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Local Service Category:	Referral for Health Care: ADAP Enrollment Worker
Amount Available:	To be determined
Unit Cost	
Budget Requirements or Restrictions (TRG Only):	Maximum 10% of budget for Administrative Cost. No direct medical costs may be billed to this grant.
DSHS Service Category Definition:	Direct people living with HIV (PLWH) to a service in person or through telephone, written, or other types of communication, including management of such services where they are not provided as part of Ambulatory Outpatient Medical Care or Case Management Services.
Local Service Category Definition:	<p>AIDS Drug Assistance Program (ADAP) Enrollment Workers (AEWs) are co-located at Ryan-White funded clinics to ensure the efficient and accurate submission of ADAP applications to the Texas HIV Medication Program (THMP). AEWs will meet with all potential ADAP enrollees to explain ADAP program benefits and requirements and assist PLWHs with the submission of complete and accurate ADAP applications. AEWs will ensure benefits continuation through timely completion of annual re-certifications by the last day of the PLWH's birth month and attestations six months later to ensure there is no lapse in ADAP eligibility and/or loss of benefits. Other responsibilities will include:</p> <ul style="list-style-type: none"> Track the ADAP application process to ensure submitted applications are processed as quick as possible, including prompt follow-up on pending applications to gather missing or questioned documentation as needed. Maintain ongoing communication with designated THMP staff to aid in resolution of PLWH inquires and questioned applications; and to ensure any issues affecting pending applications and/or PLWHs are mediated as quickly as possible. <p>AEWs must maintain relationships with the Ryan White ADAP Network (RWAN).</p>
Target Population (age, gender, geographic, race, ethnicity, etc.):	People living with HIV in the Houston HDSA in need of medications through the Texas HIV Medication Program.
Services to be Provided:	Services include but are not limited to provision of education on available benefits programs applicable to the PLWH; completion of ADAP application including enrollment/recertification/six-month attestation; aid the PLWH in gathering all required supporting documentation to complete benefits application(s) including ADAP; provide a streamlined process for submission of completed ADAP applications and/or other benefits applications; assist in benefits continuation including six-month attestation and necessary follow-up; liaison with THMP and the PLWH throughout the ADAP application process
Service Unit Definition(s) (TRG Only):	One unit of service is defined as 15 minutes of direct PLWH services or coordination of application process on behalf of PLWH.
Financial Eligibility:	Income at or below 500% of Federal Poverty Guidelines
Eligibility for Service:	People living with HIV in the Houston HDSA
Agency Requirements (TRG Only):	<p>Agency must be funded for Outpatient Ambulatory Medical Care bundled service category under Ryan White Part A/B/DSHS SS.</p> <p>Agency must obtain and maintain access to TakeChargeTexas, the online system to submit THMP applications.</p>
Staff Requirements:	Not Applicable.
Special Requirements (TRG Only):	The agency must comply with the DSHS Referral to Healthcare Standards of Care and the Houston HSDA Referral for Health Care and Support Services Standards of Care . The agency must have

	policies and procedures in place that comply with the standards <i>prior</i> to delivery of the service.
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FY 2024 RWPC “How to Best Meet the Need” Decision Process

Step in Process: Council		Date: 06/08/2023
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: Steering Committee		Date: 06/01/2023
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: Quality Improvement Committee		Date: 05/2023
Recommendations:	Approved: Y: _____ No: _____ Approved With Changes: _____	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: HTBMTN Workgroup #1		Date: 04/19/2023
Recommendations:	Financial Eligibility:	
1.		
2.		
3.		

RYAN WHITE PART B/DSHS STATE SERVICES
23-24 HOUSTON HSDA STANDARDS OF CARE
REFERRAL FOR HEALTH CARE
ADAP ENROLLMENT WORKERS

Effective Date: April 1, 2023/September 1, 2023

HRSA Definition:

Referral for Health Care and Support Services directs a PLWH to needed core medical or support services in person or through telephone, written, or other type of communication. Activities provided under this service category may include referrals to assist people living with HIV (PLWH) to obtain access to other public and private programs for which they may be eligible (e.g., Medicaid, Medicare Part D, State Pharmacy Assistance Programs, Pharmaceutical Manufacturer's Patient Assistance Programs, and other state or local health care and supportive services, or health insurance Marketplace plans).

Program Guidance:

Referrals for Health Care and Support Services provided by outpatient/ambulatory health care providers should be reported under the Outpatient/Ambulatory Health Services category. Referrals for health care and support services provided by case managers (medical and non-medical) should be reported in the appropriate case management service category (i.e., Medical Case Management or Non-Medical Case Management).

DSHS Definition: (If Applicable)

Referral for Health Care and Support Services includes benefits/entitlement counseling and referral to health care services to assist eligible PLWH to obtain access to other public and private programs for which they may be eligible.

