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Appendix

RWHAP Legislation: Core Medical Services

Outpatient/Ambulatory Health Services

Description:

Outpatient/Ambulatory Health Services are diagnostic and therapeutic services provided directly to a client by a licensed healthcare provider in an outpatient medical setting. Outpatient medical settings include clinics, medical offices, and mobile vans where clients do not stay overnight. Emergency room or urgent care services are not considered outpatient settings. Allowable activities include:

- Medical history taking
- Physical examination
- Diagnostic testing, including laboratory testing
- Treatment and management of physical and behavioral health conditions
- Behavioral risk assessment, subsequent counseling, and referral
- Preventive care and screening
- Pediatric developmental assessment
- Prescription, and management of medication therapy
- Treatment adherence
- Education and counseling on health and prevention issues
- Referral to and provision of specialty care related to HIV diagnosis

Program Guidance:

Treatment Adherence services provided during an Outpatient/Ambulatory Health Service visit should be reported under the Outpatient/Ambulatory Health Services category whereas Treatment Adherence services provided during a Medical Case Management visit should be reported in the Medical Case Management service category.

See Policy Notice 13-04: Clarifications Regarding Clients Eligibility for Private Health Insurance and Coverage of Services by Ryan White HIV/AIDS Program See Early Intervention Services

AIDS Drug Assistance Program Treatments

Description:

The AIDS Drug Assistance Program (ADAP) is a state-administered program authorized under Part B of the RWHAP to provide FDA-approved medications to lowincome clients with HIV disease who have no coverage or limited health care coverage. ADAPs may also use program funds to purchase health insurance for eligible clients and for services that enhance access to, adherence to, and monitoring of antiretroviral therapy. RWHAP ADAP recipients must conduct a cost effectiveness analysis to ensure that purchasing health insurance is cost effective compared to the cost of medications in the aggregate.

Eligible ADAP clients must be living with HIV and meet income and other eligibility criteria as established by the state.

Program Guidance:

See PCN 07-03: The Use of Ryan White HIV/AIDS Program, Part B (formerly Title II), AIDS Drug Assistance Program (ADAP) Funds for Access, Adherence, and Monitoring Services;

PCN 13-05: <u>Clarifications Regarding Use of Ryan White HIV/AIDS Program Funds</u> for Premium and Cost-Sharing Assistance for Private Health Insurance; and

PCN 13-06: <u>Clarifications Regarding Use of Ryan White HIV/AIDS Program Funds</u> for Premium and Cost-Sharing Assistance for Medicaid

See also AIDS Pharmaceutical Assistance and Emergency Financial Assistance

AIDS Pharmaceutical Assistance

Description:

AIDS Pharmaceutical Assistance services fall into two categories, based on RWHAP Part funding.

 Local Pharmaceutical Assistance Program (LPAP) is operated by a RWHAP Part A or B recipient or subrecipient as a supplemental means of providing medication assistance when an ADAP has a restricted formulary, waiting list and/or restricted financial eligibility criteria.

RWHAP Part A or B recipients using the LPAP service category must establish the following:

- Uniform benefits for all enrolled clients throughout the service area
- A recordkeeping system for distributed medications
- An LPAP advisory board
- A drug formulary approved by the local advisory committee/board
- A drug distribution system
- A client enrollment and eligibility determination process that includes screening for ADAP and LPAP eligibility with rescreening at minimum of every six months
- Coordination with the state's RWHAP Part B ADAP
 - A statement of need should specify restrictions of the state ADAP and the need for the LPAP
- Implementation in accordance with requirements of the 340B Drug Pricing Program and the Prime Vendor Program
- Community Pharmaceutical Assistance Program is provided by a RWHAP Part C or D recipient for the provision of long-term medication assistance to eligible clients <u>in the absence of any other resources</u>. The medication assistance must be greater than 90 days.

RWHAP Part C or D recipients using this service category must establish the following:

- A financial eligibility criteria and determination process for this specific service category
- A drug formulary consisting of HIV primary care medications not otherwise available to the client
- Implementation in accordance with the requirements of the 340B Drug Pricing Program and the Prime Vendor Program

Program Guidance:

For LPAPs: Only RWHAP Part A grant award funds or Part B Base award funds may be used to support an LPAP. ADAP funds may not be used for LPAP support. LPAP funds are not to be used for Emergency Financial Assistance. Emergency Financial Assistance may assist with medications not covered by the LPAP.

For Community Pharmaceutical Assistance: This service category should be used when RWHAP Part C or D funding is expended to routinely refill medications. RWHAP Part C or D recipients should use the Outpatient Ambulatory Health Services or Emergency Financial Assistance service for non-routine, short-term medication assistance.

See <u>Ryan White HIV/AIDS Program Part A and B National Monitoring Standards</u> See also LPAP Policy Clarification Memo

See also AIDS Drug Assistance Program Treatments and Emergency Financial Assistance

Oral Health Care

Description:

Oral Health Care services provide outpatient diagnostic, preventive, and therapeutic services by dental health care professionals, including general dental practitioners, dental specialists, dental hygienists, and licensed dental assistants.

Program Guidance: None at this time.

Early Intervention Services (EIS)

Description:

The RWHAP legislation defines EIS for Parts A, B, and C. See § 2651(e) of the Public Health Service Act.

Program Guidance:

The elements of EIS often overlap with other service category descriptions; however, EIS is the combination of such services rather than a stand-alone service. RWHAP Part recipients should be aware of programmatic expectations that stipulate the allocation of funds into specific service categories.

- RWHAP Parts A and B EIS services must include the following four components:
 - Targeted HIV testing to help the unaware learn of their HIV status and receive referral to HIV care and treatment services if found to be HIVinfected
 - Recipients must coordinate these testing services with other HIV prevention and testing programs to avoid duplication of efforts
 - HIV testing paid for by EIS cannot supplant testing efforts paid for by other sources
 - Referral services to improve HIV care and treatment services at key points of entry
 - Access and linkage to HIV care and treatment services such as HIV Outpatient/Ambulatory Health Services, Medical Case Management, and Substance Abuse Care
 - Outreach Services and Health Education/Risk Reduction related to HIV diagnosis
- RWHAP Part C EIS services must include the following four components:
 - Counseling individuals with respect to HIV
 - High risk targeted HIV testing (confirmation and diagnosis of the extent of immune deficiency)
 - Recipients must coordinate these testing services under Part C EIS with other HIV prevention and testing programs to avoid duplication of efforts
 - The HIV testing services supported by Part C EIS funds cannot supplant testing efforts covered by other sources
 - Referral and linkage to care of HIV-infected clients to Outpatient/Ambulatory Health Services, Medical Case Management, Substance Abuse Care, and other services as part of a comprehensive care system including a system for tracking and monitoring referrals
 - Other clinical and diagnostic services related to HIV diagnosis

Health Insurance Premium and Cost Sharing Assistance for Low-Income Individuals

Description:

Health Insurance Premium and Cost Sharing Assistance provides financial assistance for eligible clients living with HIV to maintain continuity of health insurance or to receive medical and pharmacy benefits under a health care coverage program. To use RWHAP funds for health insurance premium and cost-sharing assistance, a RWHAP Part recipient must implement a methodology that incorporates the following requirements:

• RWHAP Part recipients must ensure that clients are buying health coverage that, at a minimum, includes at least one drug in each class of core

antiretroviral therapeutics from the <u>Department of Health and Human</u> <u>Services (HHS) treatment guidelines</u> along with appropriate HIV outpatient/ambulatory health services

 RWHAP Part recipients must assess and compare the aggregate cost of paying for the health coverage option versus paying for the aggregate full cost for medications and other appropriate HIV outpatient/ambulatory health services, and allocate funding to Health Insurance Premium and Cost Sharing Assistance only when determined to be cost effective

The service provision consists of either or both of the following:

- Paying health insurance premiums to provide comprehensive HIV
 Outpatient/Ambulatory Health Services and pharmacy benefits that
 provide a full range of HIV medications for eligible clients
- Paying cost-sharing on behalf of the client

Program Guidance:

Traditionally, RWHAP Parts A and B funding support health insurance premiums and cost-sharing assistance. If a RWHAP Part C or D recipient has the resources to provide this service, an equitable enrollment policy must be in place and it must be cost-effective and sustainable.

