to that transition,
15 everyone has -- they don't seem confidence in
16 letting you know how to do this or how to build
17 your own confidence to do this. As I said, you
18 know, I went to HASA and two different answers and
19 then you go okay, so perhaps this is not the way
20 to go in transition. HASA has no answers for me
21 today.

22 So then you regress. So, I think those
23 are the things that need to be looked at because
24 it's a personal experience. How you go in
25 transition.

1 There's the case, especially for
2 transgender. The fact that it's a world where
3 degrees are important. Where the more education
4 you have with a little paper may give you, open
5 doors for you regardless of whether you are gay or
6 transgender, but a nice piece of paper.

7 And so we have [Indecipherable] like you
8 know, you do volunteer work, they certify you for
9 this, yet the feeling is that is that enough to
10 put a good picture of me when I am interviewed?
11 What other background things I have to do to
12 ensure that I'm at my optimum at that interview
13 process. Not because I'm gay, not because I'm
14 transgender. It's am I qualified because our
15 society runs on okay, you work for so long, or oh
16 you have all these degrees or you have all this
17 experience, but how do you feel confident in those
18 things.

19 To teach those who are in transition to
20 feel confident about those, whether if you
21 volunteer. Great. But how do you feel confident
22 about that volunteer work to go and confront an
23 interview and say, listen I have that experience.
24 You know, it becomes numbing to you, the process
25 because you are unsure because there are so many

1 other criteria needed that sometimes go beyond
2 just being gay or transgender. I mean, I met a
3 lot of transgender girls who have degrees in
4 cosmetology and they want to do it, but it's where
5 do I go to get a loan? Can I get a loan? Am I
6 respectable enough to get a loan?

7 So it is behavioral on so many levels
8 because it's not that you don't think that you
9 can. It's get out of that fear.

10 MR. MISROK: Okay. So real quick, I
11 want to address the HASA specific issue.

12 We're currently working with our new
13 Director of Policies, Procedures and Training to
14 get desk guides, not just for this issue of income
15 disregard, but for all of the actions that we do
16 to really make a one pager for everybody so
17 everybody understands exactly what all of these
18 processes are and they are complicated, unless you
19 do this everyday like I've been doing forever and
20 ever. So that's number one.

21 Number two, I'd like to give you my
22 information at the end. And then I'm going to
23 look into your case on my own, if you would like
24 that. Thank you.

25 MALE: We have time for just one more

1 question.

2 MALE: I have just another question. I
3 have a simple statement.

4 MS. BARRETT: Okay.

5 MALE: Each individual agency within New
6 York State; HASA, all of them have different,
7 different -- I can't think of the word. It's not
8 coming to my mind. Of what you can do and earn
9 going back to work. They all have different
10 things. And they all seem to keep it under wraps.
11 How do we, as clients, find out what they are?
12 Because as he said, he went to two different HASA
13 workers and they both gave him different answers,
14 as there is no one, one --

15 MS. BARRETT: There's not one answer to
16 fit. There's not one size to fit everything.

17 MALE: Everything. So --

18 MS. BARRETT: Right.

19 MALE: -- even if you go to a lawyer and
20 say, 'Can you help me find out what it is I need
21 to know?' They will tell you, 'I got this answer
22 and I got this answer.' And it's happened to
23 friends of mine that have done it.

24 MS. BARRETT: Uh-huh.

25 MALE: I had a friend who went to work

1 for the summer. He made so much money, they told
2 him they have to cut his budget because he made
3 too much money over the summer and he only worked
4 for the summer. He made, only made too much money
5 within the time that he was working, so they had
6 to cut his budget because he made too much money.

7 MS. BARRETT: Uh-huh.

8 MR. MISROK: Okay. Real quick and then
9 I'm going to wrap this up.

10 MS. BARRETT: Okay. Wait, I'm sorry. I
11 know that we need to answer, but we have another
12 panel and these are very important questions that
13 we need to address, so David, your information
14 will be, we'll give out your information so that
15 we can -- you can address some of the questions
16 and we can email because these are very, very
17 important, but we need to be respectful of the
18 other panel and time.

19 Panelists, I do thank you. Questions,
20 I'll answer any questions. I do thank you, but we
21 need to wrap this up. Thanks everyone.

22 So we have a five minute break. Five
23 minute just to go to the bathroom and come back.

24 MR. LESIEUR: All right, folks. I
25 really want to get this started. If people could

1 please grab a seat. We have our last panel on
2 housing. Don't make me call people's names out.
3 All right, folks. I know we need to clear this
4 room out by a set time and I have the glory of
5 having to go to Albany later on, so we want to get
6 this show started.

7 All right, folks. So welcome to the
8 last track. If folks could -- I know I'm talking
9 loud enough, so. We have our last track. We're
10 just going to talk about housing across the entire
11 [Indecipherable] metropolitan area which consists
12 of the five boroughs of New York City, as well as
13 West Chester, Rockland and Putnam and as you're
14 going to learn through this panel, the needs and
15 the life situations between those two -- between
16 the five boroughs and the three counties north of
17 the city are very, very different and their needs
18 are very different.

19 Before we start with our panel and
20 introduce our panel, I'm going to allow our
21 esteemed presenter here, Pamela -- I'm not even
22 going to try and pronounce your last name.

23 MS. FARQUHAR: Farquhar.

24 MR. LESIEUR: Farquhar. Pamela Farquhar
25 who's the Director of Housing in the New York City

1 Department of Health and Mental Hygiene is going
2 to start us off with a presentation to set our
3 minds right and then I'll start with our panel.

4 MS. FARQUHAR: Okay. I think we moved
5 into afternoon now. As Matt introduced myself, I
6 am Pam Farquhar. I'm the Director of Housing in
7 the Housing Services Unit at the Department of
8 Health and Mental Hygiene. I'm glad to be here to
9 provide some context and some background to the
10 housing services that we provide based on the two
11 grants that we administer, both Ryan White and
12 [indecipherable] at the Department totaling about
13 over fifty-seven million dollars in housing
14 services for New York City, as well as the tri-
15 county region.

16 So for 2016, for the Ryan White EMA,
17 there are approximately ten million dollars
18 allocated by the Planning Council for New York
19 City housing services that were spread across
20 three major service categories; short-term
21 housing, supporting housing. Basically providers
22 providing housing services as well as traditional
23 case management services and non-traditional, such
24 as housing readiness workshops, ADL skills
25 assessment and provision of services, in addition

1 to [indecipherable] and other advocacy referral
2 services regarding case management.

3 Additionally, we have the service
4 category, housing placement assistance. Our HPA
5 providers work very diligently with brokers,
6 landlords and building management companies to
7 secure housing -- identify and secure housing on
8 behalf of clients. Clients can be placed in
9 congregate or scatter site facilities based on
10 their needs and their services that they are
11 needed for.