Benefits counseling: Services should facilitate a PLWH's access to public/private health and disability benefits and programs. This service category works to maximize public funding by assisting PLWH in identifying all available health and disability benefits supported by funding streams other RWHAP Part B and/or State Services funds. PLWH should be educated about and assisted with accessing and securing all available public and private benefits and entitlement programs.

Health care services: PLWH should be provided assistance in accessing health insurance or Marketplace health insurance plans to assist with engagement in the health care system and HIV Continuum of Care, including medication payment plans or programs. Services focus on assisting PLWH's entry into and movement through the care service delivery network such that RWHAP and/or State Services funds are payer of last resort.

Telehealth and Telemedicine is an alternative modality to provide most Ryan White Part B and State Services funded services. For the Ryan White Part B/SS funded providers and Administrative Agencies, telehealth & telemedicine services are to be provided in real-time via audio and video communication technology which can include videoconferencing software.

DSHS HIV Care Services requires that for Ryan White Part B or SS funded services providers must use features to protect ePHI transmission between PLWH and providers. RW Providers must use a telehealth vendor that provides assurances to protect ePHI that includes the vendor signing a business associate agreement (BAA). Ryan White Providers using telehealth must also follow DSHS HIV Care Services guidelines for telehealth and telemedicine outlined in DSHS Telemedicine Guidance.

Local Definition:

AIDS Drug Assistance Program (ADAP) Enrollment Workers (AEWs) are co-located at Ryan-White funded clinics to ensure the efficient and accurate submission of ADAP applications to the Texas HIV Medication Program (THMP). AEWs will meet with all potential ADAP enrollees to explain ADAP program benefits and requirements and assist PLWHs with the submission of complete and accurate ADAP applications. AEWs will ensure benefits continuation through timely completion of annual re-certifications by the last day of the PLWH's birth month and attestations six months later to ensure there is no lapse in ADAP eligibility and/or loss of benefits. Other responsibilities will include:

- Track the ADAP application process to ensure submitted applications are processed as quick as possible, including prompt follow-up on pending applications to gather missing or questioned documentation as needed.
- Maintain ongoing communication with designated THMP staff to aid in resolution of PLWH inquires and questioned applications; and to ensure any issues affecting pending applications and/or PLWHs are mediated as quickly as possible.

AIDS Drug Assistance Program (ADAP) Enrollment Workers will be co-located at Ryan-White Part A funded primary care providers to ensure the efficient and accurate submission of ADAP applications to the Texas HIV Medication Program (THMP). AEWs must maintain relationships with the Ryan White ADAP Network (RWAN).

Scope of Services:

Referral for Health Care and Support Services includes benefits/entitlement counseling and referral to health care services to assist eligible PLWH to obtain access to other public and private programs for which they may be eligible.

AEW Benefits Counseling: Services should facilitate a PLWH's access to public/private health and disability benefits and programs. This service category works to maximize public funding by assisting PLWH in identifying all available health and disability benefits supported by funding streams other than RWHAP Part B and/or State Services funds. PLWH should be educated about and assisted with accessing and securing all available public and private benefits and entitlement programs.

Health Care Services: PLWH should be provided assistance in accessing health insurance or Marketplace plans to assist with engagement in the health care system and HIV Continuum of Care, including medication payment plans or programs. Services focus on assisting PLWH's entry into and movement through the care service delivery network such that RWHAP and/or State Services funds are payer of last resort.

Standard	Evidence
<p style="text-align: center;">Program</p> <p><u>1.1 Provision of Service</u> Staff will educate PLWH about available benefit programs, assess eligibility, assist with applications, provide advocacy with appeals and denials, assist with re-certifications and provide advocacy in other areas relevant to maintaining benefits/resources.</p> <p>ADAP Enrollment Workers (AEW) will meet with new potential and established ADAP enrollees to:</p> <ol style="list-style-type: none"> 1. Explain ADAP program benefits and requirements 2. Assist PLWH and or staff with the submission of complete, accurate ADAP applications 3. Ensure there is no lapse in ADAP eligibility and loss of benefits, and 4. AEW will maintain relationships through the Ryan White ADAP Network (RWAN) 	<ul style="list-style-type: none"> • Provision of service per established criteria documented in the primary service record.
<p><u>1.2 Initial Provision of Education</u> The initial education to PLWH regarding the THMP process should include, but not limited to:</p> <ul style="list-style-type: none"> • Discussion of confidentiality, specific to the THMP process including that THMP regards all information in the application as confidential and the information cannot be released, except as allowed by law or as specifically designated by the PLWH. • Applicants should realize that their physician and pharmacist would also be aware of their diagnosis. • Discussion outlining that approved medication assistance through THMP may require a \$5.00 co-payment fee per prescription to the participating pharmacy for each month's supply at the time the drug is dispensed and the availability of financial assistance for the dispensing fee. • Discussion outlining the recertification process, specific to THMP eligibility, including birth month recertification, half-birth month attestation and consequences of lapse. 	<ul style="list-style-type: none"> • Initial education per established criteria documented in the primary service record. • Exceptions documented in the primary service record.
<p><u>1.3 Benefits Counseling</u> Activities should be individualized to the PLWH and facilitate access to and maintenance of health and disability benefits and services. It is the primary responsibility of staff to ensure PLWH are receiving all needed public</p>	<ul style="list-style-type: none"> • Benefits counseling documented in the primary service record. • Completed applications as appropriate and per established timeframe documented in the primary service record.