See PCN 07-05: Program Part B ADAP Funds to Purchase Health Insurance; PCN 13-05: Clarifications Regarding Use of Ryan White HIV/AIDS Program Funds for Premium and Cost-Sharing Assistance for Private Health Insurance; PCN 13-06: Clarifications Regarding Use of Ryan White HIV/AIDS Program Funds for Premium and Cost-Sharing Assistance for Medicaid; and PCN 14-01: Revised 4/3/2015: Clarifications Regarding the Ryan White HIV/AIDS Program and Reconciliation of Premium Tax Credits under the Affordable Care Act

Home Health Care

Description:

Home Health Care is the provision of services in the home that are appropriate to a client's needs and are performed by licensed professionals. Services must relate to the client's HIV disease and may include:

- Administration of prescribed therapeutics (e.g. intravenous and aerosolized treatment, and parenteral feeding)
- Preventive and specialty care
- Wound care
- Routine diagnostics testing administered in the home
- Other medical therapies

Program Guidance:

The provision of Home Health Care is limited to clients that are homebound. Home settings do not include nursing facilities or inpatient mental health/substance abuse treatment facilities.

Medical Nutrition Therapy

Description:

Medical Nutrition Therapy includes:

- Nutrition assessment and screening
- Dietary/nutritional evaluation
- Food and/or nutritional supplements per medical provider's recommendation
- Nutrition education and/or counseling

These services can be provided in individual and/or group settings and outside of HIV Outpatient/Ambulatory Health Services.

Program Guidance:

All services performed under this service category must be pursuant to a medical provider's referral and based on a nutritional plan developed by the registered dietitian or other licensed nutrition professional. Services not provided by a registered/licensed dietician should be considered Psychosocial Support Services under the RWHAP.

See Food-Bank/Home Delivered Meals

Hospice Services

Description:

Hospice Services are end-of-life care services provided to clients in the terminal stage of an HIV-related illness. Allowable services are:

- Mental health counseling
- Nursing care
- Palliative therapeutics
- Physician services
- Room and board

Program Guidance:

Services may be provided in a home or other residential setting, including a nonacute care section of a hospital that has been designated and staffed to provide hospice services. This service category does not extend to skilled nursing facilities or nursing homes.

To meet the need for hospice services, a physician must certify that a patient is terminally ill and has a defined life expectancy as established by the recipient. Counseling services provided in the context of hospice care must be consistent with the definition of mental health counseling. Palliative therapies must be consistent with those covered under respective state Medicaid programs.

Home and Community-Based Health Services

Description:

Home and Community-Based Health Services are provided to a client living with HIV in an integrated setting appropriate to a client's needs, based on a written plan of care established by a medical care team under the direction of a licensed clinical provider. Services include:

- Appropriate mental health, developmental, and rehabilitation services
- Day treatment or other partial hospitalization services
- Durable medical equipment
- Home health aide services and personal care services in the home

Program Guidance:

Inpatient hospitals, nursing homes, and other long-term care facilities are not considered an integrated setting for the purposes of providing home and community-based health services.

Mental Health Services

Description:

Mental Health Services are the provision of outpatient psychological and psychiatric screening, assessment, diagnosis, treatment, and counseling services offered to clients living with HIV. Services are based on a treatment plan, conducted in an outpatient group or individual session, 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.

Program Guidance:

Mental Health Services are allowable only for HIV-infected clients.

See Psychosocial Support Services

Substance Abuse Outpatient Care

Description:

Substance Abuse Outpatient Care is the provision of outpatient services for the treatment of drug or alcohol use disorders. Services include:

- Screening
- Assessment
- Diagnosis, and/or
- Treatment of substance use disorder, including:
 - Pretreatment/recovery readiness programs
 - Harm reduction
 - Behavioral health counseling associated with substance use disorder
 - Outpatient drug-free treatment and counseling
 - Medication assisted therapy
 - Neuro-psychiatric pharmaceuticals
 - Relapse prevention

Program Guidance:

Acupuncture therapy may be allowable under this service category only when, as part of a substance use disorder treatment program funded under the RWHAP, it is included in a documented plan.

Syringe access services are allowable, to the extent that they comport with current appropriations law and applicable HHS guidance, including HRSA- or HAB-specific guidance.

See Substance Abuse Services (residential)

Medical Case Management, including Treatment Adherence Services *Description:*

Medical Case Management is the provision of a range of client-centered activities focused on improving health outcomes in support of the HIV care continuum. Activities may be prescribed by an interdisciplinary team that includes other specialty care providers. Medical Case Management includes all types of case management encounters (e.g., face-to-face, phone contact, and any other forms of communication). Key activities include:

- Initial assessment of service needs
- Development of a comprehensive, individualized care plan
- Timely and coordinated access to medically appropriate levels of health and support services and continuity of care
- Continuous client monitoring to assess the efficacy of the care plan
- Re-evaluation of the care plan at least every 6 months with adaptations as necessary
- Ongoing assessment of the client's and other key family members' needs and personal support systems
- Treatment adherence counseling to ensure readiness for and adherence to complex HIV treatments
- Client-specific advocacy and/or review of utilization of services

In addition to providing the medically oriented services above, Medical Case Management may also provide benefits counseling by assisting eligible clients in obtaining 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, other state or local health care and supportive services, and insurance plans through the health insurance Marketplaces/Exchanges).

Program Guidance:

Medical Case Management services have as their objective <u>improving health care</u> <u>outcomes</u> whereas Non-Medical Case Management Services have as their objective providing guidance and assistance in <u>improving access</u> to needed services.

Visits to ensure readiness for, and adherence to, complex HIV treatments shall be considered Medical Case Management or Outpatient/Ambulatory Health Services. Treatment Adherence Services provided during a Medical Case Management visit should be reported in the Medical Case Management service category whereas Treatment Adherence services provided during an Outpatient/Ambulatory Health Service visit should be reported under the Outpatient/Ambulatory Health Services category.

RWHAP Legislation: Support Services

Non-Medical Case Management Services

Description:

Non-Medical Case Management Services (NMCM) provide guidance and assistance in accessing medical, social, community, legal, financial, and other needed services. Non-Medical Case management services may also include assisting eligible clients to obtain access to other public and private programs for which they may be eligible, such as Medicaid, Medicare Part D, State Pharmacy Assistance Programs, Pharmaceutical Manufacturer's Patient Assistance Programs, other state or local health care and supportive services, or health insurance Marketplace plans. This service category includes several methods of communication including face-to-face, phone contact, and any other forms of communication deemed appropriate by the RWHAP Part recipient. Key activities include:

- Initial assessment of service needs
- Development of a comprehensive, individualized care plan
- Continuous client monitoring to assess the efficacy of the care plan
- Re-evaluation of the care plan at least every 6 months with adaptations as necessary
- Ongoing assessment of the client's and other key family members' needs and personal support systems

Program Guidance:

Non-Medical Case Management Services have as their objective providing guidance and assistance in <u>improving access</u> to needed services whereas Medical Case Management services have as their objective <u>improving health care outcomes</u>.

Child Care Services

Description:

The RWHAP supports intermittent child care services for the children living in the household of HIV-infected clients for the purpose of enabling clients to attend medical visits, related appointments, and/or RWHAP-related meetings, groups, or training sessions.

Allowable use of funds include:

• A licensed or registered child care provider to deliver intermittent care

• Informal child care provided by a neighbor, family member, or other person (with the understanding that existing federal restrictions prohibit giving cash to clients or primary caregivers to pay for these services)

Program Guidance:

The use of funds under this service category should be limited and carefully monitored. Direct cash payments to clients are not permitted.

Such arrangements may also raise liability issues for the funding source which should be carefully weighed in the decision process.

Emergency Financial Assistance

Description:

Emergency Financial Assistance provides limited one-time or short-term payments to assist the RWHAP client with an emergent need for paying for essential utilities, housing, food (including groceries, and food vouchers), transportation, and medication. Emergency financial assistance can occur as a direct payment to an agency or through a voucher program.

Program Guidance:

Direct cash payments to clients are not permitted.

It is expected that all other sources of funding in the community for emergency financial assistance will be effectively used and that any allocation of RWHAP funds for these purposes will be as the payer of last resort, and for limited amounts, uses, and periods of time. Continuous provision of an allowable service to a client should not be funded through emergency financial assistance.