12 Last category, short-term rental
13 assistance. Basically, it's for clients who are
14 not HASA eligible. We heard a lot about that in
15 our previous section, who for the most part, have
16 their housing unit, however they need assistance
17 in paying their monthly rent and so they seek
18 rental assistance from our short-term housing
19 rental assistance provider.

20 So again, those are the three categories
21 that are funded under Ryan White. Ryan White
22 exclusively supports emergency and transitional
23 housing and I'll talk in the next light about
24 [indecipherable].

25 In regard to tri-county, Ryan White

1 funding, in 2016 there are approximately just
2 short of five hundred and seventy thousand dollars
3 allocated for housing services in the tri-county
4 region, specifically for short-term rent, mortgage
5 and utility, however in New York City, there's a
6 little caveat. The mortgage piece is not
7 included. It is rent and utilities that is
8 covered.

9 As I mentioned, the [indecipherable]
10 EMSA. [Indecipherable] decides to add an S in, so
11 it's eligible metropolitan [Indecipherable] area
12 for [indecipherable]. In 2015, there was a forty-
13 seven million dollar allocation for housing
14 services, the bulk of which was for New York City.
15 Similar categories; supportive housing, housing
16 placement assistance, rental assistance, as well
17 as just straight case management or supportive
18 services that were primarily provided by HASA with
19 regard to straight administrative supportive
20 services. Excuse me.

21 Tri-county received an allocation of
22 about two point one million dollars for rental
23 assistance and supportive services and in 2014,
24 HUD decided to expand the New York City EMSA to
25 include three counties in New Jersey that we're

1 responsible for administering. That's Ocean,
2 Middlesex and [indecipherable] and they receive a
3 little over one point three million dollars in
4 funding.

5 When we talk about housing instability,
6 these are the service -- the inclusions when we
7 talk about individuals who are precariously housed
8 or homeless, so includes, of course, street
9 homelessness, emergency shelter, residing in an
10 SRO could be funded by HASA or not, but occupancy
11 in an SRO or a hotel or motel would certainly
12 include you for being unstably housed, as well as
13 if you were residing in a transitional supportive
14 housing program, anything not permanent housing is
15 considered transitional/emergency or being
16 categorized as homeless as well as living double
17 or tripled up with a friend or family which also
18 consider you to be homeless.

19 How am I doing Matt? All right,
20 awesome.

21 So Ryan White housing clients served in
22 2014. There are approximately one thousand, four
23 hundred and forty-three clients who were served.
24 These are unique clients. All who received at
25 least one service from their respective provider.

1 And in tri-county, one hundred and
2 fifty-nine clients were served, again using the
3 same barometer.

4 This is the slide that we want to
5 really, just really hone in on for this
6 presentation and for our discussion this
7 afternoon. In tri-county, Ryan White clients,
8 there are about one thousand two hundred and
9 fifteen clients who were served in 2014 of which
10 one hundred and fifty-nine or thirteen percent who
11 received housing services, which leaves a large
12 percentage of clients who did not receive housing
13 services and of those who did not receive housing
14 services, only eight hundred and forty-two -- or
15 not only, but eighty percent of those, we know
16 their housing status and two hundred and fourteen
17 whose housing status was unknown; either just
18 based on not providing the information in our E-
19 share system that was talked about by Justine this
20 morning and Dr. Irvine.

21 And of those for known status, eleven
22 percent were unstably housed and seven hundred and
23 forty-eight individuals were stably housed.

24 But we want to hone in on those who were
25 not -- who were unstably housed for this

1 presentation and I guess for this discussion when
2 we talk about the needs in tri-county in regard to
3 housing services.

4 So when we look at the individuals who
5 are unstably housed, they are most likely to be
6 male, under the age of thirty, unemployed, as well
7 as ever been incarcerated.

8 So I just wanted to -- I'm glad to be
9 able to provide this context for the discussion
10 this afternoon and to really talk about the needs
11 in tri-county and what's it -- in order to
12 hopefully be able to reallocate monies as
13 necessary without hopefully strangling those
14 individuals who are receiving services in New York
15 City.

16 FEMALE: Thank you.

17 MR. LESIEUR: Let's take this thing out.
18 My ADD kicks in and I can't stand that still. So
19 I want to start with Barbara and go all the way to
20 Jason and I want you guys to just introduce
21 yourselves and where you're from.

22 MS. BENTO-FLEMING: Hi there. Barbara
23 Bento-Fleming, Director of Housing Services
24 Lifting Up West Chester. And just to quickly
25 cover, we have both Ryan White and

1 [indecipherable] contracts in the funds we
2 administer.

3 MR. ALVAREZ: Yes. My name is Victor
4 Alvarez. I'm a consumer and director of living
5 together, which is an organization by and for
6 people with HIV and Aids and we started in 1993
7 and we're funded in the Ryan White part A care
8 act.

9 MS. AHMED: Hi, I'm Danielle Ahmed. I'm
10 the Program Supervisor at Lifting Up West Chester
11 and I oversee the Ryan White part A program
12 housing rental assistance and also the
13 [Indecipherable] case management program.

14 MS. AIDALA: Hello. I'm Angela Aidala
15 and I'm [indecipherable] Public Health and I'm the
16 Co-PI of Study Director of the Chain Project.

17 MR. WALKER: Hello. Good afternoon. My
18 name is Jason Walker. I am the Coordinator of the
19 Aids Housing Advocacy Network for Vocal New York.
20 Vocal New York is also formerly known as the New
21 York City Aids Housing Network. Yeah.

22 MR. LESIEUR: So we have a couple of
23 formal questions that the Department gave me,
24 hints on what I could ask. But I'm going to start
25 with Angela. Since you've been running a chain

1 study since as long as I can remember and so you
2 guys have been a wealth of information on the
3 intersection of HIV and a lot of other factors. I
4 wonder if you could sort of provide us with a
5 brief overview on what's the relationship between
6 HIV and housing?

7 MS. AIDALA: Sure. I put together a
8 little quick briefing paper, which is really
9 literally hot off the press and in answer to the
10 question that was particularly interested in
11 looking at some of the differences perhaps between
12 New York City
13 and tri-county.

14 And you know, again, just on the first
15 page, we can see you know, and it's no news, but
16 we have lots of data from 1994 over time, several
17 thousands. We've done about nine thousand
18 interviews now, you know, that we do on a regular
19 basis. New York City and the tri-county area for
20 again, approximately yearly, close to eighteen
21 months from now, so that sort of large sample size
22 designed to be a probability sample, meaning that
23 we design it to be representative of people who
24 have had some contact with the service system, but
25 not necessarily in-care social service or we

1 recruit people from social service or working with
2 providers, such as you all. Recruit folks that
3 may have had some involvement with the care
4 system, but not necessarily in care over time.

