



THE AIDS INSTITUTE

PUBLIC COMMENT
by
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before the
PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS
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Good morning. My name is Lindsey Dawson, Public Policy Associate at The AIDS Institute. Today we are focusing our comments on the importance of transparency and data collection in the Ryan White Program. This is particularly important in order to assess the future of the Ryan White Program as the Affordable Care Act (ACA) is implemented. Only after the ACA is implemented and such data is collected and analyzed can we appropriately assess the needs of Ryan White in the future and plan for a program that best improves outcomes along each stage of the care continuum.

We begin today by asking that CDC release the HIV and AIDS case counts that are used by HRSA to formulate Part A & B grant awards. It has been years since this data has been publicly released. Additionally, while the total award for each Part A jurisdiction has been released it would be helpful to know how much of each award is formula driven and how much is for the supplemental. Finally, for Parts A and B, HRSA should release the extent to which each jurisdiction is protected by the “hold harmless” provision. Having this baseline data will be a critical first step and allow us to better evaluate and plan for the Program’s future.

We greatly appreciate that the Administration is proceeding with studies relative to the ACA and Ryan White. We are eagerly awaiting the ASPE-Mathematica study that will examine the service needs under the Ryan White Program as the ACA is implemented and identify strategies to direct federal resources to areas of greatest need. We are also highly supportive of the two HRSA studies proposed in the President’s budget: One to examine the coverage completion services offered by non-Ryan White payers and the other to more broadly assess the impact of ACA implementation on the Ryan White Program. Data from these studies should be released on an ongoing timely basis.

As these and other studies are undertaken, we urge our Federal partners including those at HRSA, the CDC, CMS and CCIIO to work together. Since the CDC and HRSA both collect viral load and CD4 counts, and other patient information, we particularly urge both these

agencies to work together. We also stress that while it will be important to analyze the impact of health reform on Ryan White as a whole, doing so with respect to diverse communities and across geographic regions will be critical to addressing health disparities.

An area in which data collection will be especially useful is to track how states use their ADAP funds now compared with after full implementation of health reform, in both expansion and non-expansion states. In particular, we will want to pay attention to how much ADAPs are paying towards premium continuation and copayments versus full pay for drugs and how many individuals are covered through this assistance. Data examining the costs and content of coverage completion services and tracking Ryan White client enrollment in exchanges and Medicaid will also be important. Each of these data points will need to be collected and released on a periodic basis.

There is no doubt that the demand for Ryan White services and funding will continue in the future but it is also certain that as millions of individuals gain access to coverage, the Ryan White Program will need to adapt. Yet, before we make changes to the Program we must obtain and scrutinize the results of these studies to ensure that any reforms are evidence-based and do not jeopardize clients' wellbeing.

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