# Attachment B. Survey Implementation Materials

Dear Sir or Madam,

I am writing to ask for your help on an important study being conducted for the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA). This study will provide HAB and policymakers with a clearer understanding of how you support the full range of services for uninsured and underinsured persons living with HIV/AIDS (PLWHA). The study will show how Part C and D grantees use a wide range of varied funding sources to insure a full continuum of care. We also want to show how you deliver robust services, as your clients change health insurance status during the course of a year, and understand how you support and track these changes.

With the upcoming Congressional reauthorization of the Ryan White HIV/AIDS Treatment Act of 2009 and the implementation of the Patient Protection and Affordable Care Act (ACA) starting January 2014, the funding landscape for the Ryan White HIV/AIDS Program (RWHAP) may potentially change. The study will provide some basic information regarding grantees' ability to continue to serve PLWHA, and will help guide and inform the development of HRSA's RWHAP policy in the future.

HAB contracted with Walter R. McDonald & Associates, Inc. (WRMA) and Mission Analytics Group, Inc. to conduct the study. The study is known as the *Understanding and Monitoring Funding Streams in Ryan White Clinics* and involves completing a survey. This is a web-based survey that will be administered to a sample of Part C and D grantees to obtain most of the information needed for the study.

You will be contacted within the next few days by a WRMA study team member to invite you to participate. I understand how busy you are and ask that you consider helping by agreeing to participate.

Everyone at HAB values the work you do, and we appreciate your commitment to deliver excellent care to PLWHA. In advance, thank you for your efforts!

Sincerely,

Brian Feit, M.P.A. HRSA, HIV/AIDS Bureau 301-443-3478 BFeit@hrsa.gov Dear [Name of Program Director],

A few days ago, Brian Feit, from the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA), sent you an e-mail to ask for your participation in the *Understanding and Monitoring Funding Streams in Ryan White Clinics* study. Participating in the study will provide important information that will help guide the development of future Ryan White HIV/AIDS Program (RWHAP) policy.

I would like to formally invite [Grantee Name] to participate in this important study. Your agency's participation would involve completing a web-based survey. The survey will collect information about:

- The different funding streams used for the provision of services to people living with HIV/AIDS (PLWHA)
- Your agency's approach to tracking health insurance coverage
- Funding sources and costs of care
- Your agency's relationships with managed care organizations

This information will also be used to help develop a tool that grantees can use with their own internal data to assess how funding streams and client insurance coverage changes over time within their organization. This tool will be offered as a technical assistance tool for grantees.

If your program is able to participate, please contact Rodolfo Matos at rmatos@wrma.com or (301) 881-2590, Ext. 257, within one week of this invitation. We will follow up with you to provide further details and coordinate timing for completing the survey. In the meantime, if you have any questions, please do not hesitate to contact me.

Thank you for considering this invitation. Your participation and contribution are important to better understand the role of the RWHAP in insuring high quality, coordinated care for PLWHA their families.

Sincerely,

#### Liz Oppenheim, J.D.

Project Director
Walter R. McDonald & Associates Inc.
12300 Twinbrook Parkway, Suite 310
Rockville, MD 20852
Phone 301-881-2590 ext. 243
loppenheim@wrma.com

Dear [Name of Program Director],

Thank you for agreeing to participate in the *Understanding and Monitoring Funding Streams in Ryan White Clinics* study. This e-mail provides you with instructions for completing the web-based survey.

A MS Word version of the survey and a glossary of terms are attached for your reference. Prior to answering the web-based survey, we recommend that you take a look at the survey to become familiar with the different topics covered. This will assist you in identifying any additional staff members who might be needed to answer all of the questions. The glossary will clarify some terms used in the survey.

You will receive a follow-up e-mail from Survey Monkey with a direct link for completing the web-based survey soon.

To complete the study, we ask that you follow the steps below:

- Access the online survey by clicking on the Survey Monkey link
- Fill out and submit the web-based Survey by XX/XX/XX

If you have any questions about participating in the study, or the survey, please contact Rodolfo Matos at rmatos@wrma.com or (301) 881-2590, Ext. 257. If you have problems accessing the web-based survey or have any technical questions, please contact XXXXX at XXXXX@wrma.com or (XXX) XXX-XXXX, Ext. XXX.