5 But just really quickly. You know, we
6 knew that lack of secure adequate housing is
7 widespread. It's associated with worse outcomes
8 in terms of medical care engagement, in terms of
9 the care cascade and not surprisingly then, worse
10 outcome.

11 Let me repeat that. Lack of secure,
12 stable, adequate housing is not just literal
13 homelessness and that's one thing that from the
14 beginning of our work, homelessness, if we think
15 about it, is about the most extreme on a continuum
16 of not having adequate, safe, secure housing.

17 People who are in housing, and this is
18 what we see a lot, particularly in tri-county, who
19 have a place. Who have an appointment, but are
20 severely rent burdened are at risk for housing
21 loss and they are often housing loss. Housing
22 cost go up. In this brochure, I looked up -- I
23 hope I got it right. The kind of fair market
24 rent, you know, whose SSI or SSDI could even cover
25 fair market rent for a studio? Yeah, exactly.

1 It's twelve forty-five now? Yeah.
2 Exactly. And it's a little bit higher actually in
3 West Chester than it is in New York City. Right?
4 So and we also know that, that there's less rental
5 units, a lower proportion of units. That's
6 probably why it's higher, right? Because the
7 communities in West Chester are not as welcoming
8 to multi unit buildings, so there's a lot of
9 things structurally.

10 And that's kind of the point that I'm
11 trying to make. That the fact that in the general
12 population as well too, this is becoming more --
13 there's attention to it now and generally the
14 persons who are housing insecure or energy
15 insecure, are also then skimp on food. You want
16 to think about well, you know, you've got to pay
17 the rent or you buy good and healthy food. Right?
18 It's not just heat. It's heat or eat or be on the
19 street. You know? So as some of our respondents
20 tell us when we do these interviews.

21 So I think that we can think about,
22 again, we don't have time now, but you know, again
23 there's direct affects. The stress, the exposure,
24 people are transient. They're moving in and out.
25 They're staying. Women especially stay in places

1 that aren't so necessarily safe. It may not be a
2 virulent, domestic violence situation, but it's
3 still a situation that they stay in that's not
4 necessarily healthy for them and particularly if
5 there's kids because there's such limited options
6 as well.

7 We have data on this. We have other
8 reports on it. I and a team of about six others,
9 Jenny Schubert [phonetic] and other academics, the
10 big review of the literature, a hundred and fifty-
11 two studies that show this as well too from 1996
12 as well as chain.

13 Unstable housing as well as homelessness
14 associated with worse connection to care, delayed
15 entry into care, dropping out of care, lack of
16 adherent ART use, lack of using ART, ART at all.
17 Right? Not using ART and again we'll kind of
18 think about why that might be. Housing costs are
19 out of reach.

20 Receipt of housing assistance then is
21 associated with improved -- persons who have
22 changed, who improve, who get housing, who get
23 their housing needs met show better outcomes.

24 Just really quickly here, if you'll look
25 at on the next page of this, the persons in tri-

1 county are more likely to be doubled up. They're
2 more likely to be doubled up. Less likely to be
3 literally homeless, street homeless, more likely
4 to be doubled up. Some in transitional housing.

5 A few words about doubled up. Doubled
6 up now means maybe good because that means you
7 have a social network or at least some place where
8 you can go to maybe be in a regular home. But it
9 also can be associated with worse outcomes. If
10 that family member, if you haven't disclosed your
11 HIV, you know, it's associated often with falling
12 out of care itself because you don't want phone
13 calls coming to that address. You don't want your
14 meds in the refrigerator and so you, you know.
15 And also in some instances, you're not -- maybe
16 you're staying in some place that's not so
17 friendly and supportive. You can't use the
18 kitchen, right? You cannot use the kitchen.

19 If you're in a -- the other thing about
20 it is you're not under the purview of any service
21 provider, so if you're in some kind of -- even in
22 the shelter, homeless shelter. I'm not
23 recommending homeless shelter, but if you're in a
24 homeless shelter, there's meals and if you're
25 having some kind of freak out or some serious

1 health issue, it comes to the attention of folks
2 that are there, particularly transitional housing
3 as well too.

4 So the fact that there are people are
5 more often in, in doubled up, you know, it's still
6 associated with worse outcomes compared to again,
7 stable, secure, you know, and adequate housing.

8 Housing programs are an addition to.
9 It's not just the little housing, but people who
10 have, you know, are facing eviction. There's a
11 stress dynamic for those as well too, of course.
12 Who are in really poor quality. We have people
13 who are living with HIV, who don't have regular
14 heat, who have mold and other kinds of you know,
15 vermin in their places because there are places
16 that they have with few resources to go otherwise.

17 What else can I say? This, this chart
18 on the back. We, we put together a classification
19 of housing need looking at persons who had their
20 own place, had a lease, but were severely -- more
21 than fifty percent of their income from all
22 sources, you know, went to rent. Severely rental
23 burden. They needed rent assistance.

24 Those that needed placement, permanent
25 housing. In other words, they didn't have their

1 own place. They were in temporary, transitional,
2 doubled up or street homeless, so they needed both
3 rent, right? But they also needed a place. And
4 then people who needed permanent supportive
5 housing.

6 And again, this just shows you the
7 relationship between some indicators. The first
8 one is emergency room use, which is an indicator
9 of poor engagement with care, suppressed viral
10 load, good physical functioning and health quality
11 of life.

12 If you look at the persons. The darker
13 color are persons who need permanent supportive
14 housing, but again comparing rental assistance.
15 So they're not unstable. They haven't moved
16 around a lot. They have a place. They have a
17 roof over their head, but they're at risk of
18 losing that and the day to day [indecipherable]
19 outcomes.

20 And again, there are a lot of other ones
21 discussed in the text. I have to quit now, I
22 think? Yes. Okay.

23 MR. LESIEUR: Well, I'd like to give the
24 other panelists some time to talk too. As always,
25 researchers love to show off all their data.

1 MS. AIDALA: Oh I know, I know, I know.
2 I know, I know. What can I say? One last thing,
3 okay?

4 We did an estimate based on those
5 categories. We did an estimate because I was
6 asked to do an estimate and this is just an
7 estimate on our data. We estimate that there are
8 about a thousand persons in the tri-county area
9 living with HIV and Aids who need rental
10 assistance, but not getting any at this point in
11 time. And three hundred and seventy-six that need
12 housing -- placement, permanent housing. Meaning
13 that they need, you know, they're homeless,
14 literally homeless, doubled up or whatever, but
15 they don't have their own place, that they need
16 housing, as well of course supportive housing -- I
17 mean rental assistance to support that.

