ACKNOWLEDGEMENTS

The CAEAR Coalition Foundation and the CAEAR Coalition thank Gilead Sciences for its generous support of the Part A Survey and the town hall. Gilead Sciences is a proven champion of the Ryan White community. It has shown time-and-time again its commitment to the Ryan White HIV/AIDS Program and to people living with HIV/AIDS by supporting not only the CAEAR Coalition Foundation and the CAEAR Coalition, but numerous AIDS service organizations from across the country.

The CAEAR Coalition Foundation thanks the Part A survey respondents; town hall participants; and Sami Abbas; Amber Casey, MPH; and Anna Thomas Ferroili, MPH, of the New York City Department of Health and Mental Hygiene, for their work analyzing the survey results. The foundation also thanks the town hall moderator and panelists for sharing their expertise and insights: Daria Boccher-Lattimore, DrPH, Director and PI, Northeast/Caribbean AIDS Education & Training Center and President, National Alliance for HIV Education and Workforce Development; Jenny Collier, JD, CEO, Collier Collective and Convener, Ryan White Medical Providers Coalition; Graham Harriman, MA, Chair, CAEAR Coalition; Ernest Hopkins (moderator), Director of Legislative Affairs, San Francisco AIDS Foundation, and Policy Chair, CAEAR Coalition; Ann Lefert, Senior Director, Policy & Legislative Affairs, National Alliance of State and Territorial AIDS Directors (NASTAD); David Reznik, DDS, President, HIV Dental Alliance; Carl Schmid, Deputy Executive Director, The AIDS Institute; and Dr. Ivy Turnbull, Deputy Executive Director, AIDS Alliance for Women, Infants, Children, Youth & Families.

As the CAEAR Coalition convenes the Ryan White community to determine next steps for the Ryan White HIV/AIDS Program, it will focus on ensuring transparency, engagement, and collaboration from all members of the community, especially those living with HIV who receive services from Ryan White.
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PURPOSE OF RYAN WHITE PART A SURVEY

In August 2018, the CAEAR Coalition initiated a survey of Ryan White Part A recipients to understand the current perspectives of its members and constituents. The purpose of the survey is to inform policy discussions with Congress and the Administration regarding any future reauthorization of the Ryan White HIV/AIDS Program. The survey will also help identify possible administrative fixes.

The program has been reauthorized four times since its inception in 1990. Each time the process has been led by the HIV advocacy community, including people living with HIV, along with federal administrators; representatives from city, county, and state public health departments; state and local elected officials; and the staff and members of Congress. During each reauthorization, and in response to community needs, portions of the program have been modified to improve its effectiveness, efficiency, and the fair distribution of limited resources. The authorization of Ryan White expired in 2013. Although Congress continues to fund the program, a new Congressional authorization would be required to change current provisions. Congress continues to fund the Ryan White Program because it has proven over time to be one of the most cost-effective, efficient, and results-driven investments in the federal portfolio. The Trump Administration has praised the program and called for its reauthorization in its budgets for both FY 2018 and FY 2019, recommending changes to ensure the program continues to respond to the needs of people living with HIV where they live today, with the services they require for optimal health and wellness.

The CAEAR Coalition is excited to engage with the 116th Congress and the new leadership in the House of Representatives to assess interest in holding hearings on the success of the program, which would be the first step in a Congressional review and potential reauthorization. CAEAR believes the Ryan White community should review how the program is working in the field and come to consensus on any changes among themselves first before promoting policy positions externally to the legislative and administrative branches of government. To that end, the CAEAR Coalition surveyed the Ryan White Program’s designated EMAs and TGAs (Part As) to ensure it understands the concerns of each jurisdiction and incorporates those concerns and recommendations in its communications with Congress and the current Administration.

The survey included 49 questions organized by topic areas: Funding Formula and Supplemental; Program Income, Performance, and Unobligated Funds; Disparities and the Minority AIDS Initiative (MAI); Expansion of Services; Administration; Clinical Quality Management (CQM); Research and Data Reporting; and Planning. Twenty-three of the 52 EMAs-TGAs responded. The survey analysis is outlined in Attachment A.
To further inform its work, the CAEAR Coalition Foundation hosted a town hall entitled Next Steps for the Ryan White HIV/AIDS Program on December 11, 2018. The purpose of town hall was to release the results of the Ryan White Part A survey and moderate a discussion with Ryan White community leaders on next steps for the program. Time was also provided for audience Q&A. Ernest Hopkins, Policy Chair, CAEAR Coalition, moderated the panel discussion. The panelists included Daria Boccher-Lattimore, DrPH, Director and PI, Northeast/Caribbean AIDS Education & Training Center and President, National Alliance for HIV Education and Workforce Development (NAHEWD); Jenny Collier, JD, CEO, Collier Collective and Convener, Ryan White Medical Providers Coalition; Graham Harriman, MA, Chair, CAEAR Coalition; Ann Lefert, Senior Director, Policy & Legislative Affairs, National Alliance of State and Territorial AIDS Directors (NASTAD); David Reznik, DDS, President, HIV Dental Alliance; Carl Schmid, Deputy Executive Director, The AIDS Institute; and Dr. Ivy Turnbull, Deputy Executive Director, AIDS Alliance for Women, Infants, Children, Youth & Families. The transcript of the panel discussion and audience Q&A is reported in Attachment B.
CAEAR Coalition is in the careful and deliberative process of determining how and what legislative and administrative actions could improve the Ryan White HIV/AIDS Program. Therefore, CAEAR is not advocating for reauthorization of the program at this time. The survey and town hall meeting with the community held on December 11, 2018, are important early steps to assess Part A recipient considerations on reauthorization and to identify administrative changes that could be made with the program that do not require reauthorization.

As Ernest Hopkins, Policy Chair of the CAEAR Coalition, noted at the conclusion of the town hall, “The process of reauthorizing this piece of legislation, as popular as it is, is always challenging. I would expect nothing less in this environment. There are regional and jurisdictional issues. There are funding issues. There are consumer versus grantee versus provider issues. All issues need to be presented and discussed. If the community can come to a consensus, then we move forward. If the community cannot, then we will not proceed. We will not proceed because as was discussed here today, the Ryan White HIV Treatment Program is too important and is working too well to risk it. The CAEAR Coalition wants to be transparent. Just because we are having the conversation does not mean we are going pursue reauthorization. The community needs to be okay with that because if we do not seek to reauthorize, there will be a very good reason why we do not.”