We appreciate your time and effort in completing the survey. The information you provide will guide and inform the development of HRSA's Ryan White HIV/AIDS Program policy in the future.

Sincerely,

#### Liz Oppenheim, J.D.

Project Director
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### **Participant Information Sheet**

The HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) is conducting a study to gain a better understanding of how the Ryan White HIV/AIDS Program (RWHAP) provides primary outpatient care and essential support services to both uninsured and underinsured people living with HIV/AIDS (PLWHA). The study seeks to identify what types of core medical services and subservices, and support services are currently not covered or not fully covered by Medicaid, Medicare, and private insurance. The information collected will help document and gain a deeper knowledge of the methods used by grantees to track funding and payment sources for the provision of HIV care in clinical settings and the mechanisms used to monitor and support patient healthcare coverage (e.g., payer source, type of insurance).

With the upcoming Congressional reauthorization of the Ryan White HIV/AIDS Treatment Act of 2009 and the full implementation of the Patient Protection and Affordable Care Act (ACA) starting January 2014, the funding landscape for the RWHAP will likely change. These events may greatly affect RWHAP services, primarily the core medical services and subservices, and support services provided by the Part C and Part D grantees. This study is important because it will help HAB understand the abilities of these grantees to support and track expanded health insurance enrollment for their clients and to adapt to the changing funding landscape. This information will guide and inform the development of HRSA's RWHAP policy in the future. This study relies on information collected through a web-based survey that will be administered to a sample of Part C and Part D grantees. The information will also be used to support the development of a technical assistance tracking tool (tracker). The tracker will help grantees monitor and assess changes in the mix of funding sources used to pay for services to PLWHA.

You are invited to participate as a respondent to this study because your program receives Part C funding, Part D funding, or both. Your input is important in helping us meet the goals of the study. We are asking you to complete a web-based survey that will take about 4 hours to fill out, including the compilation of information in advance of completing the survey.

Here are some things we want you to know about participating in the study:

- Participation is completely voluntary. You may choose to discontinue the survey at any time, for any reason.
- Your responses are confidential. Your name and the name of your program will not be used in any reports about this survey.
- There will be no direct benefit to you from participating in this study. The risk may be the discomfort some people feel when expressing their opinions or experiences.
- A final report that describes the study, its findings, and recommendations will be submitted to HAB and may be shared on the HAB website.
- Any questions you have about the study can be answered before the start of the survey.

Any further questions you may have about the study may be directed to Liz Oppenheim at Walter R. MacDonald & Associates, Inc., Rockville, MD (303) 881-2590 x243.

This study has been classified as exempt from full review by the Institutional Review Board for the Protection of Human Subjects at Walter R. McDonald & Associates, Inc.

# Understanding and Monitoring Funding Streams in Ryan White Clinics – Glossary of Terms

## Ryan-White Core and Support Service Definitions<sup>1</sup>

**Child care services** are care for the children of clients who are HIV positive while the clients are attending medical or other appointments, or RWHAP-related meetings, groups, or training. These do not include child care while the client is at work.

**Health education/risk education** activities educate clients living with HIV about how HIV is transmitted and how to reduce the risk of transmission. It includes the provision of information about medical and psychosocial support services and counseling to help clients living with HIV improve their health status.

HIV counseling and testing may include antibody tests, rapid tests, ELISA (Enzyme-Linked Immunosorbent Assay), and Western Blot administered by health professionals to determine and confirm the presence of HIV infection. HIV counseling may include discussions of the benefits of testing, including primary care; legal provisions relating to confidentiality, including information about any disclosures authorized under applicable law; availability of anonymous counseling and testing; and the significance of the results, including the potential for developing HIV disease.

Counseling and testing do not include tests to measure the extent of the deficiency in the immune system, because these tests are fundamental components of comprehensive outpatient/ambulatory medical care. This service category also excludes mental health counseling/therapy, substance abuse counseling/treatment, and psychosocial support services. These services are reported separately.

HIV counseling and testing are components of Early Intervention Services for Parts A and B but are reported in the Provider Report in the HIV Counseling and Testing section. They are required components of a Part C program. Part D funds may also be used to support these services.