18 Okay. I quit.

19 MR. LESIEUR: Angela, take a deep
20 breath. Thank you. That's a lot of data.

21 So I want to switch from, we just heard
22 a lot, a lot of data, very valuable data and I
23 want to switch to Victor. You described yourself
24 as a consumer. I know that at least on more than
25 one occasion, we've gone to New York to Washington

1 D.C. and you've told the consumer's perspective on
2 what's going on in the tri-county. So I want to
3 give this audience a sense of what happens to that
4 consumer who's losing their housing or who's
5 unstably housed. What happens to them?

6 MR. ALVAREZ: It becomes very difficult.
7 I mean, she said it very well earlier. It's not
8 just about taking meds and seeing your doctor.
9 It's about a stable home. If you don't have a
10 stable home, then probably your nutrition isn't
11 stable. You're not getting enough food. You're
12 not getting proper food. So it just goes on and
13 on and on and it escalates.

14 Now my job is, you know, I work very
15 closely with Barbara. She's always been there.
16 She's a sweetheart, but my job is to teach people
17 while you're going through those transitions to
18 still try to take your meds. Still try to keep up
19 with your doctor because the last thing that you
20 want is to get a nice apartment to find out you
21 end up in the hospital. Okay? So it's how do you
22 do that and that's my job and that's what I do.
23 I'm like the goal keeper. When they come out of
24 play, I kick them back into play. You know?

25 But it's very difficult because you

1 know, we talk about affordable housing.
2 Affordable for who in West Chester County? I pay
3 seventeen hundred dollars a month for a two
4 bedroom apartment. But listen to this, I paid
5 thirty dollars a month for water. We live on a
6 planet that's three quarters water and I'm paying
7 for water and it's not even drinkable. So you
8 know what I mean, so you know.

9 When you look at that and you look at
10 the rents and you look at we have people in a
11 furnished room who can't have visitors, can't have
12 anything to cook or anything, paying six, seven
13 hundred dollars for a little bitty rooms where
14 I've seen prison cells that are bigger. You know,
15 and then you expect people not to become
16 disenchanted and not, you know, and not to fall
17 out of care. When you figure if no one else cares
18 about me, the hell with it. And that's what
19 happens. That's the reality.

20 You know, I don't like to deal with
21 statistics and percentages. Those are numbers. I
22 deal with people. With human beings. You know,
23 where are you at right now and what are you going
24 through right now and how can we help you and what
25 can we get.

1 And we talk about ending the epidemic in
2 2020. I don't see how you're going to do that if
3 you keep cutting funding. It just doesn't make
4 sense to me. It makes absolutely no sense. You
5 know? We just found out that [indecipherable] may
6 be cut. You know, we lost another housing program
7 because of the new guidelines for the new RFP that
8 went out. The agency that was doing it can no
9 longer do it, so what are we going to do?

10 MR. LESIEUR: Parver [phonetic] or
11 Danielle. You're both in the same agency, so I'm
12 trying to get a sense of what your service -- who
13 does what in the agency, but can you just tell --
14 the client walks in your door and they're saying
15 they're about to wind up on the street. What
16 options do they have?

17 MS. AHMED: Well, I mean I think that
18 it's kind of been covered, but just to reiterate,
19 we'd want to take a look at what their income is.
20 It is true that most people in tri-county are
21 unstably housed.

22 There's not a lot of street
23 homelessness. I think, I think there are many
24 reasons for that, but I think the primary reason
25 being that tri-county is largely residential.

1 It's a lot of private homes. That doesn't really
2 lend itself to street homelessness. And even when
3 you have these city based buildings, the tenants
4 themselves are not really receptive to the idea of
5 street homelessness.

6 I think that tri-county does do a pretty
7 good job of trying to get people off the street
8 and into a shelter, so if the person is in the
9 shelter, in a sense they actually may be better
10 off.

11 We do have a couple of buildings that
12 were housing projects that were specifically
13 developed to address street level HIV
14 homelessness, so that you could actually go into
15 the shelter, be assessed if you disclose. If you
16 don't disclose, then you get a regular -- what was
17 it, Department of Satanic Services? You get a
18 regular -- and I think it's Department of
19 Satanists or a Sadist because it's quite painful
20 even as, even as a staff person.

21 But if you do disclose, then you can be
22 placed in housing and it becomes permanent housing
23 if you choose that housing. They're basically
24 studio buildings and it's two different locations.
25 One building has a lot more supportive services

1 and food and the other one has less supportive
2 services. Although they both have really nice,
3 shiny floors because I've rented them. That's
4 just an aside. Hohman [phonetic] Garden fan,
5 here, so.

6 But I think that it's harder for you if
7 you don't disclose. If you don't disclose, then
8 you can't be placed in these projects and then you
9 become unstable. So we would take a look at the
10 person's budget and see what they can afford
11 through our rental assistance program. For our
12 West Chester program, we can give up to five
13 hundred and fifty dollars per month for rent.
14 It's short term housing assistance that was
15 originally designed to be there for six months and
16 --

17 MALE: Five hundred and fifty and what's
18 the average rent cost up there?

19 MS. AHMED: I mean, it's -- it depends.
20 Honestly, it depends on what city you're in,
21 whether you are a southern or a northern resident
22 of that city, but just as she was saying, the one
23 bedroom, the fair market rent levels are now
24 twelve forty-five for a one bedroom in West
25 Chester, which may cover an apartment in Mount

1 Vernon, but certainly not in Dobbs Ferry.

2 So and then there's some places that,
3 you know, that wouldn't -- there's also a law,
4 just in case you don't know that just because you
5 have a housing subsidy like [indecipherable] or
6 section eight, a law was actually passed in New
7 York State that does not, does not mandate
8 landlords to take your subsidy. So even if you
9 can afford the rent with the subsidy, the landlord
10 can say, We don't take any subsidies. We don't
11 take [indecipherable]. We don't take section
12 eight. We don't take DSS.' And either the person
13 can pay or we're not renting to them and
14 apparently that's very legal.

15 So you know, we can find housing
16 sometimes and still not be able to secure the
17 unit. But in general, we'd have to take a look at
18 what they're looking at. We like to direct people
19 towards studios and I have to say there are some
20 people that will say to me, Well, why should I
21 live in a studio or even a one bedroom in Yonkers
22 if I can live with my mother in White Plains?'
23 There are some town preferences in tri-county.
24 Even lower West Chester, but certainly middle and
25 upper West Chester, let alone Rockland and Putnam.

1 They are not really accessible by public
2 transportation at all.

3 So if your family all lives in
4 Greenburgh, we may be able to house you in
5 Yonkers, but people will say, No. My mother is
6 eighty and how am I going to get to Greenburgh.'
7 Or you know, where is your doctor becomes the
8 other factor. Can you get housing in the place
9 where your doctor is located?