See AIDS Drug Assistance Program Treatments, AIDS Pharmaceutical Assistance, and other corresponding categories

Food Bank/Home Delivered Meals

Description:

Food Bank/Home Delivered Meals refers to the provision of actual food items, hot meals, or a voucher program to purchase food. This also includes the provision of essential non-food items that are limited to the following:

- Personal hygiene products
- Household cleaning supplies
- Water filtration/purification systems in communities where issues of water safety exist

Program Guidance:

Unallowable costs include household appliances, pet foods, and other non-essential products.

See Medical Nutrition Therapy. Nutritional services and nutritional supplements provided by a registered dietitian are considered a core medical service under the RWHAP.

Health Education/Risk Reduction

Description:

Health Education/Risk Reduction is the provision of education to clients living with HIV about HIV transmission and how to reduce the risk of HIV transmission. It includes sharing information about medical and psychosocial support services and counseling with clients to improve their health status. Topics covered may include:

- Education on risk reduction strategies to reduce transmission such as preexposure prophylaxis (PrEP) for clients' partners and treatment as prevention
- Education on health care coverage options (e.g., qualified health plans through the Marketplace, Medicaid coverage, Medicare coverage)
- Health literacy
- Treatment adherence education

Program Guidance:

Health Education/Risk Reduction services cannot be delivered anonymously.

See Early Intervention Services

Housing

Description:

Housing services provide limited short-term assistance to support emergency, temporary, or transitional housing to enable a client or family to gain or maintain outpatient/ambulatory health services. Housing-related referral services include assessment, search, placement, advocacy, and the fees associated with these services.

Housing services are transitional in nature and for the purposes of moving or maintaining a client or family in a long-term, stable living situation. Therefore, such assistance cannot be provided on a permanent basis and must be accompanied by a strategy to identify, relocate, and/or ensure the client or family is moved to, or capable of maintaining, a long-term, stable living situation.

Eligible housing can include housing that provides some type of medical or supportive services (such as residential substance use disorder services or mental health services, residential foster care, or assisted living residential services) and housing that does not provide direct medical or supportive services, but is essential for a client or family to gain or maintain access to and compliance with HIV-related outpatient/ambulatory health services and treatment.

Program Guidance:

RWHAP Part recipients must have mechanisms in place to allow newly identified clients access to housing services. Upon request, RWHAP recipients must provide HAB with an individualized written housing plan, consistent with RWHAP Housing

Policy 11-01, covering each client receiving short term, transitional and emergency housing services. RWHAP recipients and local decision making planning bodies, (i.e., Part A and Part B) are strongly encouraged to institute duration limits to provide transitional and emergency housing services. The US Department of Housing and Urban Development (HUD) defines transitional housing as up to 24 months and HRSA/HAB recommends that recipients consider using HUD's definition as their standard.

Housing services funds cannot be in the form of direct cash payments to clients and cannot be used for mortgage payments.

See PCN 11-01 The Use of Ryan White HIV/AIDS Program Funds for Housing Referral Services and Short-term or Emergency Housing Needs

Legal Services

See Other Professional Services

Linguistic Services

Description:

Linguistic Services provide interpretation and translation services, both oral and written, to eligible clients. These services must be provided by qualified linguistic services providers as a component of HIV service delivery between the healthcare provider and the client. These services are to be provided when such services are necessary to facilitate communication between the provider and client and/or support delivery of RWHAP-eligible services.

Program Guidance:

Services provided must comply with the National Standards for Culturally and Linguistically Appropriate Services (CLAS).

Medical Transportation

Description:

Medical Transportation is the provision of nonemergency transportation services that enables an eligible client to access or be retained in core medical and support services.

Program Guidance:

Medical transportation may be provided through:

- Contracts with providers of transportation services
- Mileage reimbursement (through a non-cash system) that enables clients to travel to needed medical or other support services, but should not in any case exceed the established rates for federal Programs (Federal Joint Travel Regulations provide further guidance on this subject)
- Purchase or lease of organizational vehicles for client transportation programs, provided the recipient receives prior approval for the purchase of a vehicle

- Organization and use of volunteer drivers (through programs with insurance and other liability issues specifically addressed)
- Voucher or token systems

Unallowable costs include:

- Direct cash payments or cash reimbursements to clients
- Direct maintenance expenses (tires, repairs, etc.) of a privately-owned vehicle
- Any other costs associated with a privately-owned vehicle such as lease, loan payments, insurance, license, or registration fees

Other Professional Services

Description:

Other Professional Services allow for the provision of professional and consultant services rendered by members of particular professions licensed and/or qualified to offer such services by local governing authorities. Such services may include:

- Legal services provided to and/or on behalf of the individual living with HIV and involving legal matters related to or arising from their HIV disease, including:
 - Assistance with public benefits such as Social Security Disability Insurance (SSDI)
 - Interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under the RWHAP
 - Preparation of:
 - Healthcare power of attorney
 - Durable powers of attorney
 - Living wills
- Permanency planning to help clients/families make decisions about the placement and care of minor children after their parents/caregivers are deceased or are no longer able to care for them, including:
 - Social service counseling or legal counsel regarding the drafting of wills or delegating powers of attorney
 - Preparation for custody options for legal dependents including standby guardianship, joint custody, or adoption
- Income tax preparation services to assist clients in filing Federal tax returns that are required by the Affordable Care Act for all individuals receiving premium tax credits

Program Guidance:

Legal services exclude criminal defense and class-action suits unless related to access to services eligible for funding under the RWHAP.

See <u>45 CFR § 75.459</u>

Outreach Services

Description:

Outreach Services include the provision of the following three activities:

- Identification of people who do not know their HIV status and linkage into Outpatient/Ambulatory Health Services
- Provision of additional information and education on health care coverage options
- Reengagement of people who know their status into Outpatient/Ambulatory Health Services

Program Guidance:

Outreach programs must be:

- Conducted at times and in places where there is a high probability that individuals with HIV infection and/or exhibiting high-risk behavior
- Designed to provide quantified program reporting of activities and outcomes to accommodate local evaluation of effectiveness
- Planned and delivered in coordination with local and state HIV prevention outreach programs to avoid duplication of effort
- Targeted to populations known, through local epidemiologic data or review of service utilization data or strategic planning processes, to be at disproportionate risk for HIV infection

Funds may not be used to pay for HIV counseling or testing under this service category.

See Policy Notice 12-01: The Use of Ryan White HIV/AIDS Program Funds for <u>Outreach Services</u>. Outreach services cannot be delivered anonymously as personally identifiable information is needed from clients for program reporting.

See Early Intervention Services

Permanency Planning

See Other Professional Services

Psychosocial Support Services

Description:

Psychosocial Support Services provide group or individual support and counseling services to assist eligible people living with HIV to address behavioral and physical health concerns. These services may include:

- Bereavement counseling
- Caregiver/respite support (RWHAP Part D)
- Child abuse and neglect counseling
- HIV support groups

- Nutrition counseling provided by a non-registered dietitian (see Medical Nutrition Therapy Services)
- Pastoral care/counseling services

Program Guidance:

Funds under this service category may not be used to provide nutritional supplements (*See* Food Bank/Home Delivered Meals).

RWHAP-funded pastoral counseling must be available to all eligible clients regardless of their religious denominational affiliation.

Funds may not be used for social/recreational activities or to pay for a client's gym membership.

For RWHAP Part D recipients, outpatient mental health services provided to affected clients (people not identified with HIV) should be reported as Psychosocial Support Services; this is generally only a permissible expense under RWHAP Part D.

See Respite Care Services

Referral for Health Care and Support Services

Description:

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 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).

Rehabilitation Services

Description:

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.

Program Guidance:

Examples of allowable services under this category are physical and occupational therapy.

Respite Care

Description:

Respite Care is the provision of periodic respite care in community or home-based settings that includes non-medical assistance designed to provide care for an HIV-infected client to relieve the primary caregiver responsible for the day-to-day care of an adult or minor living with HIV.

Program Guidance:

Recreational and social activities are allowable program activities as part of a respite care service provided in a licensed or certified provider setting including drop-in centers within HIV Outpatient/Ambulatory Health Services or satellite facilities.

Funds may not be used for off premise social/recreational activities or to pay for a client's gym membership.

Funds may be used to support informal, home-based Respite Care, but liability issues should be included in the consideration of this expenditure. Direct cash payments to clients are not permitted.