<p>and/or private benefits and/or resources for which they are eligible.</p> <p>Staff will explore the following as possible options for PLWH, as appropriate:</p> <ul style="list-style-type: none"> • AIDS Drug Assistance Program (ADAP) • Health Insurance Plans/Payment Options (CARE/HIPP, COBRA, OBRA, Health Insurance Assistance (HIA), Medicaid, Medicare, Private, ACA/ Marketplace) • SNAP • Pharmaceutical Patient Assistance Programs (PAPS) • Social Security Programs (SSI, SSDI, SDI) • Temporary Aid to Needy Families (TANF) • Veteran's Administration Benefits (VA) • Women, Infants and Children (WIC) • Other public/private benefits programs • Other professional services <p>Staff will assist eligible PLWH with completion of benefits application(s) as appropriate within fourteen (14) business days of the eligibility determination date.</p> <p>Conduct a follow-up within ninety (90) days of completed application to determine if additional and/or ongoing needs are present.</p>	<ul style="list-style-type: none"> • Follow-up per established timeframe and result(s) of application documented in the primary service record. • Exceptions documented in the primary service record.
<p><u>1.4 Healthcare Services</u></p> <p>PLWH should be provided assistance in accessing health insurance or Marketplace plans to assist with engagement in the health care system and HIV Continuum of Care, including medication payment plans or programs.</p> <ul style="list-style-type: none"> • Eligible PLWH will be referred to Health Insurance Premium and Cost-Sharing Assistance (HIA) to assist PLWH in accessing health insurance or Marketplace plans within one (1) week of the referral for health care and support services intake. <p>Eligible PLWH should be referred to other core services (outside of a medical, MCM, or NMCM appointment), as applicable to the PLWH's needs, with education provided to the PLWH on how to access these services.</p> <ul style="list-style-type: none"> • Eligible PLWH are referred to additional support services (outside of a medical, MCM, NMCM appointment), as applicable to the PLWH's needs, with education provided to the PLWH on how to access these services. 	<ul style="list-style-type: none"> • Assistance accessing healthcare documented in the primary service record. • Referral education on how to access the service documented in the primary service record. • Follow-up for referrals per established timeframe documented in the primary service record. • Exceptions documented in the primary service record.

<p>Staff will follow-up within (10) business days of an applicable referral provided to HIA, any core or support service to ensure the PLWH accessed the service(s).</p>	
<p><u>1.5 THMP Intake Process</u> Staff are expected to meet with new/potential PLWH to complete a comprehensive THMP intake including explanation of program benefits and requirements. The intake will also include the determination of PLWH eligibility for the ADAP program in accordance with the THMP eligibility policies including Modified Adjusted Gross Income (MAGI).</p> <p>Staff should identify and screen PLWH for third party payer and potential abuse</p> <p>Staff should obtain, maintain, and submit the required documentation for PLWH application including residency, income, and the THMP Medical Certification Form (MCF).</p>	<ul style="list-style-type: none"> • THMP education to new/potential PLWH documented in the primary service record. • Completed THMP application and supporting documentation (including proof of residency, income and MCF) documented in the primary service record.
<p><u>1.6 Benefits Continuation Process (ADAP)</u> ADAP Enrollment Workers are expected to meet with new/potential and established ADAP enrollees; explain ADAP program benefits and requirements; and assist PLWH and or staff with the submission of complete, accurate ADAP applications.</p> <p>Birth Month/Recertification</p> <ul style="list-style-type: none"> • Staff should conduct annual recertifications for enrolled PLWH in accordance with THMP policies. Recertification should include completion of the ADAP application, obtaining and verifying all eligibility documentation and timely submission to THMP for approval. • Recertification process should include screening PLWH for third party payer to avoid potential abuse. • Complete ADAP application includes proof of residency, proof of income, and the THMP Medical Certification Form (MCF). • Staff must ensure Birth Month/Recertifications are submitted by the last day of PLWH’s birth month to ensure no lapse in program benefits. • Proactively contact ADAP enrollees 60-90 days prior to the enrollee’s recertification deadline to ensure all 	<ul style="list-style-type: none"> • Attempts to contact PLWH for attestations and recertifications per established timeframe documented in the primary service record. • Completed attestations and recertifications documented in the primary service record. • Lapse benefits due to non-completion of timely recertification/attestation documented in the primary service record. • Exceptions documented in the primary service record.