**NEXT STEPS**

- The CAEAR Coalition will prepare a list of administrative fixes to the Ryan White Program and arrange a meeting with HRSA-HAB to discuss.
- The CAEAR Coalition will develop a list of initial recommendations based on the Part A survey results and town hall discussion, so it is prepared should the Administration and/or the Congress decide to pursue reauthorization of the Ryan White Program.
- The CAEAR Coalition will re-issue the ten-question Planning survey to the Part A planning councils to increase participation and will host a call to discuss the results.
Attachment A: Analysis of Ryan White Part A Survey

section

RESPONDENT DEMOGRAPHICS

REGIONAL REPRESENTATION

<table>
<thead>
<tr>
<th>REGION</th>
<th>NUMBER OF RESPONDENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>0</td>
</tr>
<tr>
<td>II</td>
<td>3</td>
</tr>
<tr>
<td>III</td>
<td>1</td>
</tr>
<tr>
<td>IV</td>
<td>5</td>
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<tr>
<td>V</td>
<td>5</td>
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<tr>
<td>VI</td>
<td>5</td>
</tr>
<tr>
<td>VII</td>
<td>3</td>
</tr>
<tr>
<td>VIII</td>
<td>1</td>
</tr>
<tr>
<td>IX</td>
<td>1</td>
</tr>
<tr>
<td>X</td>
<td>1</td>
</tr>
</tbody>
</table>

AMOUNT OF RYAN WHITE PART A GRANT

Number of respondents: 23

<table>
<thead>
<tr>
<th>AMOUNT OF PART A GRANT</th>
<th>PERCENT OF RESPONDENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;$5M</td>
<td>0%</td>
</tr>
<tr>
<td>$5M-$10M</td>
<td>20%</td>
</tr>
<tr>
<td>&gt;$10M</td>
<td>80%</td>
</tr>
</tbody>
</table>
EMA AND TGA THRESHOLD CRITERIA

The current criteria to determine an EMA and TGA is as follows: For an EMA, there are at least 2,000 reported cumulative AIDS cases (both living and deceased) in the past five years. For a TGA, there are between 1,000-1,999 reported cumulative AIDS cases (both living and deceased) in the past five years. EMA and TGA designation differ from Ryan White HIV/AIDS Program funding formulas, which are based on living HIV and AIDS cases.

Seventy percent of respondents indicated that the criteria for EMAs and TGAs was no longer relevant (Q1).

Twelve respondents indicated the criteria should be changed to incorporate prevalence of HIV in a jurisdiction, rather than AIDS cases.

The most common reason cited was that the current criteria penalizes jurisdictions that successfully prevent PLWH from progressing to AIDS.

Two respondents indicated that prevalence is preferred because it more accurately reflects service needs.

Additional threshold criteria to be considered include:

- a measure of poverty and/or cost of living (4)
- a measure of aging/long-term survival (3)
- care engagement and/or viral load suppression (3)
- race of PLWH in the jurisdiction (1)

FUNDING FORMULA RECOMMENDATIONS

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>The RWPA funding formula should be based on current living HIV/AIDS cases. (Q2)</td>
<td>92%</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>RW programs are able to address outcome disparities by gender (transgender men and women and cisgender men and women). (Q13)</td>
<td>31%</td>
<td>4%</td>
<td>65%</td>
</tr>
<tr>
<td>RW programs are able to address outcome disparities for men who have sex with men. (Q14)</td>
<td>57%</td>
<td>17%</td>
<td>26%</td>
</tr>
</tbody>
</table>

CONSIDER MULTIPLE FACTORS WHEN ESTIMATING NEED FOR A SUPPLEMENTAL AWARD (Q5)
## Program Income, Performance, and Unobligated Funds

### Program Income and Pay for Performance Incentives

<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program income should continue to be used exclusively for Ryan White activities. (Q6)</td>
<td>65%</td>
<td>13%</td>
<td>22%</td>
</tr>
<tr>
<td>Program income should be available to expand programs for Ryan White and HIV prevention services like PrEP. (Q7)</td>
<td>70%</td>
<td>13%</td>
<td>17%</td>
</tr>
<tr>
<td>EMAs and TGAs should research and implement pay-for-performance incentives in sub-recipient contracts. (Q8)</td>
<td>44%</td>
<td>26%</td>
<td>30%</td>
</tr>
<tr>
<td>HRSA/HAB should research and implement pay-for-performance incentives in sub-recipient contracts. (Q9)</td>
<td>52%</td>
<td>31%</td>
<td>17%</td>
</tr>
</tbody>
</table>

### Unobligated Funds

<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unobligated funds should be tracked in terms of their origin and use. (Q10)</td>
<td>61%</td>
<td>22%</td>
<td>17%</td>
</tr>
<tr>
<td>Unobligated funds in one part (Parts A-F) of the Ryan White HIV/AIDS Program should have full flexibility to be used in other parts of the program. (Q11)</td>
<td>61%</td>
<td>17%</td>
<td>22%</td>
</tr>
</tbody>
</table>
WHAT SHOULD BE THE PRIORITY OF THE MINORITY AIDS INITIATIVE?

RECOMMENDATIONS FOR MAI RESOURCES IN YOUR JURISDICTION (Q18)

MAI resources to be used to support, via funding and capacity building, small subcontractor organizations that are run by and/or serve people of color (five of 10 responses).

- Of the five, two indicated that the support should be for organizations led by people of color.
- Three respondents recommend MAI funding for innovative projects, with two of the three recommending provider education projects.
- Two respondents wish to provide support for data reporting/collection, including simplifying reporting requirements.
- One respondent indicated that jurisdictions that primarily serve people of color should be allowed to use MAI funding to support existing Part A services, rather than requiring distinctly different services.

OUTCOME DISPARITIES

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>As the Ryan White Program is currently structured, it is able to address outcome disparities by race and ethnicity. (Q12)</td>
<td>61%</td>
<td>30%</td>
<td>9%</td>
</tr>
<tr>
<td>RW programs are able to address outcome disparities by gender (transgender men and women and cisgender men and women). (Q13)</td>
<td>52%</td>
<td>22%</td>
<td>26%</td>
</tr>
<tr>
<td>RW programs are able to address outcome disparities for men who have sex with men. (Q14)</td>
<td>65%</td>
<td>18%</td>
<td>17%</td>
</tr>
<tr>
<td>RW programs are able to address outcome disparities for people who inject drugs. (Q15)</td>
<td>33%</td>
<td>22%</td>
<td>35%</td>
</tr>
</tbody>
</table>
EXPANSION OF SERVICES

ADDITIONAL FUNDING

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>With commensurate additional funding, the Ryan White HIV/AIDS Program should be expanded to include:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Services for mono-infected individuals with hepatitis A, B, and C (Q19)</td>
<td>69%</td>
<td>9%</td>
<td>22%</td>
</tr>
<tr>
<td>Access to PrEP and PEP through ADAPs (Q20)</td>
<td>96%</td>
<td>0%</td>
<td>4%</td>
</tr>
<tr>
<td>Services that address the opioid epidemic (Q21)</td>
<td>61%</td>
<td>17%</td>
<td>22%</td>
</tr>
</tbody>
</table>

OTHER SERVICES

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ryan White housing support should be expanded to include housing subsidies and other services connected to long-term housing. (Q22)</td>
<td>73%</td>
<td>13%</td>
<td>4%</td>
</tr>
<tr>
<td>HAB should reinstate employment services as an allowable service category (Q23)</td>
<td>78%</td>
<td>13%</td>
<td>9%</td>
</tr>
</tbody>
</table>

EXPANSION OF ALLOWABLE SERVICES

Respondents want to provide additional housing and clinical services (11 respondents).

- Providers wish to expand housing assistance to pay for deposits and credit checks (4 of 11)
- Desired clinical services include durable medical equipment, complementary and alternative therapies, financial incentives for visits, comprehensive pain management, and more expansive vision services

Other desired allowable services include:

- Data entry (presumably with program rather than administrative $)
- Collaborations with other provider types
- Services related to non-opiate drug use
- A peer navigation service category
- Fees for driver’s licenses
- Needle exchange
- Media campaigns
- Services to incarcerated people regardless of facility type
- Services for transgender women regardless of HIV status

---

1 Red font indicates currently unallowable services per HRSA policy. A number of responses indicate a need for consistent communication with RWPA jurisdictions to clarify HRSA policy. Many of these can be provided under current rules. For example, vision services and some alternative therapies can be provided if they are on the ADAP formulary. Acupuncture is currently allowable as a substance use treatment modality. Financial incentives may be provided as long as a jurisdiction has an incentive policy.
ALMOST ALL RESPONDENTS (87%) WISH TO SIMPLIFY THE RYAN WHITE FUNDING APPLICATION (Q25).