See Psychosocial Support Services

Substance Abuse Services (residential)

Description:

Substance Abuse Services (residential) is the provision of services for the treatment of drug or alcohol use disorders in a residential setting to include screening, assessment, diagnosis, and treatment of substance use disorder. This service includes:

- Pretreatment/recovery readiness programs
- Harm reduction
- Behavioral health counseling associated with substance use disorder
- Medication assisted therapy
- Neuro-psychiatric pharmaceuticals
- Relapse prevention
- Detoxification, if offered in a separate licensed residential setting (including a separately-licensed detoxification facility within the walls of an inpatient medical or psychiatric hospital)

Program Guidance:

Substance Abuse Services (residential) is permitted only when the client has received a written referral from the clinical provider as part of a substance use disorder treatment program funded under the RWHAP.

Substance Abuse Services (residential) are not allowable services under RWHAP Parts C and D.

Acupuncture therapy may be allowable funded under this service category only when it is included in a documented plan as part of a substance use disorder treatment program funded under the RWHAP.

RWHAP funds may not be used for inpatient detoxification in a hospital setting, unless the detoxification facility has a separate license.

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Core Medical Services

Core medical services are specified in the Ryan White HIV/AIDS Treatment Extension Act of 2009. They are a set of essential, direct health care services provided to Ryan White HIV/AIDS Program clients who are HIV positive or HIV indeterminate, with one exception. HIV-negative clients may receive HIV counseling and testing (HC&T) services under Early Intervention Services for Parts A and B; HC&T data are reported in the Provider Report.

Outpatient/ambulatory medical care includes the provision of professional diagnostic and therapeutic services directly to a client by a physician, physician assistant, clinical nurse specialist, nurse practitioner, or other health care 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 other drug therapies, including prophylaxis and treatment of opportunistic infections and combination ARV therapies.

AIDS Drug Assistance Program (ADAP) is a State-administered program authorized under Part B of the Ryan White HIV/AIDS Program that provides FDA-approved medications to low-income individuals with HIV/AIDS disease who have limited or no coverage from private insurance, Medicaid, or Medicare. Program funds may also be used to purchase health insurance for eligible clients and for services that enhance access to, adherence to, and monitoring of drug treatments.

Local AIDS pharmaceutical assistance (APA, not ADAP) includes local pharmacy assistance programs implemented by Part A or Part B grantees to provide HIV/AIDS medications to clients. This assistance can be funded with Part A grant funds or Part B base award funds. These organizations may or may not provide other services (e.g., outpatient/ambulatory medical care or case management) to the clients they serve through a RWHAP contract with their grantee.

Programs are considered APAs if they provide HIV/AIDS medications to clients and meet all of the following criteria:

- Have a client enrollment process;
- Have uniform benefits for all enrolled clients;
- Have a record system for distributed medications; and
- Have a drug distribution system.

Programs are not APAs if they dispense medications in one of the following situations:

- As a result or component of a primary medical visit;
- On an emergency basis (defined as a single occurrence of short duration); or
- By giving vouchers to a client to procure medications.

Local APAs are similar to AIDS Drug Assistance Programs (ADAPs) in that they provide medications for the treatment of HIV disease. However, local APAs are not paid for with Part B funds "earmarked" for ADAP.

Oral health care includes diagnostic, preventive, and therapeutic services provided by a dental health care 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.

Early intervention services (EIS) for Parts A and B include counseling individuals with respect to HIV/AIDS; testing (including tests to confirm the presence of the disease, to diagnose the extent of immune deficiency, and to provide information on appropriate therapeutic measures); referrals; other clinical and diagnostic services regarding HIV/AIDS; periodic medical evaluations for individuals with HIV/AIDS; and provision of therapeutic measures.

While HIV counseling and testing (HC&T) activities are an integral part of EIS, HIV-negative individuals who receive HC&T services under EIS for Parts A and B should be reported only in the RSR Provider Report. This includes data on individuals with preliminary positive or invalid rapid HIV tests and negative confirmatory HIV tests.

Health insurance premium and cost-sharing assistance, also referred to as Health Insurance Program (HIP), is the provision of financial assistance for eligible individuals living with HIV to maintain continuity of health insurance or to receive medical benefits under a health insurance program. This includes premium payments, risk pools, co-payments, and deductibles.

Home health care is the provision of services in the home by licensed health care professionals, such as nurses, and the administration of intravenous and aerosolized treatment, parenteral feeding, diagnostic testing, and other medical therapies.

Home and community-based health services includes skilled health services furnished to the individual in the individual's home, based on a written plan of care established by a case management team that includes appropriate health care professionals. Services include durable medical equipment; home health aide services and personal care services in the home; day treatment or other partial hospitalization services; home intravenous and aerosolized drug therapy (including prescription drugs administered as part of such therapy); routine diagnostics testing administered in the home; and appropriate mental health, developmental, and rehabilitation services.

Hospice services are end-of-life care provided to clients in the terminal stage of an illness. They include room, board, nursing care, counseling, physician services, and palliative therapeutics. Services may be provided in a residential setting, including a non-acute care section of a hospital that has been designated and staffed to provide hospice services. A physician must certify that a patient is terminal, defined under Medicaid hospice regulations as having a life expectancy of 6 months or less. Counseling services provided in the context of hospice care must be consistent with the definition of mental health counseling. Palliative therapies must be consistent with those covered under respective State Medicaid Programs.

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.

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 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 health care 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 of 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; (2) development of a 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.

Substance abuse services (outpatient) 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 health care provider and the service is provided by certified or licensed practitioners and/or programs, wherever State certification or licensure exists.

Support Services

Support services are a set of services needed to achieve medical outcomes that affect the HIV-related clinical status of a person living with HIV/AIDS. Support services may be provided to HIV-positive and HIV-indeterminate clients as needed. Support services may also be provided to HIV-affected clients. However, the services provided to HIV-affected clients must always support a medical outcome for the HIV-positive client or HIV-indeterminate infant.

Case management services (non-medical) include 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.

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.

Pediatric developmental assessment and early intervention services are professional early interventions by physicians, developmental psychologists, educators, and others for the psychosocial 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, drug exposure, and other factors. Provision of information about access to Head Start services, appropriate educational settings for HIV-infected clients, and education/assistance to schools also should be reported in this category.

Emergency financial assistance is the provision of one-time or short-term payments to agencies or the establishment of voucher programs when other resources are not available to help with emergency expenses related to essential utilities, housing, food (including groceries, food vouchers, and food stamps), transportation, and medication. Part A and Part B programs must allocate, track, and report these funds under specific service categories, as described under 2.6 in DSS Program Policy Guidance No. 2 (formerly Policy No. 97-02).

It is expected that all other sources of funding in the community for emergency assistance will be effectively used and that any allocation of Ryan White HIV/AIDS Program funds for these purposes will be the payer of last resort, and for limited amounts, use and periods of time. Continuous provision of an allowable service to a client should be reported in the applicable service category.

Food bank/home-delivered meals involve the provision of actual food or meals. It does not include finances to purchase food or meals, but may include vouchers to purchase food. The provision of essential household supplies, such as hygiene items and household cleaning supplies, should also be included in this item. The provision of food or nutritional supplements by someone other than a registered dietician should be included in this item as well.

Food vouchers provided as an ongoing service to a client should be reported in this service category. Food vouchers provided on a one-time or intermittent basis should be reported in the Emergency financial assistance category.

Health education/risk reduction 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.

Housing services are short-term assistance to support emergency, temporary, or transitional housing to enable an individual or family to gain or maintain medical care. Housing-related referral services include assessment, search, placement, advocacy, and the fees associated with them. Eligible housing can include both housing that provides some type of medical or supportive services (such as residential substance abuse or mental health services, residential foster care, or assisted living residential services) and housing that does not provide direct medical or supportive services but is essential for an individual or family to gain or maintain access to and compliance with HIV-related medical care and treatment.

Housing funds cannot be in the form of direct cash payments to recipients for services and cannot be used for mortgage payments. Short-term or emergency assistance is understood as transitional in nature and for the purposes of moving or maintaining an individual or family in a long-term, stable living situation. Therefore, such assistance cannot be permanent and must be accompanied by a strategy to identify, relocate, and/or ensure the individual or family is moved to, or capable of maintaining, a long-term, stable living situation. For more information, see the policy "The Use of Ryan White HIV/AIDS Program Funds for Housing Referral Services and Short-term or Emergency Housing Needs" at http://hab.hrsa.gov/manageyourgrant/policiesletters.html.