10 So each case is different and not
11 everyone who's unstably housed feels that they're
12 unstably housed. You know, if you are actually in
13 your parents home and it's very spacious and there
14 are some older home owners who have maybe children
15 in my generation, but their parents have houses
16 and they're like I'd rather stay and help my mom
17 and be in this house.

18 FEMALE: And I wanted to add that to
19 clarify those facilities Danielle was speaking of,
20 unfortunately are for singles.

21 MS. AHMED: Right.

22 FEMALE: So that's only for a single
23 individual coming in, willing to disclose and say
24 they're homeless and accept Yonkers.

25 MS. AHMED: Uh-huh.

1 FEMALE: And a building that's
2 "identifiable" so we clearly get those calls where
3 the resource that are out there aren't acceptable
4 and a person absolutely has a right to choose
5 where they live.

6 MR. LESIEUR: Do we have any sense of
7 what's the need in the tri-county area for Ryan
8 White or for housing services people with HIV?

9 FEMALE: Well, it's difficult because
10 again, with our Ryan White, it's a supplement.

11 MS. AHMED: Right.

12 FEMALE: So as you were saying, the
13 average one bedroom rent, we are a
14 [indecipherable] provider, still above thirteen
15 hundred dollars, so the five fifty may not even
16 get you where you need to be. There's certainly a
17 cap on the number of [indecipherable] slots.
18 There are eight years section eight waiting list,
19 so in terms of the need, it's hundreds of people
20 that as Danielle said, may not identify as
21 unstably housed, but they're not in their
22 permanent situation.

23 And we do have, as Danielle and Lisa was
24 talking about, people don't even talk about it
25 because it's so dysfunctional. It's a

1 dysfunctional version of HASA. There is something
2 called the enhanced shelter allowance in West
3 Chester. First of all, even if you disclose to
4 social services, the workers don't know about it.
5 You do have to be at that threshold in terms of
6 your health being in decline and we've actually
7 had situations in that program if you stabilize
8 and got healthy, they took it away.

9 And again, when we're talking about rent
10 levels, I heard two fifteen, I think, for -- it's
11 two seventy-one in West Chester and if you are
12 eligible for the rent enhancement, then you get
13 four hundred and eighty dollars to find an
14 apartment with. Which, as Victor said, the rooms
15 are six hundred and above.

16 So, I mean we did some canvassing of
17 some of the providers just to get a sense in terms
18 of who they're seeing, who may report that they're
19 unstably housed, but that's really we found, you
20 know, a clear -- the clearest way to find out who
21 they are. If they're not coming through that door
22 and particularly in West Chester, you have to
23 disclose and come through a service provider door
24 before you can even figure out what services are.

25 Where like in the New York City system,

1 you're aware that there are services around you.
2 So that's one of the problems too, so typically
3 our network is very important because if they show
4 up with Victor, he can say have you been here and
5 we'll be sending consumers for support with living
6 together.

7 FEMALE: I just want to say like one
8 thing in terms of housing subsidies. Because of
9 federal reductions, we've lost money for the
10 [indecipherable] grant and also because section
11 eight has been almost continuously frozen for like
12 a decade. There's no movement. When I started,
13 which was eleven years ago, there was movement.
14 You might be in Ryan White for one year, six
15 months, three years, and then you would either be
16 able to go into [Indecipherable] because a spot
17 was available, or a lot of our folks went into
18 section eight. You know and that was continuous
19 movement.

20 Since section eight closed, that, you
21 know, they, they were actually a private
22 organization took over the county section eight
23 and they're no longer accepting new applications.
24 So if you didn't put your application in four
25 years ago, you cannot apply at this time.

1 Now people will periodically get into
2 section eight. It opens up for like two months
3 and it's like lotto. Oh, I won a section eight
4 voucher. And then again comes the mad dash to
5 find someone, a landlord, that will take your
6 voucher at that rent level.

7 Just to let you know the other thing
8 that happened is that the fair market rent levels
9 are actually from when, Mark? 2010 or are they
10 the levels that they're going by now?

11 MR. MISROK: Well, no. They just
12 changed. Our problem is they've gone up and then
13 they've come down again.

14 FEMALE: Right.

15 MR. MISROK: So even folks that we've
16 stabilized and this is what we're seeing in our
17 [indecipherable] program, you've been stable five
18 or six years. Your landlord is entitled to a
19 legal rent increase.

20 Well, the fair market rent in 2010 was
21 thirteen hundred and ninety-four dollars and as of
22 2016, it's twelve hundred and forty-five dollars.
23 So, even if your landlord is not lowering the rent
24 --

25 MR. LESIEUR: Make sure your microphone

1 is to your mouth so we can hear.

2 MR. MISROK: Oh, I'm sorry.

3 MR. LESIEUR: Yeah. And I just we -- I
4 also want to give Jason a chance too to talk. So
5 we have a very friendly congress, not really. We
6 haven't seen an increase in section eight
7 vouchers, was it the last president? I'm not
8 certain. There's not going to be an increase in
9 Ryan White funds coming out for the foreseeable
10 future. You know, [indecipherable] sometimes we
11 get a dollar here and there increase, but it
12 doesn't come to the city.

13 So what is being done to kind of close
14 the gap? What can advocates do? What is Vocal
15 doing? What are we doing to try to address some
16 of these unmet needs, being aware that the federal
17 government is going to be AWOL in this process?

18 MR. WALKER: So we're really looking to
19 lean on and very strongly on the governor this
20 year. Particularly around really honing him and
21 make sure he owns up to his plan to end the Aids
22 epidemic in New York City by 2020, right?

23 World Aids day, the Governor came out
24 and made this huge announcement in front of
25 thousands of people saying that he had two hundred

1 million dollars that he was going to put into his
2 budget this year. We looked at the budget and
3 didn't see any of that money. We were expecting
4 that this money would do one of two very important
5 things when it comes to housing. One, expanding
6 housing services to include asymptomatic folks
7 living with HIV.

8 Mayor de Blasio put up his portion of
9 the dollars and we see that in the budget, but we
10 do not see anything in the governor's budget.

11 The second thing that we expected the
12 two hundred million dollars to do is also to
13 create housing, similar programs as HASA, but
14 really specifically just focusing on providing
15 enhanced rental assistance for folks throughout
16 the state. Right. And some of these, like the
17 [indecipherable] county area, Buffalo, Syracuse,
18 Rochester.

19 So the Governor is upset with Vocal
20 because we really came out hard on him. Like
21 yesterday in Politico, but we're going up there on
22 March the 9th for our annual HIV/Aids
23 [indecipherable]. There's flyers up front.

24 But as I'm listening more and learning a
25 lot more about what's going on in the tri-state

1 area, I mean the tri-county area, I think it's
2 very critical and important that the planning
3 counsel and many folks from the tri-county area
4 goes up there and talk about the need.