Suggested strategies:
- Less frequent or more brief applications (10 of 17)
  - removal or reduction of the EIIHA section (3)
  - simplifying the template (2)
  - Reducing the demonstrated need section (2)
- Align funding cycles with other RW parts (3 of 17)

Other application suggestions:
- Award points for improvement in care continuum indicators and for decreasing prevalence (2)
- More transparency about the relationship between scores and supplemental funds awarded (1)
- Allowing carry-over of all funds within the cycle years (1)

RESPONDENTS ARE SPLIT ON ELIMINATION OF THE 75% CORE MEDICAL SERVICES REQUIREMENT.

Twelve respondents want to eliminate the waiver, 11 would keep the CMS requirement.

Many recommend changes:
- More flexibility in which services are considered core (4).
  - Medication costs, even when paid via Emergency Financial Assistance (EFA), should be considered core (2).
  - Substance Abuse Services (Residential) should be considered core, in the same way as Substance Abuse Services (Outpatient).
- Local planning bodies should have more flexibility and control in the allocation of funds (1).
- Core medical services waiver should be simplified or streamlined (3).
  - subsequent applications after approval should be shorter (1).
  - one indicating the waiver application should happen before the grant application (1).
- Importance of continued prioritization of viral load suppression-focused activities (2).
- No change to the current CMS waiver process (3).

ADDITIONAL STRATEGIES TO REDUCE THE ADMINISTRATIVE BURDEN (Q29)

Additional suggestions fell into the following categories:
- Make reporting requirement changes (review OMB forms, RSR eligible scope, streamline COA, eliminate reporting by service category and WICY)
- Increase contract oversight flexibility (allow desk audits, eliminate six-month eligibility and annual site visit)
- Improve coordination (deadlines for application and reports, between Parts A-F and other Federal Funders, and reduce requests for duplicate data)
- Increase budget flexibility (cap on Admin, restriction of 5% formula carryover, extend timeline for FFR reporting)
- Make concessions for TGAs/small jurisdictions.
CLINICAL QUALITY MANAGEMENT (CQM)

<table>
<thead>
<tr>
<th></th>
<th>AGREE</th>
<th>NEUTRAL</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>The use of funds for CQM is too restrictive. (Q28)</td>
<td>78%</td>
<td>9%</td>
<td>13%</td>
</tr>
<tr>
<td>The 5% of $3,000,000 cap (whichever is less) for CQM should be combined with the 10% Administration cap for a 15% overall administration/CQM cap to provide more flexibility in how funds are used to meet CQM and program goals. (Q29)</td>
<td>100%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>The combined 15% Administration/CQM cap is sufficient to cover costs of operating a comprehensive Ryan White program. (Q30)</td>
<td>22%</td>
<td>52%</td>
<td>26%</td>
</tr>
</tbody>
</table>

ADDITIONAL CQI RESPONSES (Q31)

Most responses (6) suggest fewer restrictions on CQM allocation, such as:

- increased funding allowance for pay for performance models/pilots
- data entry
- decentralization of Continuous Quality Improvement (CQI) to support sub recipient programs

Additional strategies include:

- increased support for TGA QM programs (with less resources for larger EMA’s)
- increased consumer engagement in Planning Councils
- increased support for Quality Assurance which is included in the legislation (section 2604 (h) (five), but not included in HRSA/HAB’s 15-02 CQM policy notice (2)

Three responses suggest changes to measures including:

- elimination of CD4 as a CQI measure
- retention in care measure should be once per year for those virally suppressed two years or more (instead of twice per year)
### RESEARCH AND DATA REPORTING

#### JURISDICTIONS WANT MORE DATA REPORTING SUPPORT

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>RW should support jurisdictions with additional funding to integrate program data with surveillance to support data-to-care activities. (Q32)</td>
<td>91%</td>
<td>9%</td>
<td>0%</td>
</tr>
<tr>
<td>RW should collect more information about HCV screening and treatment for the co-infected. (Q33)</td>
<td>61%</td>
<td>35%</td>
<td>4%</td>
</tr>
<tr>
<td>RW should support jurisdictions with additional funding to integrate program data with HOPWA data. (Q34)</td>
<td>82%</td>
<td>9%</td>
<td>9%</td>
</tr>
<tr>
<td>HRSA/HAB should streamline and limit frequency of changes to RSR reporting to avoid reprogramming of client database systems and to coordinate with software systems administrators (Q35)</td>
<td>91%</td>
<td>9%</td>
<td>0%</td>
</tr>
</tbody>
</table>
## Planning Councils

<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Ryan White legislation requires Part A EMAs/TGAs to have Planning Councils and Planning Bodies. Do you support this requirement? (Q36)</td>
<td>87%</td>
<td></td>
<td>13%</td>
</tr>
<tr>
<td>Does your jurisdiction support the continued legislative authority of the Planning Councils’ development of priorities and resource allocation? (Q37)</td>
<td>74%</td>
<td></td>
<td>16%</td>
</tr>
<tr>
<td>Planning Councils are effective in ensuring the Ryan White HIV/AIDS Program meets local unmet needs. (Q38)</td>
<td>48%</td>
<td>4%</td>
<td>9%</td>
</tr>
</tbody>
</table>

## Integrated Planning

<table>
<thead>
<tr>
<th>Question</th>
<th>Agree</th>
<th>Neutral</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your jurisdiction have an integrated prevention and care planning body? (Q40)</td>
<td>52%</td>
<td></td>
<td>48%</td>
</tr>
<tr>
<td>Do you support integrated HIV Prevention (CDC) and HIV Care (Ryan White) planning bodies? (Q41)</td>
<td>96%</td>
<td></td>
<td>4%</td>
</tr>
<tr>
<td>An integrated HIV Prevention and Care Plan is a means of using resources efficiently. (Q42)</td>
<td>70%</td>
<td>26%</td>
<td>4%</td>
</tr>
<tr>
<td>The result of integrating HIV Prevention and HIV Care planning bodies is improved care for PLWH. (Q43)</td>
<td>47%</td>
<td>44%</td>
<td>9%</td>
</tr>
</tbody>
</table>
OTHER ISSUES

Additional items mentioned include recommendations regarding:

- 340B (allow access to 340B drug pricing, flexibility in use of 340B rebate dollars and use of dollars to be considered in planning for services)
- Special Projects of National Significance (SPNS) Programs
- Funding changes (ACA implementation considerations, Maintenance of Effort (MOE), addressing health disparities in the South)
MODERATOR AND PANELISTS

Ernest Hopkins, Policy Chair, CAEAR Coalition, moderated the panel discussion. The panelists included Daria Boccher-Lattimore, DrPH, Director and PI, Northeast/Caribbean AIDS Education & Training Center and President, National Alliance for HIV Education and Workforce Development (NAHEWD); Jenny Collier, JD, CEO, Collier Collective and Convener, Ryan White Medical Providers Coalition; Graham Harriman, MA, Chair, CAEAR Coalition; Ann Lefert, Senior Director, Policy & Legislative Affairs, National Alliance of State and Territorial AIDS Directors (NASTAD); David Reznik, DDS, President, HIV Dental Alliance; Carl Schmid, Deputy Executive Director, The AIDS Institute; and Dr. Ivy Turnbull, Deputy Executive Director, AIDS Alliance for Women, Infants, Children, Youth & Families.