<p>necessary documentation is collected and accurate to complete the recertification process on or before the deadline.</p> <p>Half-Birth Month/6-month Self Attestation</p> <ul style="list-style-type: none"> • Staff should conduct a 6-month half-birth month/self-attestation for all enrolled PLWH in accordance with THMP policies. Staff will obtain and submit the PLWH’s self-attestation with any applicable updated eligibility documentation. • Proactively contact ADAP enrollees 60-90 days prior to the enrollee’s attestation deadline to ensure all necessary documentation is collected and accurate to complete the attestation on or before the deadline. <p>Half-birth/6-month self-attestations must be submitted by the last day of the PLWH’s half-birth month to ensure no lapse in program benefits</p>	
<p><u>1.7 TCT Application Process</u></p> <p>The TakeChargeTexas (TCT) Application Process is the uniform practice for submission and approval of ADAP applications (with supportive documentation). This process ensures accurate submission and timely approvals, thereby expediting the ADAP application process.</p> <ul style="list-style-type: none"> • ADAP Applications (with supportive documentation) must be completed through the TCT Application Process for THMP consideration. All uploaded applications must be reviewed and certified as “complete” prior to upload. • ADAP applications should be completed according to the THMP established guidelines and applicable guidelines as given by AA. • To ensure timely access to medications, all completed ADAP applications must be completed in TCT within one (1) business day of completion • To ensure receipt of the completed ADAP application by THMP, notification must be sent according to THMP guidelines within three (3) business days of the completed application in TCT. • Upload option is only available for ADAP applications; other benefits applications should be maintained separately and submitted according to instruction. 	<ul style="list-style-type: none"> • Uploaded THMP application per established timeframe documented in ARIES. • Notification of THMP upload per established timeframe documented in primary service record.
<p><u>1.8 Tracking of THMP Application</u></p> <p>Track the status of all pending applications and promptly follow-up with applicants regarding missing</p>	<ul style="list-style-type: none"> • Tracking of application status documented.

<p>documentation or other needed information to ensure completed applications are submitted as quickly as feasible</p> <p>Maintain communication with designated THMP staff to quickly resolve any missing or questioned application information or documentation to ensure any issues affecting pending applications are resolved as quickly as possible</p>	<ul style="list-style-type: none"> Follow-up for missing or other information documented in primary service record.
<p><u>1.9 Case Closure Summary</u> PLWH who are no longer in need of assistance through Referral for Health Care and Support Services must have their cases closed with a case closure summary narrative documented in the primary service record.</p> <p>The case closure summary must include a brief synopsis of all services provided and the result of those services documented as ‘completed’ and/or ‘not completed.’ A supervisor must sign the case closure summary. Electronic signatures are acceptable.</p>	<ul style="list-style-type: none"> Case closure summary per established criteria documented in primary service record.
Administrative	
<p><u>2.1 Program Policies and/or Procedures</u> Program will develop and maintain policies and/or procedures that outline the delivery of service including, but not limited to, the marketing of the service to applicable community stakeholders and process of utilizing the AEW service. Program will disseminate policies and/or procedures to providers seeking to utilize the service.</p> <p>Additionally, Program will have policies and procedures that comply with applicable DSHS Universal Standards.</p>	<ul style="list-style-type: none"> Program’s Policies and Procedures document systems to comply with: <ul style="list-style-type: none"> DSHS Universal Standards TRG Contract and Attachments Standards of Care Collection of Performance Measures
<p><u>2.2 Staff Education</u> Education can be defined locally, but must at minimum require a high school degree or equivalency</p>	<ul style="list-style-type: none"> Staff education documented in the personnel file.
<p><u>2.3 Staff Qualifications</u> All personnel providing care shall have (or receive training) in the following minimum qualifications:</p> <ul style="list-style-type: none"> Ability to work with diverse populations in a non-judgmental way Working with Persons Living With HIV/AIDS or other chronic health conditions Ability to (demonstrate) or learn health care insurance literacy, (Third Party Insurance and Affordable Care Act (ACA) Marketplace plans). 	<ul style="list-style-type: none"> Assessment of staff qualifications documented in personnel file. Exceptions documented in personnel file. Training to increase staff qualifications documented in personnel file.