5 The governor is challenging to work with
6 sometimes, but I think he does respond to public
7 pressure. So we are implementing and going to be
8 exercising some actions throughout the next month,
9 so we'll definitely keep folks in the planning
10 counsel abreast in the loop.

11 But I think it is very important that
12 right now, we should just actually like cease this
13 opportunity and really lean on the state and
14 really lean on our local governments and really
15 step up, especially if we are looking at cuts
16 coming from [indecipherable]. I'm not too quite
17 sure if it's going to pass the senate right now,
18 but who knows what things may look like in the
19 next upcoming years.

20 But that's essentially what we're doing.
21 We're trying to hold our political officials to
22 the fire and really just make sure that we get the
23 people, particularly people living with HIV/Aids
24 for service advisers, folks who are often
25 [indecipherable] HIV to really join up with us in

1 solidarity to make sure that we get the governor
2 to put this two hundred million dollars in his
3 budget this financial year.

4 FEMALE: And I think that's so very
5 important because that is the only reason these
6 services are here now and I've been doing this a
7 long time. Dating myself, but we're made progress
8 and then it rolls back. Because I can remember
9 going to Washington D.C. and we all had tee shirts
10 that said, 'Housing is an AIDS issue.' That was
11 like, I don't know, 1995 or something. So here we
12 go. It gets better and maybe we get complacent
13 and your voice is so important because we have to
14 just, you know, bring it back up to the forefront
15 again.

16 MR. LESIEUR: Victor, so most of us who
17 live within the five boroughs, we know elected
18 officials and we talk about HIV needs, the
19 response, can I just a little higher for you. And
20 I'm just wondering if you could sort of, without
21 naming names, but what's the kind of receptiveness
22 that you've gotten from elected officials outside
23 of the five boroughs on HIV service needs?

24 FEMALE: We can absolutely say names.
25 Nina Louise [phonetic] is on the top of the list.

1 MR. LESIEUR: If you want to name names,
2 follow me.

3 MR. ALVAREZ: We have a few that have
4 always been very supportive.

5 FEMALE: Absolutely.

6 MR. ALVAREZ: Okay. Absolutely. Have
7 always been very supportive. But then, there's
8 that other that are very two faced. They'll tell
9 you one thing when they see you and then
10 completely vote in the opposite direction when it
11 comes time. So, you know, this is part of the
12 game.

13 And what Barbara was talking about years
14 back, that's when I had hair. We're going back a
15 long ways. Okay. Because in two years, I'll be
16 seventy, so you know, I'm not. You know, with
17 everything considered, everything considered, you
18 know, heart disease, HIV and now I was just told I
19 have diabetes, but no. We really need to be more
20 proactive. Okay.

21 And she was right. What happened for
22 many years, we were getting increases when I was
23 on the planning counsel. Under Giuliani, we got
24 more money, more money. Some people just got
25 complacent and said oh this is, you know, let's

1 not rock the boat. But that's changing now. And
2 you know, even we can see there may be a day when
3 there's no more Ryan White with managed care
4 taking in, expanded Medicaid taking over services.
5 And you know Ryan White is the payer of last
6 resort.

7 And so as you begin to take -- and other
8 agencies begin to pick up the -- what happens to
9 Ryan White? But you know, again what happens to
10 the undocumented? What happens to the people who
11 are not in care? I feel disenfranchised, the
12 transgender. You know, what happens to those
13 people?

14 MR. LESIEUR: One questions and then
15 we're going ask the audience. So in terms of the
16 sense of people who not eligible for public
17 assistance, the U word, I'll call it. What's the
18 sort of need in the tri-county area for those
19 populations who may have not been born in the
20 United States?

21 MS. BENTO-FLEMING: Are you speaking
22 about undocumented?

23 MR. LESIEUR: The U-word.

24 MS. BENTO-FLEMING: And when we talk
25 about tri-county, that is important question

1 you're raising Matt because there is clearly a
2 distinction as we all talk about between West
3 Chester, Rockland and Putnam.

4 MR. LESIEUR: Microphone.

5 MS. BENTO-FLEMING: Rockland staff has
6 been doing wonderful work in terms of outreach and
7 so many of who they serve are undocumented
8 population, so they can get them in for treatment,
9 but then all the other services, support services
10 are lacking.

11 MR. ALVAREZ: One of the issues, you
12 have to remember, when you talk about West
13 Chester, Rockland, Putnam, even further up,
14 Dutchess, Orange County. You have a big migrant
15 population. They move around. You know, they go
16 to work on different farms to make their money and
17 they move around, so it's very hard to get them,
18 to service them, to get them tested, to get them
19 into care because they're too busy trying to
20 survive.

21 MR. LESIEUR: Uh-huh.

22 MR. ALVAREZ: You know, there was
23 something I heard about eighteen years ago at an
24 [indecipherable] conference and it's always stuck
25 with me. There's a woman from Africa who came and

1 she was speaking and she said, "You people here
2 don't understand, but I'd rather die in ten years
3 of Aids than tomorrow of starvation." And that
4 always stuck with me.

5 And then you know, that's what she was
6 talking about before. It's about survival. It's
7 not just about taking meds and medication and
8 seeing your doctor. But it's about survival. You
9 know, yeah there's people abuse and use the
10 system, but what I find most of the people are
11 just struggling to survive. That's just it. They
12 just want to put food on the table and move
13 forward ahead.

14 And you know, people tell me, they say
15 Victor. We were talking, Danielle and I were
16 talking about when I have to do E-share and the
17 reporting and I look at someone's income and
18 they're getting seven hundred and thirty-three
19 dollars a month and I'm saying how do you live on
20 that? How do you -- and then if you have kids,
21 how do you do that? You've got to pay rent,
22 light, gas, cable and depending on where you live,
23 you pay for water.

24 West Chester is considered the richest
25 county in the state and they get you for

1 everything and even, we have a transportation
2 program. Without it, we'd be dead. The busses
3 don't run all the time. They run every couple of
4 hours. After nine o'clock, they stop. So
5 depending on where you live, you can't even get to
6 a doctor.

7 MS. BENTO-FLEMING: I just want to say
8 one more thing very quickly.

9 MR. LESIEUR: Yeah. Of course.

10 MS. BENTO-FLEMING: In terms of like the
11 needs, yes the need is absolutely for full housing
12 subsidies in tri-county, but I have to say that
13 with a caveat, it wouldn't be just reallocating
14 the existing fund because one person, to
15 [indecipherable] one person in, in West Chester
16 county, which I understood was actually the third
17 richest county in the nation with a year's full of
18 rent would be twelve thousand dollars. If we got
19 sixty thousand dollars, we could house five
20 people.

21 So it can't just be a redistribution of
22 the current pie. That's going to wipe out other
23 programs that people desperately need like
24 transportation since they don't have busses and
25 you probably don't have a car, or even food and

1 just one last thing and then I promise, I will
2 stop.