MODERATOR ERNEST HOPKINS: Thank you and welcome. The CAEAR Coalition is always excited to play its role in convening the community to discuss next steps for the Ryan White legislation. The CAEAR Coalition was there at the beginning, and we will continue to play our role in shaping this successful piece of legislation.

I have prepared a set of questions for today’s panelists to highlight critical issues and challenges should reauthorization of the Ryan White Program be pursued.

One of the things I noted from CAEAR’s survey of grantees and planning councils is that people love the Ryan White Program so much they would love to see it be a more integral part of healthcare for other people, people who are not living with HIV. To that end, I am curious to know how we would justify a person who is sexually active in the U.S., who is not living with HIV, who lives in a high-prevalence area, getting access to a supplemental healthcare program to access PrEP? What would the criteria need to be? This question gets to the challenges we might face as we go to Congress. Healthcare was the number one polling issue in the 2018 election and will be a priority for the new House majority. Give me your best thinking, Carl Schmid, on this issue.

CARL SCHMID: I have broached this question before with Ernest. Do we really expect Ryan White to buy insurance for people who want PrEP? Let me back up. The Ryan White Program is a perfect model to deliver PrEP. It is in the locations where people at risk of HIV reside. Ryan White-funded health clinics and AIDS service organizations are culturally competent. Many are prescribers. The Ryan White Program has the doctors, providers, and prevention and outreach programs, so it is a perfect delivery system. The issue is paying for it. There are two things we should look at: paying for the drugs and paying for the services. There are also people who are insured and not insured in the Ryan White system. For those insured, PrEP should be covered. We also have the U.S. Preventative Services Task Force recommendation that there be no copays, so hopefully that will be implemented in the next year or two. PrEP is currently authorized through Medicaid and Medicare as a preventive service and fully covered for people who live in states that have expanded Medicaid to low-income residents in addition to low-income residents living with disabilities. This leaves out residents in states that did not expand Medicaid, which includes many southern states. There is also the issue of middle-income residents who choose not to purchase insurance or cannot afford to do so. We still
need to address the PrEP needs of these uninsured. I think that could be a role for the Ryan White Program on a limited basis.

ERNEST HOPKINS: There was some ambivalence in the slide highlighting the use of Ryan White program income. I do not know if people picked up on it. According to the survey results, we would like our resources to continue to be used for Ryan White, and in the next statement, we would like our Ryan White services to be expanded to include PrEP. You would be a Ryan White client using PrEP. Would you have access to everything else that a Ryan White client currently has access to or would you only be able to use Ryan White for PrEP?

David Reznik lives in a state that did not expand Medicaid where there are many uninsured folks who are not HIV infected. It would be interesting to know what you think about how to assist people who are not HIV infected in Atlanta who would now become members of your Ryan White Program to access PrEP. Would you think they would only be able to access PrEP or would they be able to access other Ryan White services?

DR. DAVID REZNIK: First, it is a moral imperative in a place like Atlanta, where if you are an African-American man who has sex with other men your chances of becoming HIV infected are 50%. We have people still dying in our hospital from AIDS, when we should not. If we are going to protect all of society, we need health equity and to operate from a position of a culture of health, which is so vitally important for people who are dealing with the negative impacts of the social determinants of health. We can address the technical issues on how to expand Ryan White, but we have to decide if we are willing to ensure health equity for all. We need to find a way. Would we do it at our clinic? We are currently expanding and renovating. You have been there, Ernest. Grady is known as an AIDS clinic. Is that the best place to give PrEP or should we have another branch for that service?

ERNEST HOPKINS: What do you think?

DR. DAVID REZNIK: It should be both. As you know, I have been in a serial discordant relationship for 23+ years. I think you should make that available to people in the program and those outside of the program. The expertise is needed, but the mechanics of expanding the program are not that difficult.

ERNEST HOPKINS: Anybody else want to share their thoughts?

DR. IVY TURNBULL: I can speak from experience regarding the Part D program. One of the things that Part D was able to do was service not only the index client, or the person who was positive, but other members of the family as well.

ERNEST HOPKINS: That was about embracing the reality that if you were providing services to a woman or you were providing services to an infected child, then all the other children’s health needs were going to be addressed. All the other family members were going to benefit.

DR. IVY TURNBULL: Correct. This is a best-practice model. Perhaps it can be applied to this situation. It could be integrated, implemented, or modified.

ERNEST HOPKINS: I hope everyone was getting where I was going. I do not think there is an easy answer to the question, but I do think that as we begin to have these conversations about expanding our perfect program to be available to other people who need access to healthcare, we need to address these questions. Is it enough to just be a sexually active person in a high prevalence area to warrant having access to this supplemental program—a program that is not insurance and is multiply funded by various funding streams? Would that be sufficient, Jenny Collier?

JENNY COLLIER: We need to remember the Ryan White Program serves both people for their individual health needs and is a public health program that resides in the public health service of HHS. The explanations we are using now to support funding for the Ryan White Program are the same arguments we would use to support PrEP’s inclusion in the program — that it addresses both an individual’s health and a public health need. We are seeing these patients anyway and their family members, so why are we not providing a
full range of services, which is what the Ryan White Program has always sought to do.

I believe we have the arguments and tools in our policy toolbox when it comes to discussing these issues with Congress. It always comes down to money, and we need to make the cost benefit argument. As ugly as that might seem, that is a fact. It is dollars-and-cents for many members and decision makers. There is an excellent case to be made for why, again, we should be finding ways to pay for PrEP and finding ways to integrate PrEP services into Ryan White clinics and other service providers that are appropriate, depending on the jurisdiction. As David said, the how-to details can be worked out, but we need to talk about the money and provide data that proves the expansion to cover PrEP is cost-effective and a public-health-ready way to enhance the Ryan White Program.

**ANN LEFERT:** I want to offer a slight counterpoint. We look at Ryan White to solve our health needs because Ryan White is comprehensive and amazing, but that lets other parts of our healthcare system off the hook. There is no reason why everybody who is a good candidate for PrEP should need to use Ryan White to achieve that service. We have Medicaid. We have dually eligible people. We have more and more people on private insurance. We have community health centers. We have Gilead’s Patient Assistance Programs. All are part of our healthcare puzzle. We do not want to assume the federal government is going to address this need through the Ryan White Program.

The studies have shown the biggest barrier to PrEP right now is not access to the medication. The main barrier is lack of education for people who are good candidates for it. Many providers do not want to take comprehensive sexual histories of people who walk into their offices. The biggest barrier is not actually getting the pill in somebody’s hands. It is identifying and educating the people who would be good candidates for PrEP. CDC does interact with prescribers. They fund STD lines, and STD programs can prescribe PrEP through their 318 Grant. There are many ways we should be looking to increase access to PrEP. Do not get me wrong. I am a fan of thinking about ways for Ryan White to be part of this service, but it is not the only thing we should be thinking about. I believe it is a small part of a more comprehensive approach. I recommend there be some demonstration projects. We should look at states who have put PrEP programs in place using the ADAP infrastructure so that we better understand what they have done. Some purchase insurance, which provides people comprehensive healthcare, which is what we would want. When we talk about how to increase access to PrEP, I want to make sure that we talk about the comprehensive health system, not just Ryan White.