<ul style="list-style-type: none"> • Ability to perform intake/eligibility, referral/ linkage and/or basic assessments of PLWH needs preferred. <ul style="list-style-type: none"> ➤ Data Entry • Quickly establish rapport in respectable manner consistent with the health literacy, preferred language, and culture of prospective PLWH 	
<p><u>2.4 Staff Training</u> AEWS must complete the following:</p> <ul style="list-style-type: none"> • THMP Training Modules within 30 days of hire • Complete the DSHS ADAP Enrollment Worker (AEW) Regional update at earliest published date after hire • DSHS ARIES Document Upload Training (to include TRG upload observation module), completed no later than (45) days after completing ARIES certificate process • Data Security and Confidentiality Training • Complete all training required of Agency new hires, including any training required by DSHS HIV Care 	<ul style="list-style-type: none"> • Completion of training requirements documented in personnel file. • Materials for training and continuing education (agendas, handouts, etc.) are on file.
<p><u>2.6 Language Accessibility</u> Language assistance must be provided to individuals who have limited English proficiency and/or other communication needs at no cost to them in order to facilitate timely access to all health care and services.</p> <p>Subrecipients must provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area to inform all individuals of the availability of language assistance services.</p> <p>All AAs and subrecipients must establish culturally and linguistically appropriate goals, policies, and management accountability, and infuse them throughout the organizations' planning and operations.</p>	<ul style="list-style-type: none"> • Language accessibility policies and documentation of training on policies are available for on-site review. • Print and multimedia materials meet requirements.

References

- HRSA/HAB Division of Metropolitan HIV/AIDS Programs Program Monitoring Standards – Part A April 2013. p. 43-44. Accessed on October 12, 2020 at: <https://hab.hrsa.gov/sites/default/files/hab/Global/programmonitoringparta.pdf>
- HRSA/HAB Division of State HIV/AIDS Programs National Monitoring Standards – Program Part B April 2013. p. 42-43. Accessed October 12, 2020 at: <https://hab.hrsa.gov/sites/default/files/hab/Global/programmonitoringpartb.pdf>
- HRSA/HAB Ryan White Program & Grants Management, Recipient Resources. Policy Notices and Program Letters, Ryan White HIV/AIDS Program Services: Eligible Individuals & Allowable Uses of Funds Policy Clarification Notice (PCN) #16-02 (Revised 10/22/18),

https://hab.hrsa.gov/sites/default/files/hab/program-grants-management/ServiceCategoryPCN_16-02Final.pdf

- DSHS Policy 591.000, Section 5.3 regarding Transitional Social Service linkage.
- Interim Guidance for the Use of Telemedicine and Telehealth for HIV Core and Support Services, March 2020. Available at: <https://www.dshs.state.tx.us/hivstd/taxonomy/telemedguidance.shtm>

DRAFT

RYAN WHITE PART B/DSHS STATE SERVICES
23-24 QUALITY ASSURANCE MEASURES
REFERRAL FOR HEALTH CARE
ADAP ENROLLMENT WORKERS

1. Percentage of PLWH with documented evidence of education provided on other public and/or private benefit programs in the primary service record.
2. Percentage of PLWH with documented evidence of other public and/or private benefit applications completed as appropriate within 14 business days of the eligibility determination date in the primary service record.
3. Percentage of eligible PLWH with documented evidence of the follow-up and result(s) to a completed benefit application in the primary service record.
4. Percentage of PLWH with documented evidence of assistance provided to access health insurance or Marketplace plans in the primary service record.
5. Percentage of PLWH who received a referral for other core services who have documented evidence of the education provided to the PLWH on how to access these services in the primary service record.
6. Percentage of PLWH who received a referral for other support services who have documented evidence of the education provided to the PLWH on how to access these services in the primary service record.
7. Percentage of PLWH with documented evidence of referrals provided for HIA assistance that had follow-up documentation within 10 business days of the referral in the primary service record.
8. Percentage of PLWH with documented evidence of referrals provided to any core services that had follow-up documentation within 10 business days of the referral in the primary service record.
9. Percentage of PLWH with documented evidence of referrals provided to any support services that had follow-up documentation within 10 business days of the referral in the primary service record.
10. Percentage of PLWH who are no longer in need of assistance through Referral for Health Care and Support Services that have a documented case closure summary in the primary service record.

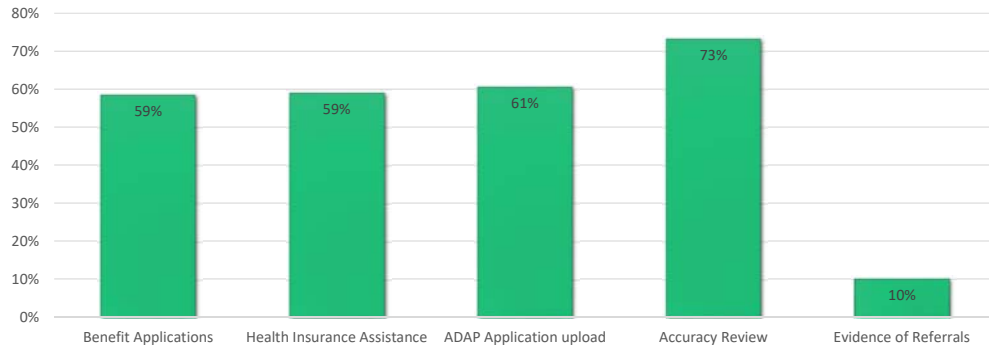
Referral for Healthcare

ADAP ENROLLMENT WORKER (AEW)