3 In terms of food stamps, there's a law
4 that says if you have section eight or if you have
5 [indecipherable], they're allowed to reduce your
6 food budget because you're getting a full rental
7 subsidy. So we have many people that are in our
8 full subsidy that will go from two hundred to one
9 eighty or one eighty-five to one sixty or one
10 sixty-five simply because they're getting a rent
11 subsidy as if you can spend the money that we're
12 giving to the landlord in the supermarket and it
13 makes no earthly sense. But I just wanted to put
14 that out there.

15 MR. LESIEUR: So I want to allow this
16 time for question and answers from the audience.

17 MR. PIERSANTE: Hi, it's David. Just
18 wanted to know, because there's such limited
19 housing in tri-county, have you thought about what
20 incentives can be developed or programs that could
21 be implemented just creatively to incentivize the
22 provision of housing in the areas in tri-county?

23 MS. BENTO-FLEMING: You mean in terms of
24 building projects?

25 MR. PIERSANTE: Right, right. People

1 who have --

2 MS. BENTO-FLEMING: They have -- there
3 has been housing development projects and I have
4 to say one thing I've seen them do recently, which
5 has benefitted some of our clientele is that
6 they've done a lot of senior housing development
7 and because for HIV infection, it's also a disease
8 now that is associated with people that are older.
9 That is one area where our clients have been able
10 to move into permanent, fully subsidized housing
11 if they got into a senior building and some of the
12 senior buildings will admit at fifty-five.

13 So I think it's almost like a
14 coincidence that our population is old enough to
15 qualify for the housing that they've really built.

16 Some landlords feel that it's better to
17 have a subsidy and know your rent is coming
18 because the foreclosures in West Chester, you have
19 no idea. It was scary. You know, I mean people
20 lost their housing of every income level, so some
21 landlords will take a subsidy just because they're
22 getting paid, but you know, there are other
23 landlords that can get, you know, thirty-five
24 hundred dollars a month for a unit in White Plains
25 or Dobbs Ferry or [indecipherable] and I can go on

1 and on and there is no incentive that I can give
2 them to make them want to rent unless they care.

3 FEMALE: Good afternoon again. I just
4 want to say and recognize that there are three
5 panelists that are sitting up there representing
6 the tri-county that are warriors and heros and
7 speaking specifically of myself, I really can
8 honestly tell you and I'm going to try not to get
9 emotional, that I would not have thrived, never
10 mind survived if it wasn't for those three
11 panelists sitting there and the other agencies
12 that serve West Chester county.

13 The resources in West Chester county are
14 extremely limited because West Chester county
15 suffers from affluenza [sic] and we are battling
16 with political leaders who will not support
17 poverty, homelessness, mothers working and never
18 mind HIV, so having said that, I just wanted to
19 play devil's advocate a little bit because the
20 few, very few programs that house people with HIV
21 living with Aids are very few. The roads to get
22 to those resources are very limited. I had to do
23 my own research when I was diagnosed, on my own,
24 to find what was available in a county that
25 doesn't want to admit that these services are

1 needed.

2 In my building where I live, there are
3 forty-five units and seven identifiable people
4 with HIV. They don't know that I know all of
5 them, but because I work with the tri-county and
6 the planning committee, I know the services they
7 get and they get their housing through mental
8 health subsidies and through section eight. We
9 are so grossly underfunded and we're so neglected
10 and we're so under-served that it's painful. It
11 is extremely painful.

12 The other thing that I just wanted to
13 say playing devil's advocate is, those houses that
14 are available, those -- they're in violent and
15 drug infested neighborhoods because nobody wants
16 them anywhere else. They're also stigmatizing so
17 people may not disclose because they want to be
18 able to blend in and live as normal a life as you
19 can.

20 I'm living a normal life because I'm not
21 living in HIV subsidized housing, but I know so
22 many people who are out on the street from a
23 street level that are not diagnosing, that are
24 homeless and because like you said, the freeze,
25 the housing resources are very limited.

1 And there's a story that's really not
2 being told and if you go on the street level and
3 talk to people from the street level and not
4 always the information given by politicians and
5 county politics, you're going to see that it is a
6 much deeper and much bigger problem.

7 But I really want to thank the providers
8 and the panelists for the information because I
9 learned a lot. But there is so much lack and so
10 much need that I hope that being here and being
11 blended with New York City is going to give us new
12 ideas and bring some new light in some ways that
13 we can help tackle the problem.

14 So thank you for listening.

15 MR. LESIEUR: Is there anybody else?

16 MALE: I just wanted to respond to David
17 and thanks. David, when you were talking about,
18 it was several years ago. Father Bob Warring
19 [phonetic] from [indecipherable]. Got brothers,
20 [indecipherable] of the atonement up in Cold
21 Spring. He raised the money to build an apartment
22 building for people with HIV and Aids. He was
23 simply told, you have to put that in Mount Vernon
24 or Yonkers. He wanted to put it up in Peekskill
25 or in Croton, but they said no. You can't have

1 that here.

2 So you got to remember the stigma in New
3 York City is not the same in stigma in West
4 Chester County. You know, I get all the time,
5 people say, "Yeah, I know, I know. I feel for
6 those poor people with Aids, but I don't want them
7 here." Yeah, that's the reality of it and so that
8 makes it even more difficult.

9 And Barbara is right. You know, you go
10 to find a place to live and the neighborhoods
11 they're offering you, you say I'd rather be in
12 prison. At least it would be cleaner.

13 MS. AIDALA: And also just to piggy back
14 on what he said. A lot of people, they come to us
15 when they lose their employment. You know,
16 there's a higher percentage of people that are
17 diagnosed that if they're not currently employed,
18 they were previously employed, so they may come to
19 us through other networks.

20 Like we used to have an eviction
21 prevention network when the government gave money
22 to eviction prevention and sometimes we would meet
23 people that were losing their housing because they
24 lost their employment and they would get a
25 referral to us through one of the agencies, maybe

1 even legal services and wind up in Ryan White
2 services that way.

3 Or people go into unemployment, maybe
4 they can't pay the rent or they're losing
5 unemployment and now they're dropping down to
6 public assistance and they wind up with us that
7 way.

8 And the struggle has been to have people
9 actually go and get the additional services that
10 they're eligible for. It's really kind of easy to
11 see us. We're in a very quiet, out of the way
12 neighborhood and we're just all by ourselves as a
13 building and no one knows what's going on there,
14 not even the neighbors. But I think to have
15 people say okay, you're eligible for
16 transportation or food, I've had a hard time
17 because of the stigma. You know, people are
18 willing to get financial assistance, but they
19 don't want any other services. I mean, I've had
20 them crying in my office because they're so afraid
21 of the stigma.