Legal services are services to individuals with respect to powers of attorney, do-not-resuscitate orders, and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under the Ryan White HIV/AIDS Program.

Legal services to arrange for guardianship or adoption of children after the death of their primary caregiver should be reported as a permanency planning service.

Linguistic services include interpretation (oral) and translation (written) services, provided by qualified individuals as a component of HIV service delivery between the provider and the client, when such services are necessary to facilitate communication between the provider and client and/or support the delivery of Ryan White–eligible services.

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.

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 effort, targeted to populations known through local epidemiologic data to be at disproportionate risk for HIV infection, 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.

Permanency planning includes services to help clients/families make decisions about the placement and care of minor children after their parents/caregivers are deceased or are no longer able to care for them. It includes the provision of social service counseling or legal counsel regarding (1) drafting of wills or delegating powers of attorney; and (2) preparation for custody options for legal dependents, including standby guardianship, joint custody, or adoption.

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 are reported in this service category.

Nutritional services and nutritional supplements provided by a licensed, registered dietician are considered a core medical service and should be reported as Medical nutrition therapy. The provision of food and/or nutritional supplements by someone other than a registered dietician should be reported in the Food bank/home-delivered meals service category.

Referral for health care/supportive services is the act of directing 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.

Referrals for health care/supportive services provided by outpatient/ambulatory medical care providers should be reported under the outpatient/ambulatory medical care service category. Referrals for health care/supportive 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.

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.

Respite care is community or home-based non-medical assistance designed to relieve the primary caregiver responsible for providing day-to-day care of a client living with HIV/AIDS.

Substance abuse services (residential) include treatment to address substance abuse problems (including alcohol and/or legal and illegal drugs) in a residential health service setting (short-term care). They include limited support of acupuncture services to HIV-positive clients, provided the client has received a written referral from his or her primary health care 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. Treatment 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.

Service Category	Recommendations QA = Quality Assurance Recommendation from 5-19-04 WG = Work Group Recommendation from 4-04	 A.) Bundle Services? B.) Eliminate duplicative services/activities. C.) Reduce services not directly related to assuring access to primary medical care. D.) Make service method. more efficient. 	Identify Alternative Funding Sources	Justify the use of Ryan White funds for this service	Justification from 2002 Needs Assessment ('02 NA), Comp Plan ('03 CP), FY 2003 Client Utilization Data (FY 03 CUD); FY 2003 Outcome Measures (FY 03 OM) and/or State of Emergency (SE). See original document for complete info. on each service category. Alloc/client – allocation per client Units/client – average units of service per client Disb/client – average disbursement per client From 02 NA: U = use; N = need; B = barrier; G = gap
Emergency Financial Assistance CLARIFICATION: Locally, this category includes 6a. Emergency Rental Assistance and 9a. Emergency Utility & In-home Assistance Vouchers from the Procurement Reports.	QA: Accept the WG recommendations. This was a close vote (5 to 5 with the chair breaking the tie. The Chair also asked that case mgmt. staff be trained re: the different sources of revenue for this service. WG: Eliminate this service that includes emergency rental assistance, emergency utility assistance and in- home assistance vouchers. This was a close vote (8 to 7 with work group chair breaking the tie) so see opposing view.	*	QA Justification: According to the HOPWA rep., they provide significant funding for emergency rent and utility assistance. (See City Council approved allocations.) <u>View #1</u> : RW is for medical needs, not a poverty mitigation program. HOPWA should be paying for all housing related services. Alternative funding sources include: HOPWA (see Houston Chronicle article 4-16-04 regarding an increase in housing funds); HUD; Title II; MHMRA and other City funds. The Council has been telling HOPWA since Dec. 2002 that it will not continue to use Title I funds for housing related programs so the City should be prepared for this change. <u>View #2</u> : HRSA does allow this service. Residency must be established to be eligible for HOPWA programs. There is not enough housing in Houston area. What if HOPWA does not step up to the plate and fill in when Title I steps back? Housing is needed to keep people in medical care. What about the rural areas? Please note that there was no HOPWA rep. at the meeting to provide additional information.	Vo compelling ustification for using RW funds.	 FY 03 OM: 427 of these clients (54.3%) accessed Title I/III/IV primary care services during this time period after receiving financial assistance. FY 03 CUD: # of clients served 804. Alloc/client: \$190. Units/client: 3. Disb/client: \$479. '02 NA: U = 27 N = 8 B = 3 G = 1 '03 CP: A1, A2, B1, B2, B3, C1

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EMA	Medications	Taxi Vouchers	Notes
DC EMA			EFA covers emergency utility, rent, hygiene, food, moving, telephone only
Ft Worth TGA	Assistance with meds when other resources are not available		Also covers essential utilities, housing, food.
NY EMA			They have never funded EFA
San Antonio TGA	One time assistance for any medication and associated dispensing fee as a result or component of a primary medical visit (30-day supply)		Also covers utilities, housing, food and prescription eye glasses.
Seattle TGA	There are many sources (including our ADAP program) to provide emergency medications	People who need transportation don't just need it ONCE, so funded under Medical Transportation	EFA not funded; emergency housing funded under housing
Tampa-St. Petersburg EMA	Short term antiretrovirals while client is enrolling in ADAP.		

Emergency Financial Assistance in Other EMAs/TGAs

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Emergency Financial Assistance (EFA) Standards of Care

Definition:

Support for Emergency Financial Assistance (EFA) for essential services including utilities, housing, food (including groceries and food vouchers), or prescriptions provided to clients with limited frequency and for a limited period of time. The intent of these funds are to support a client for a short duration.

Limitations:

Direct cash payments to clients are not permitted

No funds may be used for any expenses associated with the ownership or maintenance of a privately owned motor vehicle.

Services:

Ryan White HIV/AIDS/State Services funds may be used to provide services in the following categories:

- 1. ADAP eligibility determination period
- 2. Dispensing fee for ADAP medications
- 3. Emergency Financial Assistance

EFA can be used during the ADAP eligibility determination period. Initial medications purchased for this use is not subject to the \$800/client/year cap.

EFA can be used to reimburse dispensing fees associated with purchased medications. Dispensing fees are not subject to the \$800/client/year cap.

EFA is an allowable support service with an \$800/year/client cap.

- The agency must set priorities, delineate and monitor what part of the overall allocation for emergency assistance is obligated for each subcategory. Careful monitoring of expenditures within a subcategory of "emergency assistance" is necessary to assure that planned amounts for specific services are being implemented, and to determine when reallocations may be necessary.
- Limitations on the provision of emergency assistance to eligible individuals/households should be delineated and consistently applied to all clients. It is expected that all other sources of funding in the community for emergency assistance will be effectively used and that any allocation of Emergency Financial Assistance funding for these purposes will be the payer-of-last-resort, and for limited amounts, limited use and limited periods of time.

Emergency Financial Assistance provides funding through:

- Short-term payments to agencies
- Establishment of voucher programs

Emergency Financial Assistance to individual clients is provided with limited frequency and for a limited period of time, with specified frequency and duration of assistance. Financial hardship must be documented each time funds are used.

- Assistance is provided only for the following essential services/subcategories:
 - Utilities such as household utilities including gas, electricity, propane, water, and all required fees
 - Housing such as rent, mortgage payment, or temporary shelter. EFA can only be used if HOPWA assistance isn't available
 - Food such as groceries and food vouchers
 - Prescription assistance such as short term, one time assistance for any medication and associated dispensing fees as a result or component of a primary medical visit (30-day supply) and the cost of corrective prescription eye wear

Agency Standards

Agency Standard	Expected Practice
Payment Methodologies Agency will establish payment method to include either direct payment to service providers/agencies or through a voucher program per HRSA National Monitoring Standards	Emergency Financial Assistance payment will be made out to the appropriate vendor for the exact amount listed on the bill. Payment will be made directly to the service provider/agency or if authorization is obtained, for pick up by the client or agency staff. No payment shall be made directly to clients, family or household members.
EFA Subcategories The grantee must set priorities, delineate and monitor what part of the overall allocation for emergency assistance is obligated for each subcategory according to HRSA National Monitoring Standards.	 Assistance can be provided for the following essential services/subcategories: Utilities Housing Food (including groceries and food vouchers) Prescription assistance Administrative Agencies must prioritize and delineate a portion of the overall allocation for Emergency Financial Assistance in one or more of the above categories.