**ERNEST HOPKINS:** For the next question, I want to address the issue of who controls the money. Carl’s slides sliced-and-diced the money regarding various Ryan White parts and then showed the importance of Part C and Part D in balancing out Part A and Part D resources in various states. The question I have for Jenny Collier is whether or not you have data on where those Part Cs are because my recollection regarding the second reauthorization was that we made a special effort to direct the Part Cs to geographically isolated areas, into rural areas. In a state like California, for example, where we have a significant amount of rural areas, I expect many of those Part Cs came on at a certain time and the locations were targeted.

**CARL SCHMID:** HRSA just did a realignment. I do not think that was because of reauthorization. That was because they are trying to align the money with the need. There are 10 new service area awards, including two in California, one in Indiana, and seven in the South (AR, FL, LA, MS, NC, SC, and TX).

**JENNY COLLIER:** Ryan White Part C clinics are one of the largest service providers for rural jurisdictions, and so the re-compete was in part to drive money to the location of the epidemic. HAB has taken a measured approach, which is appropriate, to ensure no one gets dramatically under-funded all at once or over-funded all at once. There are limits on that transition, but we will be able to gleam something for the addition of the 10 new service areas. It will be helpful because Ryan White Part C and Part D clinics – many clinics are
both C and D – are the places where medical homes are created. To get back to Ann Lefert’s point, I did not hear Ernest question whether Ryan White should be the only payer of PrEP, but rather a payer of PrEP.

**ERNEST HOPKINS:** That is correct.

**JENNY COLLIER:** I agree with Ann. I am sure many people in this room feel that to overcome health disparities in general is to provide better healthcare coverage writ-large for all Americans. I’m married to a Canadian who is also a trained physician. He hates going to the doctor in this country because he never knows what the bill is going to be or what hoops are required to access coverage. One of the things that Ryan White and Medicaid-expansion states have seen is a dramatic decrease in the number of uninsured patients. For example, I have two clinics, one in Kentucky and one in Ohio, that as a result of Medicaid expansion, the rate of uninsured patients fell from 30% or 40% to less than 10%. This is a dramatic decrease. Their patients were not only seeing an increase in services related to their HIV, but they were seeing increases in services that they needed overall. This is an important point. As Dr. Fauci said earlier today, people are aging, just like all of us on this panel, into other health issues. Bone issues, back issues, heart issues, diabetes, mental health issues, substance-use disorders, etc. These are issues people need insurance coverage to address. To really focus on reducing disparities writ-large, we need to provide access to quality healthcare coverage to people across the U.S.

The Ryan White Part C and D medical homes were used when Medicaid was expanded in an incredibly effective way, and so we should think about that every time we talk about the Ryan White Program and money for the program. We should also think about what we are doing to help ensure people have access to healthcare coverage to help them not only with their HIV care, but with other healthcare needs as well.

**ERNEST HOPKINS:** Another thing that I know will come up in discussion on next steps for the Ryan White Program is the idea of who counts and where they count. At one point, we used a cumulative AIDS case count. That did not work because it was not responsive to the epidemic as it moved along and as people died. We had a rolling 10-year, weighted band, which worked for a while, but then it did not because it did not acknowledge the fact that certain jurisdictions were keeping people alive, and the model made assumptions about death that were not true.

Now we count living HIV cases and AIDS, but we know that people make choices. Jurisdictions make choices for people sometimes. Where you are diagnosed is not necessarily where you receive your care. Where you reside is not necessarily where you receive your care. I will use San Francisco as an example. Your doctor may be in San Francisco, but you may live in Richmond, CA. You may live in a jurisdiction directly outside of the town that’s a 15-minute ride on the metro into town, but you are counted where you live.

**ERNEST HOPKINS:** Have we solved this problem?

**CARL SCHMID:** The supplemental does consider other factors.

**ERNEST HOPKINS:** The supplemental does, but I would like to address the funding formula. That is the meat and potatoes.

**CARL SCHMID:** The supplemental for Part B is quite large, compared to the base. It is one third of the Part As’ funding, so that is a considerable amount of money. What you are going to see – you heard this from both Secretary Azar and Dr. Fauci today – they are focusing on the areas that are most impacted, which are the 47 counties with over 50% of the cases. You talk about where you are diagnosed or where you now reside. What about considering who uses Ryan White services? We do not count that.

**ERNEST HOPKINS:** You think utilization should be a factor.

**CARL SCHMID:** I think the cost of care, poverty rate, insurance coverage, death rate, etc.

**ERNEST HOPKINS:** That is a lot of factors in a formula. You want to include all of those?

**CARL SCHMID:** Many of these factors are addressed in the supplementals.
ERNEST HOPKINS: Let’s stay on the funding formula for a minute because I am sympathetic to some of the concerns since I am in California where we have the same issue with snow birds that New York and Florida have. We have people who live in Northern California, then go to Southern California for a certain part of the year, then come back. Who gets the case? This is the kind of thing that is difficult for policy makers to understand and address when they are legislating. Thoughts on that?

DAVID REZNIK: I know this has been an issue for 15+ years. If you are diagnosed in Atlanta and you move to Savannah, how are you going to have the money follow the patient? We have talked about the money following the disease. I get that. But how do you have the money follow a patient when we are not an insurance program. We are a grant-based program. It makes it more difficult.

ANN LEFERT: Funding formulas across all sorts of programs are difficult to determine. In the 2006 reauthorization, we did a severity-of-need index where HRSA looked at a variety of factors – cost of care, poverty, death rates, all sorts of things. They did this as a research project. They then had the option to advocate for the implementation of it in the next reauthorization. By and large, those factors did not change the way funding was allocated. The greatest driver was where the cases were. Now, that does not always account for people moving or living half the year in one place and the remainder of the year in another, but no funding formula can address that. There is no client-level data that will account for that either. Are you going to give half of a year’s funding to one jurisdiction and the second half to another? That is too complicated and that is not how governmental funding formulas work. When you look at several government studies regarding funding formulas, if you include more items in the criteria, it does not affect the main item you are addressing. In this case, people living with HIV. It is best to keep the formula simple. There is no total data set across jurisdictions that could be measured equally. It is hard to have uniformity when you are looking at funding formulas.

ERNEST HOPKINS: Thank you. Let me go to the dark place because we always need to go to the dark place at a certain point in this conversation. The Obama Administration tried in three budget cycles to collapse Part D into Part C, combine the money, and provide additional money for the consolidation process. Everybody said, “We don’t care what the data says. We don’t care that the data says that women have better health outcomes when they are receiving services from sites that are multiply funded. We don’t care about that. We need to have our program by itself because we are culturally competent to provide the kind of services that our people need. If you take this program away, harm will be done.” We advocated the hell out of that position and won the battle.