22 And one last thing about the doubling up
23 or living in your parents' houses, I've had, you
24 know, people tell me, well you know, I can live
25 with my parents, but they make me eat off of paper

1 plates or I have my own separate dishware or
2 silverware and this is in West Chester. You know,
3 this is not in Iowa or Timbuktu. It's just in
4 West Chester, so I think the stigma is extremely
5 powerful in West Chester.

6 I think even being a working class
7 person, there's a stigma associated with it. When
8 I drive my little Honda, you know, and I'm passing
9 all these Lexus and BMWs and they're like, Oh,
10 we're so sorry, you're in a Honda.' So I mean,
11 and that's how I feel. I feel sorry for myself
12 once I leave the Bronx. I'm pitiful, but you
13 know, and I really am. It's a really wealthy
14 neighborhood.

15 You know, I love working in West
16 Chester. I never do my food shopping in upper or
17 mid West Chester. I have to come down to the
18 Bronx or southern West Chester because even the
19 food is cheaper. You know. And don't get me
20 started on the food. Someone stop me.

21 MR. LESIEUR: So we have time for like
22 maybe two more questions.

23 MALE: Yeah, I have one over here.

24 FEMALE: Hi. I just want to say that up
25 in the tri-county area is the worst. Besides the

1 stigma, the barriers with the transportation, then
2 you have to face how to juggle your medical
3 appointments which is just crazy. If you're not
4 blessed with somebody that can understand your
5 appointments that you have to keep for your
6 doctors, for your own health, then you've got to
7 say working.

8 Now, I had to work as a home health aid
9 which they don't give you a break. You have to
10 get somebody to cover for you. I had to work
11 seven days a week, so that didn't leave me much
12 time for a support group. So that got me
13 disconnected from everything else.

14 So these people have done an amazing job
15 for us all, our population because otherwise, we
16 would be having more problems than just a little.

17 And the stigma, the stigma is still
18 there. I mean thirty years later and we still
19 have that stigma that we got to get past. And the
20 clients, I mean they have those identifiable
21 buildings are, people with a stigma problem are
22 not going to want to go there because they're
23 going to say, oh there goes those people in the
24 Aids building.

25 They already have -- and the

1 transportation, if you don't have metro card,
2 you're out of luck. And it's so limited as far as
3 the transportation because there's set times you
4 have to get somewhere. It's between the pharmacy,
5 medical appointments and the stigma. It's all
6 there.

7 Thank you.

8 MR. LESIEUR: I got one here. That will
9 be the last one.

10 MR. SHERWIN: Okay. Thanks. Hi, I'm
11 Howard Sherwin and I work, I work at Legal Aid of
12 Rockland County, so to bring a prospective from
13 Rockland County.

14 We do have a homelessness problem in
15 Rockland County. There is no shelter in Rockland
16 County for single people; only for families. And
17 there -- I don't know the numbers, but it is an
18 issue and we're grappling with that.

19 And as you mentioned undocumented
20 people. It is a real, a fairly large population
21 in Rockland County and yes, the health department,
22 the infectious disease unit of the department of
23 health have identified a lot of those people and a
24 lot of them are doubling up, I would guess and are
25 too busy dealing with working and everything else

1 to access services.

2 But the one thing I would say about
3 Rockland County is that Department of Social
4 Services is fairly good and we don't hear a lot of
5 the problems that we hear in West Chester about
6 dealing with them, so it's great to have a
7 relationship with your department of social
8 services meet with them and try and foster a good
9 relationship.

10 Thanks.

11 MR. LESIEUR: And I want to close.
12 Jason, what can people do specifically to impact
13 change? I know you guys are planning a big event.
14 I'll give you my microphone.

15 I want to close with Jason. What are
16 some things that people can do to effect change in
17 this area?

18 MR. WALKER: Hello.

19 MR. LESIEUR: Okay.

20 MR. WALKER: So definitely one thing is
21 to join us up in Albany on March 9th. Vocal New
22 York will be providing free transportation for
23 people. I think we have a pick up location in
24 [Indecipherable] Union Square, one in Harlem and
25 one in the Bronx. We're providing free

1 transportation, a fifteen dollar meal stipend for
2 low income folks living with HIV to make sure we
3 get up there.

4 And definitely like participate and talk
5 to legislators and get them to really push the
6 governor to really start funding like housing
7 initiatives for folks living with HIV in New York
8 City and throughout the rest of the state as well,
9 right, so that's not only the expense of HASA, but
10 also making sure that we provide enhanced rental
11 assistance for folks throughout the state. Right.

12 We have the resources, we have the
13 dollars to do it. It's just really, it's just
14 exercising political will to make sure that it
15 happens.

16 MR. LESIEUR: I want to thank my panel.
17 Great presentations. Thank you everyone. And we
18 do have next [indecipherable]. That wasn't me. I
19 think we're going to close with the governmental
20 co-chair from the planning council, Ms. Jan Park.

21 MS. PARK: Thank you, Matt. Thank you
22 everybody for being here today and I'm the
23 governmental co-chair of the Planning Council.
24 I'm the Director.

25 MALE: Closer to your face.

1 MS. PARK: Can you hear me now?

2 MANY: Yes.

3 MS. PARK: Of all people, a deaf person,
4 I'm asking if you can hear me.

5 Thank you panelists. This was a great
6 panel. We are very fortunate to be able to get
7 all of you here and to discuss tri-county issues.
8 It's part of our integration, bringing tri-county
9 into our city planning process in a way that we
10 haven't done previously and we're going to learn a
11 lot from that process.

12 Great ideas today. Great conversation
13 today. Now we have to turn those into actions.

14 I want to thank the chairs of the Needs
15 Assessment Committee; Carrie and Daniel. The
16 chairs of the Consumer Committee; Billy and
17 Katrina. The members of the Planning Council who
18 found the funding in order to put this day
19 together.

20 I want to especially thank Planning
21 Council staff and the Grand [Indecipherable]
22 staff.

23 But in particular, Dr. Rothschild,
24 please stand. You cannot believe the amount of
25 emails that she had to endure in order to get all

1 of these people here. And it really was her
2 perseverance, her late evenings and weekends that
3 pulled this day together and is really a testament
4 to your good works, so thank you very much.

5 And with that said, I'm going to
6 conclude today's session and we'll do this again.
7 I think it was very useful. We talked three hot
8 topics and those are going to be driving much of
9 the work the Planning Council for the next six
10 months.

11 Thank you very much. Have a good
12 evening.

13 (End)

C E R T I F I C A T E

I, Randel Raison, certified electronic court transcriber, do hereby certify that I typed the proceeding in the foregoing matter from audio recording, or the transcript was prepared under my direction, and that this is as accurate a transcript of what happened at that time and place as best as is possible, due to conditions of recording and/or duplicating.



Randel Raison, CET 340