Description of Service

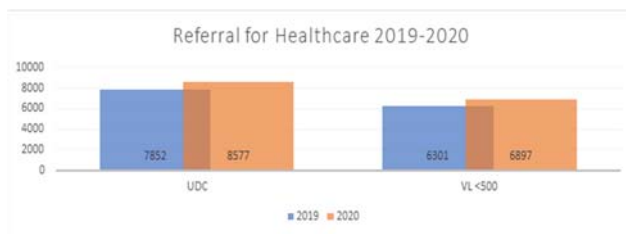
Referral for Health Care and Support Services directs a client to needed core medical or support services in person or through telephone, written, or other type of communication. This service may include referrals to assist eligible clients to obtain access to other public or private programs for which they may be eligible (e.g., Medicaid, Medicare Part D, State Pharmacy Assistance Programs, Pharmaceutical Manufacturer's Patient Assistance Programs, and other state or local health care and supportive services, or health insurance Marketplace plans).

Chart Review Highlights- 2019



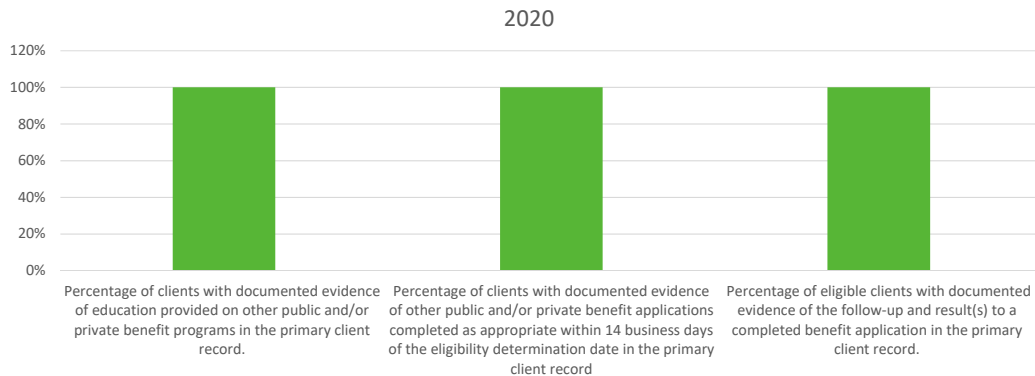
AEW workers provided assistance with 4035 applications, 1797 attestations, and 2446 recertifications during the calendar year. They also entered 18,928 service encounters!

Referral for Healthcare



Referral for Healthcare- AEW is the most highly utilized service in our HSDA. From calendar year 2019 to 2020 there was an 8.5% increase in utilization for AEW services. The AEW workers completed over thirty-one thousand (31,869 UOS) units of service in 2020. In 2020, a little over 80% of clients accessing this service has a viral load count less than 500 copies/ml.

AEW Chart Review Highlights- 2020





Non-adherence to HIV treatment for cost-saving reasons reported by 8% in American study

Roger Pebody

Published: 27 March 2019

Much of the excessive cost of prescription drugs in the United States falls on patients, and national surveillance data has now found that this has a real impact on HIV treatment outcomes. A study presented at the [Conference on Retroviruses and Opportunistic Infections \(CROI 2019\)](#) earlier this month found that 13% of people with diagnosed HIV reported at least one cost-saving strategy, including 8% who did not always adhere to their treatment to cut costs. Rates of viral suppression and engagement in care were lower in those reporting non-adherence for economic reasons.

Dr Linda Beer of the Centers of Disease Control and Prevention (CDC) presented the study. Data came from the Medical Monitoring Project, which collects clinical and behavioural information from individuals carefully sampled to be representative of the range of people diagnosed with HIV in the United States. Interview data and medical records were available for 3650 people taking prescription drugs in 2015-2016.

Based on self-report:

- 8% had asked their doctor for a lower-cost medication to save money
- 1% had bought prescription drugs from another country to save money
- 2% had used alternative therapies to save money
- 4% had skipped medication doses to save money
- 4% had taken less medicine to save money
- 6% had delayed filling a prescription to save money

Looking specifically at the last three of those strategies, they were more common in individuals with private insurance (prevalence ratio 1.76, $p < 0.01$), reflecting the problem of incomplete coverage and co-payments associated with private insurance. As might be expected, they were more common in individuals who had sought, but not received, help from the Ryan White AIDS Drug Assistance Program (prevalence ratio 3.88, $p < 0.01$). They were also more common in individuals who had a disability (prevalence ratio 1.91, $p < 0.01$).

Individuals reporting these cost-saving non-adherence strategies were significantly less likely to be virally suppressed (prevalence ratio 0.83, $p < 0.01$) or engaged in care (prevalence ratio 0.88, $p < 0.01$).

They were also more likely to have visited an emergency room or been hospitalised more than once.