**Medical case management services** (including treatment adherence) are a range of client-centered services that link clients with health care, psychosocial, and other services provided by trained professionals, including both medically credentialed and other healthcare staff. The coordination and follow up of medical treatments are a component of medical case management. These services ensure timely and coordinated access to medically appropriate levels of health and support services and continuity or care through ongoing assessment of the needs and personal support systems of the client and other key family members. Medical case management includes the provision of treatment adherence counseling to ensure readiness for, and adherence to, complex HIV/AIDS treatments. Key activities include: (1) initial assessment of service needs;

 $<sup>^{1}</sup>$  Service definitions were obtained from the 2012 Annual Ryan White HIV/AIDS Program Services Report (RSR) Instruction Manual: http://hab.hrsa.gov/manageyourgrant/files/rsrmanual.pdf Funding Streams

(2) development of comprehensive individualized service plan; (3) coordination of services required to implement the plan; (4) client monitoring to assess the efficacy of the plan; and (5) periodic reevaluation and adaptation of the plan, at least every 6 months, as necessary over the life of the client. It includes client-specific advocacy, and review of utilization of services. This includes all types of case management, including face-to-face meetings, telephone calls, and any other forms of communication.

**Medical nutrition therapy,** including nutritional supplements, is provided by a licensed, registered dietitian outside of an outpatient/ambulatory medical care visit. The provision of food may be provided pursuant to a physician's recommendation and a nutritional plan developed by a licensed, registered dietician. Nutritional counseling services and nutritional supplements not provided by a licensed, registered dietician shall be considered a support service and be reported under psychosocial support services and food bank/home-delivered meals, respectively. Food not provided pursuant to a physician's recommendation and a nutritional plan developed by a licensed, registered dietician should also be considered a support service, and is reported under food bank/home-delivered meals.

**Medical transportation services** are conveyance services provided, directly or through a voucher, to a client to enable him or her to access health care services.

**Mental health services** are psychological and psychiatric treatment and counseling services for individuals with a diagnosed mental illness. They are conducted in a group or individual setting and provided by a mental health professional licensed or authorized within the state to render such services. Such professionals typically include psychiatrists, psychologists, and licensed clinical social workers.

**Non-medical case management** includes advice and assistance in obtaining medical, social, community, legal, financial, and other needed services. Non-medical case management does not involve coordination and follow-up of medical treatments.

**Oral health care** includes diagnostic, preventative, and therapeutic services provided by a dental healthcare professional licensed to provide health care in the state or jurisdiction, including general dental practitioners, dental specialists, and dental hygienists, as well as licensed and trained dental assistants.

Outpatient/ambulatory medical care or other healthcare professional certified in his or her jurisdiction to prescribe antiretroviral (ARV) therapy in an outpatient setting. These settings include clinics, medical offices, and mobile vans where clients generally do not stay overnight. Emergency room services are not considered outpatient settings. Services include diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care (includes all medical subspecialties). Primary medical care for the treatment of HIV infection includes the provision of care that is consistent with the PHS's guidelines. Such care must include access to ARV and includes the provision of professional diagnostic and therapeutic services directly to a client by a physician, physician assistant, clinical

nurse specialist, nurse practitioner, other drug therapies, including prophylaxis and treatment of opportunistic infections and combination ARV therapies.

**Outreach services** are programs that have as their principal purpose identification of people with unknown HIV disease or those who know their status (i.e., case finding) so that they may become aware of, and may be enrolled in, care and treatment services. Outreach services do not include HIV counseling and testing or HIV prevention education. Broad activities such as providing leaflets at a subway stop or a poster at a bus shelter or tabling at a health fair would not meet the intent of the law. These services should target high-risk communities or individuals. Outreach programs must be planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of efforts targeted to populations known through local epidemiologic data to be at disproportionate risk for HIV infection. Programs should be conducted at times and in places where there is a high probability of reaching individuals with HIV infection, and designed with quantified program reporting that will accommodate local effectiveness evaluation.

**Pediatric Development Assessment /early intervention services** are professional early interventions by physicians, developmental psychologists, educators, and others for the psychological and intellectual development of infants and children. They involve the assessment of an infant or child's developmental status and needs in relation to the education system, including early assessment of educational intervention services. They include comprehensive assessment, taking into account the effects of chronic conditions associated with HIV Start services, appropriate educational settings for HIV-infected clients, and education/assistance to schools should also be reported in this category.