If Congress asks HRSA what they think should be done based on their professional judgment, they might say, “There are a lot of parts. We have been trying to consolidate Parts C and D and would like to move forward with that effort again. What do the panelists think about that? You know, Ann and I have become friends in part because we have had to go to battle on many occasions about the collapsing of resources between the cities and the states. Each side has rationales as to why consolidation should not occur. But the directly-funded Part C clinics and the directly-funded Part D programs as well as the AETCs and the SPNS programs, both of which have been under attack by this Administration, are open questions. Daria, what do you think?

DARIA BOCCHER-LATTIMORE: Every presentation today talked about the strength of the Ryan White Program. I would argue that its strength and success come from it being based in local clinics, in cities, in states, in territories, and in regions. Each part brings something different to the program. That is why it is successful. The first thing to discuss when looking to address needed changes or updates should not be about how to pick this successful program apart.

ERNEST HOPKINS: Let’s consolidate it.

DARIA BOCCHER-LATTIMORE: No. Let’s look at what works and why it is working. We just discussed the need to expand resources to include PrEP. We are already addressing this issue in the AIDS Education Training
Centers. We are educating providers on PrEP. We are dealing with the purview paradox of who is going to be providing PrEP. Is it going to be the Ryan White provider? Is it going to be the community-based or the federally-qualified health center? And no, no one really wants to do it. When we partner the federally-qualified health centers with Ryan White centers, the health center feels more comfortable providing PrEP. We are being forced into these false dichotomies. We are asked to shrink ourselves at the same time we are asked to end the epidemic. Our success is measured against quality indicators, but we are not fully funded.

**ERNEST HOPKINS:** Do the arguments of *economies of scale* and *efficiency* not wash with you?

**DARIA BOCCHER-LATTIMORE:** They do, but I do not think we start from the point of saying, “This is your funding and now provide all the needed services.” The point should be, “This is how we end the epidemic and these are funds to make that happen.” I do not want to buy into their argument.

**ERNEST HOPKINS:** I do not know that there is a “their” argument.

**DARIA BOCCHER-LATTIMORE:** Well, we have seen it in the funding cuts.

**ERNEST HOPKINS:** I’m curious, is there any diversity of opinion on the panel? In other words, would you willfully cut your throat. That is the question.

**DAVID REZNICK:** Ernest, I often say “WWJD” or What Would Jacqui [Muther] Do. At this point, I’m thinking “WWJS” or What Would Jackie Say. She would say, “Leave it as is.”

**DR. IVY TURNBULL:** I would say the same thing. I would also note that President Trump’s FY 2019 budget focuses on the accelerated elimination of perinatal HIV transmission. This speaks to having to address each Administration’s particular focus or request. If the Obama Administration had been successful, the history, experience, lessons learned, and best practices garnered under the Part D program might have been lost and trying to address the current Administration’s priorities would be difficult.

**ERNEST HOPKINS:** My understanding of the Obama Administration’s proposal was that they were planning not to get rid of those sites. They were planning to multiply fund them. There may have been some consolidation, but remember, there were additional resources.

**DR. IVY TURNBULL:** No. I do not believe there were additional resources.

**ERNEST HOPKINS:** There were definitely additional resources.

**DR. IVY TURNBULL:** The fear was that the funding would go away or be reduced significantly, and they [the Part Cs] would be responsible for all those populations without getting any of the dollars.

**ERNEST HOPKINS:** That was never on the table.

**JENNY COLLIER:** You are correct that it was never on the table, but you know, having done advocacy work for many years, that when you say something can be consolidated, that is a.k.a. for “it could be cut”, so you lose resources. There are plenty of cautionary tales. For example, let’s talk about the Substance Abuse Prevention and Treatment Block Grant, which was block granted a couple of decades ago. Bill McColl and I used to work on the SAMHSA reauthorization together. The set aside for women’s treatment services were taken away. They block granted the program, and the expertise was lost. Years later, I implemented a special lobbying project to try and get women’s treatment programs funded again because the money went away. And guess what? Despite increases during the Clinton Administration and early in the Bush Administration, we lost expertise and access was reduced. This outcome, combined with the opioid epidemic, has gotten us to where we are today. Where we have gravely insufficient funding and expertise in substance use disorder treatment. I think that is a cautionary tale, and why we do need the separate Ryan White parts. The diversity of the parts is the program’s strength. That is why today Dr. Fauci could say the Ryan White Program is HHS’ best program in terms of outcomes. And as we know, what Dr. Fauci says, always goes.
ERNEST HOPKINS: He did say it. I do not think you are going to find much disagreement in the room. The CAEAR Coalition has used the block grant analogy to sell the program. We have said, “We are like a block grant. We give the money to states, the cities. We then, based on our local needs or our statewide plan, use the resources and allocate them appropriately based on what’s going on in a particular area.” Legislators love that language, and we have addressed their concerns effectively when we use it. I do think the conversation is going to be inevitable — why do we have all these different parts, some of which appear to do the same thing, some of which are directly funded, some of which are controlled by jurisdictions. What is the rationale for that? The panel has provided some solid arguments. It will be interesting to see if these arguments, which worked in the past, will work in the current environment. Let us hope they do.

Now, let’s discuss administrative costs. There was a time early in the program when the community fought against expansion of the administrative cap. The argument was all the money needs to go to services. We are in a crisis; we are in an emergency. Let the public health departments find the money from somewhere else. We do not want them taking a significant chunk of resources to do all the things they say they need to do in public health. Fast forward to now. Many of us would love to have the data analytics that could come from a higher percentage of resources going to the administration and monitoring these grants. Congress is not inclined to give us more money. We have tried on multiple occasions. It has not been successful. What do you think the health departments and the cities could say that would be compelling to policy makers now that has not worked in the past?

GRAHAM HARRIMAN: One of the things that came up in the survey is maintenance of effort, and we have unequal local contributions to the system of care for persons with HIV. We can see that there are different health outcomes between those jurisdictions that contribute quite a bit and those jurisdictions that contribute a lot less. In my opinion, those additional resources are what make the biggest difference in a jurisdiction’s ability to administer the Ryan White Program.

ANN LEFERT: I agree. We need to get better at explaining what grant administration activities include. I think Congress believes it includes some salaries, toner, and paper. I do not think they understand how much more experience is needed to do the work we are doing. As Dr. Fauci and Dr. Cheever said today, getting those last Ryan White patients to be virally suppressed is going to take significantly more effort than what it took to get the first 50 percent of patients virally suppressed. It just is. If it was going to be easy, it would be done already. It will require more work, more data, and more analysis. We need to get better at showing what those activities are. One of the conversations we have had, and we talk about this with the CDC Surveillance and Prevention Grants, is that surveillance is not what it used to be. Epidemiology is not what it was 10 years ago. The skillsets are different; the training is different. It is not the same as just entering lab and test results into a computer. These are more nuanced activities and it costs more. We also need to talk about all the program income that is not held to the administrative cap or other caps that apply to the program. For most jurisdictions and the vast majority of entities, I would assume there is far more money being put into grant administration to run a successful program than is being shown by the five percent administrative cap.

ERNEST HOPKINS: But does that help our argument?

ANN LEFERT: I do not know if it helps our argument, but we need to think about it because it is happening. We need to be honest. There are also benefits that are accruing to the program because some jurisdictions have those resources to put towards program administration—quality management, adherence support, and all the other things that are capped across the program.