Reference

Beer L et al. *Nonadherence due to prescription drug costs among U.S. adults with HIV, 2015-2016*. Conference on Retroviruses and Opportunistic Infections, Seattle, abstract 1078, 2019.

[View the abstract and poster on the conference website.](#)



This content was checked for accuracy at the time it was written. It may have been superseded by more recent developments. NAM recommends checking whether this is the most current information when making decisions that may affect your health.



Invited Commentary | Health Policy

Cost-Sharing Under Medicare Part D Paying Dearly to End the HIV Epidemic?

Julie E. Myers, MD, MPH

In 2019, the first-ever national plan to end HIV in the US was announced. Treatment and prevention with antiretroviral drugs (ie, preexposure prophylaxis [PrEP]), both highly effective strategies, are at the core of this plan. However, access to medications to prevent or treat HIV is not ensured currently, particularly because drug costs are high and insurance coverage can sometimes leave gaps that may limit uptake and detract from adherence.

The study by Tseng and colleagues¹ helps to answer a critical, practical question about such gaps: exactly how much do individuals with Medicare Part D health plan coverage pay in out-of-pocket costs for antiretroviral drugs for treatment or prevention? They analyzed 3326 Part D plans from around the US for the first quarter of 2019 to determine the annual treatment cost for 18 HIV treatment regimens and 2 HIV PrEP drugs and calculated how much each involved entity (ie, patient, plan, Medicare, or manufacturer) would pay monthly for patients with or without low-income subsidies. What they found is staggering: in the face of median annual antiretroviral prices exceeding \$35 000 for treatment and \$20 000 for prevention, individuals lacking low-income subsidies could have to pay as much as \$3000 to \$4000 out of pocket annually for HIV medications alone. Tseng et al¹ also reported that cost-sharing varied throughout the year, with the highest burden to patients early on. Once the catastrophic coverage threshold was breached between February and May, Medicare bore the brunt of costs, shouldering 53% to 67% of the costs for treatment and 50% of the costs for prevention.

Yet, as shocking as the estimated out-of-pocket costs are, they may actually underrepresent the severity of the situation. Medicare recipients living with HIV, especially the 21% who are recipients by virtue of their age² (and not disability), often use several prescription medications beyond their antiretroviral therapy. Yet the estimate provided by Tseng et al¹ included only antiretroviral therapy or PrEP and no other prescription drugs, therefore likely significantly underestimating actual out-of-pocket costs, especially for people with HIV, although the antiretroviral drug class is certainly among the most expensive, with among the fewest generic options.

Furthermore, at the same time that the US has experienced a 3-fold increase in the proportion of Medicare recipients who are living with HIV since the mid-1990s,² the number of Medicare enrollees in need of antiretroviral drugs for treatment (or prevention) will continue to increase as more people with HIV (and people who are at increased risk of HIV) age into Medicare in the years ahead. In fact, Medicare is the single largest source of federal funding for HIV care and treatment, and the proportion of care that is funded by Medicare will likely only continue to increase.²

Tseng et al¹ used 2019 data for their analysis, but we can expect out-of-pocket costs to increase, as 2020 brings change to Medicare Part D.³ As in the past, there are increases in the deductible and the initial coverage limit. However, the most substantial change, one that comes as a result of an expiration of a provision of the Patient Protection and Affordable Care Act that constrained increases of out-of-pocket costs for Medicare Part D enrollees during 2014 to 2019, is an increase of \$1250 in the out-of-pocket spending threshold. Although only approximately 1.0 million of 44.6 million enrollees (2.2%) without low-income subsidies reached the catastrophic phase in 2017, that proportion will likely increase in 2020, and presumably a greater proportion of enrollees than ever will be living with HIV, although the proportion will likely be fewer than 1%. However, for these individuals, the burden is likely significant: relatively few Medicare recipients are wealthy enough to

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afford thousands of dollars in drug costs. For reference, in 2016, the median annual income for Medicare recipients was \$26 200, and only 5% of Medicare recipients had incomes higher than \$103 450 per year.⁴

The concern with such a high cost burden on the individual is that adherence and, ultimately, health outcomes, are likely to deteriorate. It is now well documented that treatment for HIV blocks viral replication, which improves individual health and prevents onward transmission to sexual partners, a phenomenon popularized as *undetectable equals untransmittable*, or *U=U*. Belenky et al⁵ found that antiretroviral therapy adherence and viral load suppression remained stable despite increased out-of-pocket spending in the context of Medicare Part D plans, but this should not be particularly reassuring: that study was conducted among dual-eligible (ie, Medicaid and Medicare eligible) women who were followed in a longitudinal cohort study; thus, this cohort was perhaps less representative of Medicare Part D recipients in general and much more likely to have received low-income subsidies as dual Medicaid and Medicare recipients.⁵ In these and other studies, focusing solely on HIV outcomes may miss other important outcomes. What is the effect of greater individual expenditures on the families of these recipients? As out-of-pocket costs increased, were their health and other needs met? What about those of their dependent family members?