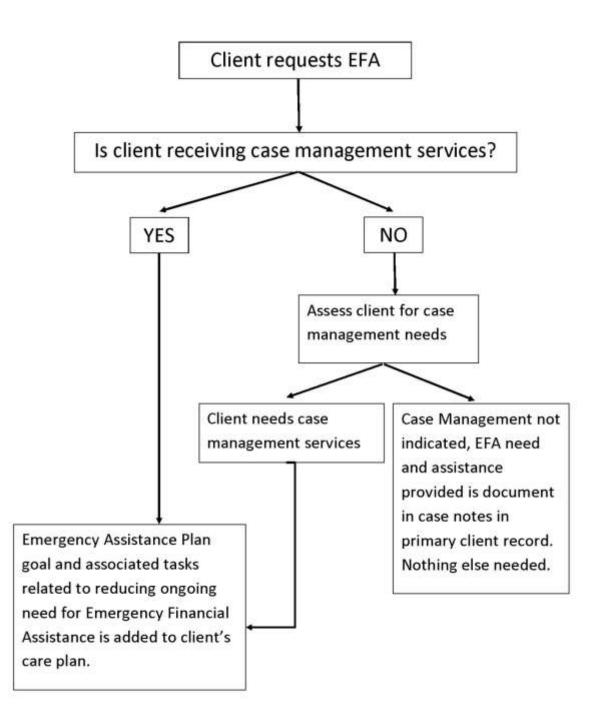
	Reallocations must be updated in ARIES if funds move between subcategories.
Payment Limitations Grantee will develop standard limitations on the provision of emergency assistance to eligible individuals/households and mandate their consistent application by all contractors in accordance with HRSA Monitoring Standards.	Agency may assist each unduplicated client up to \$800 per year per region. These limits will be applied consistently throughout the state. The Administrative Agency may set additional limitations on type of services covered within each subcategory.
Payer of Last Resort	The AA must establish or adopt the DSHS Payer of Last Resort policy for agencies in their region. Agencies providing EFA medications must develop policies and procedures to pursue all feasible alternative revenues systems (e.g., pharmaceutical company patient assistance programs) before requesting reimbursement through EFA.
Dispensing Fee	Agency may reimburse the pharmacy a minimal dispensing fee per prescriptions as outlined in a MOU.
Client confidentiality Maintained in accordance with DSHS HIV/STD Program Operating Procedures and Standards.	Agency has a procedure to protect client confidentiality when making payments for assistance, (e.g., checks that do not identify the agency as an HIV/AIDS agency).

Standards of Care

Purchasing Medications during ADAP	No more than a 30 day supply of medication on the ADAP formulary can be purchased at a time for each client. If more than 30 days is needed, the medication can be refilled for another 30 days.
application period	-If the ADAP denied the coverage, the agency staff should work with the client and the client's attending physician to find alternate funding sources which may include manufacturer's compassionate programs, religious groups, or other community resources.
Client Eligibility for Emergency Financial Assistance	 Applicants must demonstrate that an unexpected hardship has left them seriously short of money so that they cannot pay their utility bills or prescriptions without assistance and risk disconnection of service due to one or more of the following: A significant increase in bills A recent decrease in income High unexpected expenses on essential items The cost of their shelter is more than 30% of the household income The cost of their utility consumption is more than 10% of the household income They are unable to provide for basic needs and shelter A failure to provide emergency financial assistance will result in danger to the physical health of client or dependent children Other emergency needs as deemed appropriate by the agency Client will be assessed for ongoing status and outcome of the emergency assistance (see attached flowchart). An EFA request should trigger a brief needs assessment for case management services. This Needs Assessment should not be time intensive, but should determine client's current status and need for case management services. Clients who do NOT need case management services The goal of this plan is to reduce the need for emergency assistance.

Emergency Financial Assistance Provided Determined in accordance with HRSA National Monitoring Standards	 Short-term assistance will only be provided for: Utilities Housing Food (groceries and food vouchers) Prescription assistance All completed requests for assistance shall be approved or denied within three (3) business days. Assistance shall be issued in response to an essential need (as identified by the staff person providing EFA) within three (3) business days of approval of request. Payment for assistance made to service providers will protect client confidentiality.
	-Check and/or envelope sent to service provider will not identify an agency solely service HIV clients.
Agency Documentation Providers/agencies are required to record and track use of EFA funds under each sub category as required by the Ryan White Services Report (RSR) in accordance with the HRSA National Monitoring Standards	 Each agency will track and report type of assistance. Emergency funds will be tracked and reported by : -Number of clients receiving assistance during ADAP eligibility determination period -Number of clients receiving dispensing fee assistance -Number of clients and amount expended for each type of EFA Summary of number of EFA services received by client Methods used to provide EFA (e.g., payments to agencies, vouchers)
Client Documentation	Client's case file will contain the following documentation: -Assistance given during the ADAP eligibility determination period -Assistance given for ADAP medication dispensing fees -Assistance given for emergency financial assistance • Eligibility criteria • Assessment of need for emergency • Date EFA was provided

 Amount paid and method of payment (direct payment or voucher) Ongoing assessment by agency staff of the outcome of the emergency assistance Status/resolution of the emergency Any referrals made and the results of those referrals
Documentation in the client's primary record must include the attempts made to access client assistance programs with pharmaceutical companies, private or public insurance programs the client may have and other community resources.



References

HRSA/HAB Division of Service Systems Program Monitoring Standards – Part A April, 2013, page 29-30.

HRSA/HAB Division of State HIV/AIDS Programs National Monitoring Standards – Program Part B April, 2013, page 29-30.

HRSA Policy Notice 10-02. Eligible Individuals & Allowable Uses of Funds for Discretely Defined Categories of Services, April 2010 located at: http://hab.hrsa.gov/manageyourgrant/pinspals/eligible1002.html

Texas Department of State Health Services HIV/STD Program Policies. Payer of Last Resort (Policy 590.001). Located at http://www.dshs.state.tx.us/hivstd/policy/policies.shtm

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2016 Proposed Idea

(Applicant must complete this two-page form as it is. Agency identifying information must be removed or the application will not be reviewed. Please read the attached documents before completing this form: 1.) HRSA HIV-Related Glossary of Service Categories to understand federal restrictions regarding each service category, 2.) Criteria for Reviewing New Ideas, and 3.) Criteria & Principles to Guide Decision Making.)

#Control NumberDate Received $02 13 17$ Proposal will be reviewed by the:Quality Assurance Committee on: $02 16 17$ (date)Priority & Allocation Committee on: $02 23/17$ (date)
THIS PAGE IS FOR THE QUALITY ASSURANCE COMMITTEE
(See Glossary of HIV-Related Service Categories & Criteria for Reviewing New Ideas)
1. SERVICE CATEGORY: Emergency Finger (ASSiSTANCe
(The service category must be one of the Ryan White Part A or B service categories as
described in the HRSA Glossary of HIV-Related Service Categories.)
This will provide 200 clients with 200 units of service.
2. ADDRESS THE FOLLOWING: A. DESCRIPTION OF SERVICE: Bridge prant To get New print. HIVMedizations in Mediately upon presentation of prese
Hilling I at a line of the the second second at Dres
All a carriers in mediately upon presentities of p
B. TARGET POPULATION (Race or ethnic group and/or geographic area): ハノウ
C. SERVICES TO BE PROVIDED (including goals and objectives): QARTINE HIV medicator
C. SERVICES TO BE PROVIDED (including goals and objectives): One Time HIV medicator promoto To eliminate WAil Time For Approval by CC
LPAP our ADAP. Elimination of Couplex Administration
D. ANTICIPATED HEALTH OUTCOMES (Related to Knowledge, Attitudes, Practices, Health
D. ANTICIPATED HEALTH OUTCOMES (Related to Knowledge, Attitudes, Practices, Health Proc Data, Quality of Life, and Cost Effectiveness): 1. Drop in YOF PATIONS (057. D. STR255 - A pat Ance of Treff with by implediate biant.
2. STRESS . A part Ance of Trefamil by impldinge blant.
3. CArlier Treatmit STANTS The better The autcome.
3. ATTACH DOCUMENTATION IN ORDER TO JUSTIFY THE NEED FOR THIS NEW
IDEA. AND, DEMONSTRATE THE NEED IN AT LEAST ONE OF THE FOLLOWING
PLANNING COUNCIL DOCUMENTS:
$\underbrace{\mathcal{V}}_{\text{Current Needs Assessment (Year: 2016)}} \qquad Page(s): \underline{\mathcal{L}}_{\text{Paragraph: }} \\ \underbrace{\mathcal{V}}_{\text{Current UIV Comprehensive Plan (Year:)}} \\ \underbrace{\mathcal{V}}_{\text{Current Vertex (a)}} \\ \underbrace{\mathcal{V}}_{\text{Current Vertex (a)} \\ \underbrace{\mathcal{V}$
Current HIV Comprehensive Plan (Year:) Page(s):Paragraph: Health Outcome Results: Date: Page(s):Paragraph:
Other Ryan White Planning Document:
Name & Date of Document: Page(s): Paragraph:
RECOMMENDATION OF QUALITY ASSURANCE COMMITTEE:
RecommendedNot RecommendedSent to How To Best Meet Need
REASON FOR RECOMMENDATION:

(Continue on Page 2 of this application form)

Proposed Idea

THIS PAGE IS FOR THE PRIORITY AND ALLOCATIONS COMMITTEE (See Criteria and Principles to Guide Decision Making)

THIS BOX TO BE COMPLETED BY RWPC SUPPORT STAFF ONLY AND INCLUDE A BRIEF HISTORY OF RELATED SERVICE CATEGORY, IF AVAILABLE.						
CURRENTLY APPROVED RELATED SERVICE CATEGORY ALLOCATION/UTILIZATION:						
Expenditure: \$	Year-to-Date					
Utilization: <u>Ø</u>	Unduplicated Clients Served Year-to-Date Units of Service Provided Year-to-Date					
AMOUNT OF FUNDING REQUESTED:						
125000 This will provide funding for the following purposes which will						
further the objectives in this s	service category: (describe how): med is at in sarch the					

PLEASE STATE HOW THIS IDEA WILL MEET THE PRIORITY AND ALLOCATIONS CRITERIA AND PRINCIPLES TO GUIDE DECISION MAKING. SITE SPECIFIC STEPS AND ITEMS WITHIN THE STEPS: A comprehensive system STATS with diagnosis and early Treatment. GetTim gaps is machine to diagnosis and early Filed Assure better results (principle A+B) Treatment delivery Filed Assure better results (principle A+B) I CRITERIA A. B. C. D. E. F. G. H. I - all criteria met. d criteria A. B. C. D. E. F. G. H. I - all criteria met.

	 ·	
RECOMMENDATION OF PRIORITY AND ALLOCATIONS COMMITTEE:		
Recommended for Funding in the Amount of: \$ Not Recommended for Funding Other:		
REASON FOR RECOMMENDATION:		

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LOCAL HIV MEDICATION ASSISTANCE

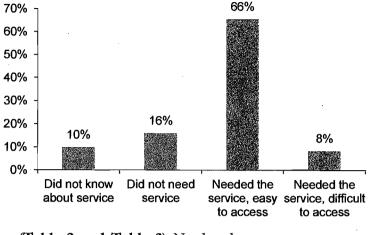
Local HIV medication assistance, technically referred to as the Local Pharmacy Assistance Program (LPAP), provides HIV-related pharmaceuticals to persons living with HIV (PLWH) who are not eligible for medications through other payer sources, including the state AIDS Drug Assistance Program (ADAP).

(Graph 1) In the 2016 Houston HIV Care Services Needs Assessment, 74% of participants indicated a need for *local HIV medication assistance* in the past 12 months. 66% reported the service was easy to access, and 8% reported difficulty. 10% stated that they did not know the service was available.

(Table 1) When barriers to local HIV medication assistance were reported, the most common barrier type was related to health insurance coverage (24%). Health insurance-related barriers reported include having coverage gaps and being uninsured.

TABLE 1-Top 5 Reported Barrier Types for Local HIV Medication Assistance, 2016					
1.		No.	%		
1.	Health Insurance Coverage (I)	8	24%		
2.	Administrative (AD)	4	12%		
3.	Education and Awareness (EA)	3	9%		
4.	Eligibility (EL)	3	9%		
5.	Financial (F)	3	9%		

GRAPH 1-Local HIV Medication Assistance, 2016



(Table 2 and Table 3) Need and access to services can be analyzed for needs assessment participants according to demographic and other characteristics, revealing the presence of any potential disparities in access to services. For *local HIV medication assistance*, this analysis shows the following:

- More females than males found the service accessible.
- More other/multiracial PLWH than other race/ethnicities found the service accessible.
- More PLWH age 18 to 24 found the service accessible than other age groups.
- In addition, rural and recently released PLWH found the service difficult to access when compared to all participants.

TABLE 2-Local HIV Medication Assistance, by Demographic Categories, 2016									
	Sex		Race/et	nnicity			Age		
Experience with the Service	Male	Female	White	Black	Hispanic	Other	18-24	25-49	50+
Did not know about service	10%	9%	7%	12%	9%	0%	5%	11%	8%
Did not need service	18%	11%	16%	17%	11%	53%	14%	14%	20%
Needed, easy to access	65%	68%	71%	62%	73%	33%	76%	66%	64%
Needed, difficult to access	7%	11%	7%	9%	7%	13%	5%	8%	8%

TABLE 3 Local HIV Medication	Assistance of	/SelecterdS	secial Popu	ilations, 2016		
Experience with the Service	Unstably Housed ^a	MSM ^b	Out of Care ^c	Recently Released ^d	Rural ^e	Transgender ^f
Did not know about service	12%	8%	100%	13%	0%	14%
Did not need service	19%	18%	0%	3%	12%	14%
Needed, easy to access	61%	67%	0%	74%	73%	71%
Needed, difficult to access	8%	8%	0%	11%	15%	0%

Persons reporting housing instability Men who have sex with men Persons with no evidence of HIV care for 12 mo.

⁴Persons released from incarceration in the past 12 mo. *Non-Houston/Harris County residents ⁴Persons with discordant sex assigned at birth and current gender

Priority and Allocations FY 2017 Guiding Principles and Decision Making Criteria

(Priority and Allocations Committee approved 02-25-16)

Priority setting and allocations must be based on clearly stated and consistently applied principles and criteria. These principles are the basic ideals for action and are based on Health Resources and Services Administration (HRSA) and Department of State Health Services (DSHS) directives. All committee decisions will be made with the understanding that **the Ryan White Program is unable to completely meet all identified needs** and following legislative mandate **the Ryan White Program will be considered funding of last resort**. Priorities are just one of many factors which help determine allocations. All Part A and Part B service categories are considered to be important in the care of people living with HIV/AIDS. Decisions will address at least one or more of the following principles **and** criteria.

Principles are the standards guiding the discussion of all service categories to be prioritized and to which resources are to be allocated. Documentation of these guiding principles in the form of printed materials such as needs assessments, focus group results, surveys, public reports, journals, legal documents, etc. will be used in highlighting and describing service categories (individual agencies are not to be considered). Therefore decisions will be based on service categories that address the following principles, in no particular order:

Principles

- A. Ensuring ongoing client access to a comprehensive system of core services as defined by HRSA
- B. Eliminating barriers to core services among affected sub-populations (racial, ethnic and behavioral) and low income, unserved, underserved and severe need populations (rural and urban)
- C. Meeting the needs of diverse populations as addressed by the epidemiology of HIV
- D. Identify individuals unaware of their status and link them to care and address the needs of those that are aware of their status and not in care.
- E. Expressing the needs of the communities with HIV for whom the services are intended

Allocations only

- F. Documented or demonstrated cost-effectiveness of services and minimization of duplication
- G. Availability of other government and non-governmental resources, including Medicaid, Medicare, CHIP, private insurance and Affordable Care Act related insurance options, local foundations and non-governmental social service agencies

Criteria are the standards on which the committee's decisions will be based. Positive decisions will only be made on service categories that satisfy at least one of the criteria in Step 1 and all criteria in Step 2. Satisfaction will be measured by printed information that address service categories such as needs assessments, focus group results, surveys, reports, public reports, journals, legal documents, etc.

