

1 **Creating New Ryan White
Comprehensive HIV/AIDS Care and Services Legislation
2009 Report**

Preview

2 **Contributing Parties**

- **The Campaign to End AIDS (C2EA)**

- **The National Association of People with AIDS (NAPWA)**

3 **Context**

- Request from Senate Health, Education, Labor and Pensions Committee (HELP) Committee to hear directly from people living with HIV/AIDS about their recommendations for future reauthorization considerations.
- C2EA and NAPWA reached out to their constituents to invite their participation in town halls both orally and via a written survey.
- C2EA and NAPWA partnered, combining resources – both human and financial - to reach more regions throughout the country.
- Report will officially be released during AIDS Watch 2009

4 **Goals**

- To develop a set of guiding principles that will guide any Ryan White Legislation
- To establish networks of communication with congress and other policy makers that inform HIV/AIDS treatment and service delivery systems
- To ensure sustained, structured role of PLWHAs receiving services in design of new/revised Ryan White service delivery system

5 **Strategy and Method**

- Stakeholder Meeting
- Town Hall Meetings
- Town Hall Meeting Toolkits
- Consumer Surveys
- Data Analysis
- Guiding Principles Development
- Strategic Report Roll Out

6 **Results – Description of Services**

- A total of 1726 individuals were surveyed using a SurveyMonkey© tool
- 86% were receiving medical care; 28.5% were very happy with the services they received.
- 15.5% received their medical services from a Ryan White (RW) funded Program.
- 46% were receiving medical case management services; 11% from a RW Funded program
- 33.4% percent of the respondents reported that they were receiving mental health services; 6.8% from a RW funded program.
- 6.3% of the respondents reported issues pertaining substance; less than 1% from a RW funded program.

7 **Results – Description of Services (cont.)**

- 22.4% reported that they were receiving housing services; 6% from a RW funded program
- 47% reported that they were receiving dental services; 41.2% from RW funded program.
- 6.3% were receiving early intervention services; 6% from a RW funded program
- 12% were receiving treatment adherence services; with almost 9% from a RW funded program
- 15% were receiving medical nutrition services; with almost 10% from a RW funded service;
- 3.8% were receiving home health care services; 2.9% from a RW funded program.

8 **Results – Description of Services (cont.)**

- 56.1% reported that they had no assistance with gaining access to services
- 30.9% utilized the services of a medical case manager
- 26.5% used other case management.
- 6.5% had friends assist them in accessing services.
- 53.4% had to wait two weeks or more between when they requested an appointment and when they saw their provider
- 11.3% of those have to wait three months.
- 89% were on medications for HIV/AIDS
- 83.8% on antiretroviral therapy
- 44.7% of respondents received their medication from ADAP programs
- 32.2% had private insurance.
- 24.2 get their medication paid for by Medicaid
- 31.4 get their medication paid for by Medicare Part D.
- 32.4% reported having problems getting their medication.

9 **Results – What Consumers would change**

1. Improve the quality of care. Respondents wanted more time with their physicians, better communication with their physicians and more information about HIV/AIDS was impacting their overall health.
2. Decrease waiting time between call to schedule a visit and their appointment as well as time spent in the waiting area of the doctor's office.
3. Address the costs of services, unaffordable co pays and medications, limited Medicaid eligibility for people with HIV, and not being allowed to take full advantage of Medicare Part D benefits when ADAP cannot be applied toward True Out of Pocket (TrOOP) expenses.
4. Establish broader and more aggressive goals around HIV; such as the pursuit of a cure, universal access to health care, and freedom from stigma.
5. Improve customer service.

10 **Results - What Consumers would change (cont.)**

6. Increase resources and availability of psychological and mental health services.
7. Several respondents stated that their healthcare was great and that there was nothing they would change. (18 out of 241 who replied with a qualitative answer – 7.4%)
8. Increase psychosocial and mental health support through the availability of support groups, addressing depression and quality psychotherapy.
9. Assistance with prescriptions and pharmaceutical issues from increasing the number of drugs on the formulary, to having to take less meds, looking at natural treatment
10. Decrease travel time to medical appointments

11 **Results – Recommendations for Policy Makers**

- Improve access to care
- Increase funding for services provided through Ryan White
- Increase access to Medicare and Medicaid, and improved private insurance such that it covers more of the necessary treatment.
- Comprehensive access to health care for all.
- PLWHAs deserve the right to play an integral role in the development or expansion of any HIV/AIDS service delivery system.

12 *This has been a collaboration between*

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