ERNEST HOPKINS: Talk to me about the role of community in the process. A lot of people, and I am one of them, cut our teeth on planning councils. We learned about service planning. We learned about doing unmet need surveys and the ways the different public health components work together. Based on
that information, we had big battles around allocation of resources. You have a fixed pot, everybody wants some and you battle. Early in the epidemic, the actual providers battled each other and carved the pie among themselves. That has since changed. Now we have what I would characterize as fail-safes to ensure that kind of self-dealing does not happen. Talk to me about how you see planning councils and the community’s relationship to the grantee in the state environment. So many of the consortia that used to be very robust and provide support to state planning have fallen by the wayside, especially after the ADAP crisis, where we had waiting lists and all the resources were being deployed to find drugs for folks. We never really got them back.

**ANN LEFERT:** One of the reasons the consortia disappeared was because HRSA categorized them as support service and administrative. As a result, they could not be used as part of one’s core medical services and that led to their elimination. There are jurisdictions, particularly those that have integrated planning between CDC and HRSA, that have put in place some thoughtful planning processes with meaningful community engagement from a variety of stakeholders from across the continuum. Now, obviously Part B does not have the requirement regarding resource allocation that Part A does, and that has always been a sticking point. The question at this point in the epidemic is: Is the consumer input needed and should it be added to Part B? This issue is always discussed when we reauthorize the program. The Part Bs and NASTAD have a lot of thoughts about that. We have seen some states do thoughtful work around integrating the community and for needs assessments and unmet need. As part of their integrated plans, some of them have put in place a significant amount of sub-work groups and population outreach to hear from their communities and providers. Like all programs, some do it better than others. This is an area where NASTAD has tried to prioritize sharing best practices. Particularly, as we look towards more jurisdictions implementing “ending the epidemic” plans. I believe there will always be a role and there should always be a role for community engagement in Ryan White. That’s what makes Ryan White unique among healthcare programs. It is about how we ensure folks are at the table and part of the process. There are good models out there.

**ERNEST HOPKINS:** Thank you for going on the record with that. Any final comments from the participants before we go to questions in the room.

**GRAHAM HARRIMAN:** I want to weigh in on the planning council issue because I know from being the program director for the Ryan White Program in New York that having that level of transparency leads to different decisions. Having that level of accountability to a community planning body helps us make decisions that keep people with HIV at the focus and the center of our system of care. It’s not always pretty. It’s not always graceful, but it works. It is beneficial for government to have that level of accountability.

**DR. IVY TURNBULL:** One final thought. Throughout this conference [2018 Ryan White National Conference on HIV Treatment & Care] you are going to hear about the success of this program. The program is successful because of the parts. It is years of work and years of expertise within each one of those parts. One of the things I would like to see, and this is something that Ann Lefert talked about earlier, is what would the program look like if we had created real collaborations and partnerships across the program earlier on. If you think we are successful now, imagine if we had done that from the beginning.

**DR. DAVID REZNICK:** To add to that, we are running a medical-dental integration project. As a result, I have seen some remarkable Part C programs interact with the Part F dental programs. I have seen remarkable funding from Part B now to help with oral health. The Ryan White program created medical homes before people started talking about it.

**ERNEST HOPKINS:** That is right.

**DR. DAVID REZNICK:** And it’s all these different parts that make it work. To me one of the most important aspects, although I don’t always agree, is consumer input. That’s really what makes us what we are. It is local decision making on how to spend the dollars, how we are going to address the epidemic. It can always be improved. What we want to hear is how can we make it better, not how do we get rid of it.
ERNEST HOPKINS: I tried to highlight today some key issues that would need to be addressed in a reauthorization, and I want to thank the panelists for their input and ideas and the lively discussion. The process of reauthorizing this piece of legislation, as popular as it is, is always challenging. I would expect nothing less in this environment. There are regional and jurisdictional issues. There are funding issues; there are consumer versus grantee versus provider issues. All issues need to be presented and discussed. If the community can come to a consensus, then we move forward. If the community cannot, then we will not proceed. We will not proceed because as was discussed here today, the Ryan White HIV/AIDS Program is too important and is working too well to risk it. The CAEAR Coalition wants to be transparent. Just because we are having the conversation does not mean we are going pursue reauthorization. The community needs to be okay with that because if we do not seek to reauthorize, there will be a very good reason why we do not.

AUDIENCE DISCUSSION

ATTENDEE 1: Only 23 of the 52 EMAs responded to the Part A survey and none from Region One. I hate to admit that I am from Region One. Perhaps the low number is a result of the turnover in directors of the HIV/AIDS services division or the bureaus within the Part A EMAs or TGAs. People may have missed the survey because of that.

GRAHAM HARRIMAN: The CAEAR Coalition was pleased with the response rate. We keep our list current. I do know it overlapped with the grant application, but we did extend the survey deadline to address that. We also sent multiple reminders. I know I receive numerous surveys a week, so this was one among many.

ERNEST HOPKINS: Please know that if reauthorization is pursued, all EMAs-TGAs will become engaged. You can take comfort in that. There will be no stone unturned and there will be no voice unheard.

JOEY WYNN: I do not want to have a conversation about reauthorization in this environment, but when there is a new administration in a few years, we will need to have it. My only question to you regards place of residence. I give myself as an example. I was diagnosed with HIV in New York City in 1987. I moved to Florida in 1989 and have been there ever since. So, with every story that you give about a technicality of a snowbird, I think you need to do some research and analysis regarding the prevalence of the people that do move. Are they people that move permanently or are they snowbirds? When we visit on representatives in their home offices or on Capitol Hill, constituents tell their stories. These stories are effective, but elected officials seem to know that sometimes a person is diagnosed in another jurisdiction, so it is important that we are clear on the issue and know the facts on how place-of-residence is determined.

ERNEST HOPKINS: You provided a perfect example of what we are not worried about, so I am glad you presented it. We are worried about people who move frequently, and do not get counted one place consistently over time. In California, we have active surveillance, which means if you moved after diagnosis, we would have sent that case to the new location. Again, we are not worried about that case. We are worried about the people who move back-and-forth within a calendar year.

JEN JAEGER, BOSTON PUBLIC HEALTH COMMISSION: To that point, folks who move back-and-forth frequently or around the country frequently are not of the same demographics as those who do not. If you cannot be rigorous in how to count these folks, the numbers are going to be skewed in terms of race, ethnicity, SOGI variables, and other risk factors, such as IV drug use.

ANN LEFERT: There have been efforts regarding data matches over the years. I believe CDC has an extremely rich data set regarding surveillance data and MMP data captured over time. There are ways that we can look at this and have a thoughtful discussion.
ERNEST HOPKINS: We have had some data in the past that showed it as a wash. That was several years ago. At this point, I would question whether that data is still accurate.

ACE ROBINSON: As we look at the current data, we see an epidemic that is darker, younger, and more queer. On one of the slides, it noted recommendations for the minority AIDS initiative. Two of the five respondents recommended ensuring organizations have black leadership. One of our colleagues in Los Angeles says, “Not the decoration, the actual foundation to the organization needs to be black and preferably queer.” How are we going to make sure we are adjusting the landscape so that there are organizations led by people who mirror the clients? You do not have to do outreach when you live in the neighborhood where the Ryan White clients are.