All of this leads to another critical question: what would be the effect of eliminating these high copayments for antiretroviral drugs? For now, this is a theoretical query. But a decade ago, a commercial health plan undertook just such a study among a different set of patients who were chronically ill: those discharged from the hospital after myocardial infarction.⁶ The plan randomly assigned these men and women to either full prescription coverage (ie, absence of copayment) or usual prescription coverage for all statin, β -blocker, angiotensin converting enzyme inhibitor, or angiotensin-receptor blocker medications. These were not people living with HIV, but they were living with an illness for which highly effective medications could avert adverse outcomes. Although there was no reduction in first major vascular event or revascularization (the primary end point), patients in the full-coverage group had a 4% to 6% increase in adherence and a decrease in the incidence of total major vascular events or revascularization; patient cost was also decreased, all without increasing total spending, offering compelling support for taking a similar approach with antiretroviral drugs.

As the study by Tseng et al¹ indicates, individuals who are eligible for low-income subsidies—77% of Medicare beneficiaries with HIV in 2014—would be spared the burden of such high out-of-pocket costs through the Part D Extra Help Program and AIDS Drug Assistance Program (ADAP). While the combination of the 2 effectively reduces what any person with HIV has to pay out of pocket for medications, this outcome is achieved through an administratively complex program, and in the case of ADAP, income eligibility thresholds that vary more than 2-fold among states. Additionally, individuals without an HIV diagnosis do not benefit from ADAP. Although some states maintain ADAP-like programs for those in need of PrEP, and the manufacturer also runs co-pay assistance programs, these are for individuals without insurance.

Tseng et al¹ highlight recent efforts to reduce patients' cost-sharing through proposed legislation to redesign Part D; possible interventions might involve capping out-of-pocket costs annually, passing discounts and rebates to patients directly, or at least making the out-of-pocket costs more predictable from month to month.¹ Ideally, whatever Part D restructuring is ultimately undertaken will further incorporate principles of value-based insurance design, in which financial incentives are better aligned with what is determined to be high-value care, helping to signal to patients in the most concrete terms—through their wallets—that antiretroviral drug uptake and adherence are worth it, the opposite of the message conveyed by thousands of dollars in costs they have to shoulder now. But how to lighten the load for patients without passing on these costs to the public?

One answer is both simple and incredibly complicated: address the high prices of drugs themselves. Drug prices are high for myriad reasons, including certain aspects of US patent law that effectively allow manufacturers to set prices and then constrain competition.⁷ Short of more

narrowly interpreting and enforcing existing antitrust laws and policies, allowing Medicare to negotiate drug prices paid for by Medicare Part D plans would likely help us move toward more affordable antiretroviral drug prices. For although success in ending HIV/AIDS in the US will obviously come at a price, we need to find a way to avoid burdening the people who are underserved and draining public coffers—a way to pay these costs fully without paying dearly.

ARTICLE INFORMATION

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REFERENCES

1. Tseng C-W, Dudley RA, Chen R, Walensky RP. Medicare Part D and cost-sharing for antiretroviral therapy and preexposure prophylaxis. *JAMA Netw Open*. 2020;3(4):e202739. doi:10.1001/jamanetworkopen.2020.2739
2. Kaiser Family Foundation. Medicare and HIV. Accessed January 31, 2020. <https://www.kff.org/hiv/aids/fact-sheet/medicare-and-hiv/>
3. Cubanski K, Neuman T. How will the Medicare Part D benefit change under current law and leading proposals? Accessed January 31, 2020. <https://www.kff.org/medicare/issue-brief/how-will-the-medicare-part-d-benefit-change-under-current-law-and-leading-proposals/>
4. Jacobson G, Griffin S, Neuman T, Smith K. Income and Assets of Medicare Beneficiaries, 2016-2035. Accessed March 9, 2020. <http://files.kff.org/attachment/Issue-Brief-Income-and-Assets-of-Medicare-Beneficiaries-2016-2035>
5. Belenky N, Pence BW, Cole SR, et al. Associations between Medicare Part D and out-of-pocket spending, HIV viral load, adherence, and ADAP use in dual eligibles with HIV. *Med Care*. 2018;56(1):47-53. doi:10.1097/MLR.0000000000000843
6. Choudhry NK, Avorn J, Glynn RJ, et al; Post-Myocardial Infarction Free Rx Event and Economic Evaluation (MI FREEE) Trial. Full coverage for preventive medications after myocardial infarction. *N Engl J Med*. 2011;365(22):2088-2097. doi:10.1056/NEJMsa1107913
7. Kesselheim AS, Avorn J, Sarpatwari A. The high cost of prescription drugs in the United States: origins and prospects for reform. *JAMA*. 2016;316(8):858-871. doi:10.1001/jama.2016.11237