**Psychosocial support** services are support and counseling activities, child abuse and neglect counseling, HIV support groups, pastoral care, caregiver support, and bereavement counseling. Nutrition counseling services provided by a non-registered dietitian reported in this service category.

**Referral for health care/support services** is the act of redirecting a client to a service in person or in writing, by telephone, or through another type of communication. These services are provided outside of an Outpatient/ambulatory medical care, Medical case management, or Non-medical case management service visit.

**Rehabilitation services** are provided by a licensed or authorized professional in accordance with an individualized plan of care intended to improve or maintain a client's quality of life and optimal capacity for self-care. These include physical and occupational therapy, speech pathology, and low-vision training.

**Substance abuse services** are medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) in an outpatient setting by a physician or under the supervision of a physician, or by other qualified personnel. They include limited support of acupuncture services to HIV-positive clients, provided the client has received a written referral from his or her primary healthcare provider and the service is provided by certified or licensed practitioners and/or programs, wherever state certification or licensure exists.

**Treatment adherence counseling** includes counseling or special programs provided outside of a medical case management or outpatient/ambulatory medical care visit by non-medical personnel to ensure readiness for, and adherence to, complex HIV/AIDS treatments. Treatments adherence counseling provided during an outpatient/ambulatory care service visit should be reported under the outpatient/ambulatory medical care service category. Likewise, treatment adherence counseling provided during a medical case management visit should be reported in the Medical case management service category.

#### **Other Definitions**

**Health Home**<sup>2</sup> is a Medicaid benefit adopted by some states as a way to improve the delivery of care to people with extensive health care needs. The benefit was created by the Patient Protection and Affordable Care Act (ACA) to provide enhanced integration and coordination of primary, acute and behavioral health, and long-term services and supports for people with chronic illness. Through a health home various health-related services are coordinated and ongoing personcentered assessments are made. States can offer the health home benefit to a high-risk person in Medicaid who meets one of the following criteria: has two or more chronic conditions; has one serious and persistent mental health condition; has one chronic condition and being at risk of developing a second chronic condition.

States can implement a managed care program through managed care organizations (MCOs), which agree to provide most Medicaid benefits to people in exchange for a monthly payment from the state. State premium payments to MCOs already include some amount for care management. By vesting health home responsibilities in MCOs, states are able to draw down 90% of Federal Medical Assistance Percentages (FMAP) and use those dollars to further expand health homes and enhance quality.

**Managed Care Organization (MCO)** is a Health Plan Organization that provides health care in return for a pre-determined monthly fee and coordinates care through a defined network of physicians and hospitals. It combines the functions of health insurance, delivery of care, and administration.

**Non-Physician Primary Care Provider**<sup>3</sup> These are providers of health care, other than physicians, who render some primary care services. Such providers may include nurse practitioners, physician assistants and some other health care providers. These providers of primary care may meet the needs of specific patients. They should provide these services in collaborative teams in which the ultimate responsibility for the patient resides with the primary care physician.

<sup>&</sup>lt;sup>2</sup> Definition was obtained from the National Alliance to End Homelessness: http://b.3cdn.net/naeh/7a2ef4b455106166c7\_trm6i2xg7.pdf

<sup>&</sup>lt;sup>3</sup> American Academy of Family Physicians. Primary care. Available at: http://www.aafp.org/about/policies/all/primary-care.html Funding Streams
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**Patient-Centered Medical Home (PCMH)** is a model of care that emphasizes coordination and communication between individual patients, and their personal physicians, and when appropriate, the patient's family. Care is facilitated by registries, information technology, health information exchange and other means to assure that patients receive care when and where they need and want it, in a culturally and linguistically appropriate manner.

**Primary Care Physician**<sup>3</sup> A primary care physician is a generalist physician who provides definitive care to the undifferentiated patient at the point of first contact and takes continuing responsibility for providing the patient's care. Such a physician must be specifically trained to provide primary care services. Primary care physicians devote the majority of their practice to providing primary care services to a defined population of patients. The style of primary care practice is such that the personal primary care physician serves as the entry point for substantially all of the patient's medical and health care needs - not limited by problem origin, organ system, or diagnosis. Primary care physicians are advocates for the patient in coordinating the use of the entire health care system to benefit the patient.