ANN LEFERT: We are very aware we are not funding organizations that have leadership reflective of the epidemic or in the locations of most need. In the past, there were micro grants to help local organizations grow. These organizations were not ready to be full-on Ryan White Part C clinics or full-on grantee subrecipients, but they were able to address some services. Often times they were partnered with a university and provided micro grants that ranged from $75,000 to $125,000 to help the organization increase and train staff with the goal of the organization being able to provide a whole gambit of services within the Ryan White program. We have moved away from this model. We need to get back to investing in organizations on the ground through these types of grants and programs.

JENNY COLLIER: I agree with Ann. We need to push government at all levels to remove the barriers and roadblocks, because what Ace said is correct. We need more representation of impacted populations in leadership positions, both as clinical and as service providers. We need to support and grow these organizations. Not only micro grants, but more robust technical assistance training. This has been done on a small scale at different federal agencies in the faith community. When we are talking to government officials and others in positions of power that are distributing the Ryan White money, we need to raise this issue. This also applies to young people. There are not that many young people in this room, and there need to be more. When you look at the statistics presented at the plenary session today, it is clear the epidemic is being driven in part by the fact that we are not helping young people access care. We need to support organizations run by youth, or young people, or whose mission is to be engaged with and listening to youth. I know HAB has identify this population and wants to do better by them. They have been very explicit about that. I think we also need to be thinking about how we can address the age disparity.

DR. IVY TURNBULL: HAB at one time funded organizations that focused specifically on youth and then they stopped funding them. These organizations were assumed within larger Part D projects. Now, we are faced with the issue of adolescence once again. These are some of the miss steps we experience in doing this work. Regarding funding opportunities for smaller organizations, Part C does have some planning grants. I believe the MAI money, could and should, be used to help build the capacity of organizations of color.

ERNEST HOPKINS: Nothing stops it. The Bush Administration became uncomfortable with MAI and the concept behind the program, because they saw it as a minority set aside. They tried to apply labor law that restricted set-aside contracts for truck drivers to the HIV programs. This derailed the progress made in the Clinton Administration.

DR. DAVID REZNIK: We also need to look at health education through a health equity lens. Many of the providers in Atlanta do not look like their patients. I trust this is true in other jurisdictions. We need to look at this inequity from a lens greater than Ryan White.

ERNEST HOPKINS: HRSA has a significant pipeline project to address the lack of minority providers serving minority patients.

BILL BLUM: Regarding the questions on changing the funding formula and the supplementals, I think it was great that it got robust and granular. I would say that
if we could get three steps down the road to actual residence, and we decrease the amount it impacts the numbers from say 15 percent to six percent, then I think we call it a victory. Regarding residence and counting cases, I am more concerned and think we need to focus more on people that are migrating for economic need, particularly transnationals across the border. We also need to think about Native Americans. It is not an uncommon pattern for Native Americans to migrate on and off reservations. I suggest we have a more intentional focus on these populations rather than snowbirds, although they are important too. Regarding PrEP, I like that the panel agreed to a multi-pronged response. I think we are going to have problems with durability, since patients are often seen for only 15 minutes by a clinician. We can get people comfortable with PrEP, but they may only adhere to the protocol intermittently. I hope we will continue to do this work and for those of us doing it, we should share our knowledge and technical expertise. I do not believe the answer is ten minutes with a clinician and a pill. Maybe for the short term, but certainly not the long term.

ERNEST HOPKINS: I was intentional about not having the conversation about transnationals. We are fortunate to have a program that robustly supports them. With Carl Schmid’s leadership [as the newly appointed co-chair of PACHA], I’m sure that will continue.

CARL SCHMID: Yes.

BILL MCCOLL, AIDS UNITED: I wanted to address the slides Graham presented on the eligibility criteria for the TGAs and EMAs. It struck me that half of your respondents said they would like to switch over to living HIV cases as the criteria for eligibility. In part because there is not a one-for-one translation there. There’s not even a three-to-one translation. Some entire cities are going to lose their eligibility, and many more would gain it, depending on how you do it. There was a discussion in the 2009 authorization about this, but it was avoided because, for one thing, we did not want to create a situation where there were 150 TGA-EMA-type entities, which could have very easily been the case. They also did not want to lose the established EMAs-TGAs. I am curious about that reaction. Regarding the question on workforce development, I wanted to note that we do not just have an aging HIV epidemic, we have an aging provider population. Practitioners are not coming into the field to fully replace those leaving.

ERNEST HOPKINS: As panelists think about how to respond to Bill’s questions, I would like to reiterate the issue of an aging population. In San Francisco, we have a significant population over 60. Are our Ryan White service centers competent in providing support for patients who have all the general care concerns of a 60+ age person, along with HIV?

DARIA BOCCHER-LATTIMORE: This morning I was part of a breakout for the Part Cs on “HIV and Aging” and the room was packed. We are hearing about this issue from patients and providers. We are hearing it from the geriatricians who need to learn more about HIV. To answer your question, no, current practitioners are not ready to face this and, no, we do not have a pipeline producing future practitioners that can address these issues. Today, we have discussed PrEP, hepatitis, the opioid crisis, and aging. Practitioners need to expand their purview, but are not prepared to do so.

A practitioner at one of our leading medical schools in New York City noted recently that if a medical student received two hours of HIV instruction over the course of four years that was pretty good. Medical students do not receive any kind of residency or integration, unless they seek it out. With the AETCs’ expansion of inter-professional education, where we are now working with medical, pharmacy, and nursing schools as well as behavioral health programs, to integrate HIV into those curriculums. This is one way to address the issue. I think we need to attack when students are still in training. A few years ago the AETC program was not able to do that. Training had to focus on prescribers and clinical providers.

ERNEST HOPKINS: That was a very elegant and potent talking point. I hope you will put in to the mix, if and when, we have to defend the program again.
**JENNY COLLIER:** At the last two annual meetings of the Ryan White Medical Providers Coalition, workforce has been a major issue, along with loan forgiveness. I’m just going to use medical school as an example, but obviously there are RN, PA, lots of different medical professions affected by the cost to earn a degree. If you go to medical school, you could have $400,000 worth of loans. If you study infectious diseases, which is a common type of HIV provider, you are going to be one of the lowest paid physicians in the country. This is particularly difficult for two practitioner couples, where you have two professionals with hundreds of thousands of dollars of loans. People make decisions for their families. If your family cannot manage $250,000 to $500,000 worth of loans, then you will pursue another type of medicine. I think that is fair, and we need to be honest about that. We cannot fill the residencies and the fellowships. We need to determine what the federal government can do to help people manage those costs more robustly, because working in a Ryan White Program does not always provide loan forgiveness.

**DR. DAVID REZNIK:** It needs to be more than the Health Professional Shortage Areas (HPSA). Dental students graduate from dental school with more debt than physicians, and they cannot access the HPSA funds.

**GRAHAM HARRIMAN:** Before we conclude, I want to answer Bill’s question on the threshold criteria. The CAEAR Coalition included that question in the survey because we had a specific southern jurisdiction that wanted us to. This is the beginning of a conversation. As we discuss and finalize our position on reauthorization, we will look at all these issues from a number of different perspectives.

I wanted to thank everyone on the panel today. David, Ivy, Jenny, Daria, Carl, Ann, and Ernest for moderating. It was great to have you here and to be part of such a robust discussion. We will prepare a synopsis of today’s discussion and include it with the Ryan White Part A Survey Report.

I want to thank Douglas Brooks and Gilead Sciences again for their generous support of the survey and today’s town hall.
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