(Continued)

DECISION MAKING CRITERIA STEP 1:

- A. Documented service need with consumer perspectives as a primary consideration
- B. Documented effectiveness of services with a high level of benefit to people and families living with HIV infection, including quality, cost, and outcome measures when applicable
- C. Documented response to the epidemiology of HIV/AIDS in the EMA and HSDA
- D. Documented response to emerging needs reflecting the changing local epidemiology of HIV/AIDS while maintaining services to those who have relied upon Ryan White funded services.
- E. When allocating unspent and carryover funds, services are of documented sustainability across fiscal years in order to avoid a disruption/discontinuation of services
- F. Documented consistency with the current Houston Area Comprehensive HIV Prevention and Care Services Plan and the Continuum of Care and their underlying principles to the extent allowable under the Ryan White Program: to build public support for HIV services; to inform people of their serostatus and, if they test positive, get them into care; to help people maintain their negative status; to help people with HIV improve their health status and quality of life and prevent the progression to AIDS; to help reduce the risk of transmission; and to help people with AIDS improve their health status and quality of life and, if necessary, support the conditions that will allow for death with dignity

DECISION MAKING CRITERIA STEP 2:

- A. Services are effective with a high level of benefit to people and families living with HIV, including cost and outcome measures when applicable
- B. Services are accessible to all populations infected, affected, or at risk, allowing for differences in need between urban, suburban, and rural consumers as applicable under Part A and B guidelines
- C. The Council will minimize duplication of both service provision and administration and services will be coordinated with other systems, including but not limited to HIV prevention, substance use, mental health, and Sexually Transmitted Infections (STIs).
- D. Services emphasize access to and use of primary medical and other essential HRSA defined core services
- E. Services are appropriate for different cultural and socioeconomic populations, as well as care needs
- F. Services are available to meet the needs of all people and families living with or at risk for HIV infection as applicable under Part A and B guidelines
- G. Services meet or exceed standards of care
- H. Services reflect latest medical advances, when appropriate
- I. Services meet a documented need that is not fully supported through other funding streams

PRIORITY SETTING AND ALLOCATIONS ARE SEPARATE DECISIONS. All decisions are expected to address needs of the overall community affected by the epidemic.

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Starting treatment

Same-day start to antiretroviral treatment leads to faster HIV suppression in San Francisco

Produced in collaboration with hivandhepatitis.com Published: 23 July 2015

A programme at San Francisco General Hospital that offers antiretroviral therapy (ART) on the same day as HIV diagnosis led to a high rate of treatment uptake and more rapid viral load suppression compared to standard practices, according to late-breaking study findings presented on Wednesday at the <u>Eighth</u> International AIDS Society Conference (IAS 2015) in Vancouver, Canada.

Newly diagnosed people with HIV and clinic providers both expressed enthusiasm about the RAPID programme, which is now being implemented more widely as part of the city's 'Getting to Zero' initiative.

Studies have convincingly shown that early antiretroviral treatment improves the health and survival of individuals living with HIV and has the added public health benefit of reducing HIV transmission. But getting people into care can be challenging and some are lost at each stage of the HIV care cascade.

Christopher Pilcher of the University of California at San Francisco presented results from the UCSF/SFGH RAPID program, which aims to provide ART as soon as possible after people are diagnosed with HIV – focusing on the "very left side of the continuum of care".

In 2010, San Francisco was the first city to recommend universal ART for everyone diagnosed with HIV regardless of CD4 cell count. A similar recommendation was included in US treatment guidelines in 2013 and <u>will soon be incorporated into the World Health Organization's global guidelines</u>.

Compared with many other cities, San Francisco has a well-financed HIV care system with experienced and culturally competent providers. Yet even with these advantages, the process of getting tested, addressing other issues that may be barriers to treatment (such as substance use or unstable housing) and figuring out how to pay for medication can take a considerable amount of time – delays that could lead to disease progression and HIV transmission while viral load is high.

In the late 2000s, when treatment initiation was based on CD4 count, it took 128 days on average for people diagnosed in San Francisco to get a prescription for ART and 218 days to achieve viral suppression (<200 copies/ml), Pilcher noted as background. After the standard of care shifted to universal treatment in 2010, it took 37 days to get ART and 132 days to attain viral suppression.

The RAPID initiative was designed to speed up this process by collapsing some of the steps of the care continuum, Pilcher explained. Instead of HIV diagnosis, initial assessment and counselling, medical evaluation and ART prescription being done over the course of multiple visits, these steps were consolidated into a single visit.

This study looked at outcomes in a demonstration project assessing the feasibility of this rapid approach. The analysis included 227 people newly diagnosed with HIV. Of these, 39 participated in the RAPID programme between July 2013 and December 2014. They were compared to people in historical standard-of-care groups that received universal ART during 2010-2013 (n = 149) or CD4-guided treatment during 2006-2009 (n = 39).

RAPID was initially designed to offer prompt treatment for people with acute HIV (infected within the past six months), as studies have shown that very early ART can limit the size of the viral reservoir. It was later expanded to include people who are newly diagnosed with HIV but have been infected longer, and who have an indication for urgent treatment such as an opportunistic illness or CD4 count below 200 cells/mm³. In this analysis, 70% of RAPID participants had acute infection.

Overall, Pilcher described the RAPID clients as a "high needs" population at risk of falling through the cracks of the healthcare system. All were men, 59% were people of colour, more than a quarter were homeless and none initially had health insurance. The average CD4 count was 474 cells/mm³ and the mean viral load was high at 4.9 log₁₀ copies/ml. This analysis included people who came in as outpatients, excluding those who started as inpatients or transferred from jail or another clinic.

People are typically referred to the RAPID programme by one of the city's public HIV test sites, which routinely do HIV RNA testing. People are generally referred to the programme the same day they receive their HIV diagnosis, though in some cases this occurs days to weeks after they actually take the test.

All newly diagnosed people receive multidisciplinary services including social support, HIV education and mental health counselling, as well as having samples collected for laboratory tests. The RAPID programme tries to minimise barriers that could discourage engagement, such as requiring people to be abstinent or undergo substance use or mental health treatment before starting ART.

RAPID participants receive same-day appointments and access to an on-call provider, along with taxi vouchers if needed to get to the clinic. They are given a five-day starter pack of antiretroviral medication and encouraged to take the first dose on the spot under the observation of their provider.

Most patients wanted same-day treatment; 90% opted to start ART on the day of the first visit, with another 5% starting the next day. On average, it took about one day from test result disclosure to taking the first pill. In contrast, in the historical standard-of-care groups only about a quarter started therapy within the first week and about 60% did so within the first month after the initial visit.

Treatment is usually offered after a brief medical evaluation but before lab test results including drug-resistance data are available. Providers choose from a list of pre-approved regimens based on local patterns of transmitted drug resistance. The prevalence of transmitted resistance is substantial in this population, with more than 20% having major NNRTI resistance mutations. Most people (90%) started treatment using an integrase inhibitor.

Meanwhile, programme counsellors helped participants establish ongoing insurance coverage. Most RAPID participants qualified for publicly funded coverage such as Medicaid or the city's Healthy San Francisco programme, but some were eligible for private insurance.

Participants in the RAPID programme achieved viral suppression in a median of 56 days, compared with 119 days for those in the universal ART standard-of-care group and 283 days in CD4-guided treatment group. After three months on ART, 75% of RAPID participants achieved viral suppression, compared with 38% in the two standard-of-care groups. After six months, the corresponding response rates were 95% vs 70%.

Among the first 39 participants who received treatment through the RAPID programme and were followed for up to 18 months, only two (5%) changed their ART regimen due to toxicity and none discontinued therapy. Pilcher said it is difficult to evaluate long-term engagement in a study of this length, but it appears favourable so far, with 35 participants (90%) remaining engaged in care.

"It was feasible to implement same-day ART initiation for outpatients with newly diagnosed HIV in a well-resourced, public health clinic setting," the researchers concluded. "Same-day ART was highly acceptable to both patients and providers" and "was associated with improved rates of virologic suppression."

Pilcher said that participants overall had "extremely positive" reactions to the programme. He added that he had expected some resistance or push-back from providers who were reluctant to start treatment so early, but this did not occur – in fact, the programme was met with "extreme enthusiasm."

The RAPID programme has become of one of the three prongs of the city's 'Getting to Zero' effort, which also includes expanded pre-exposure prophylaxis (PrEP) and efforts to retain people with HIV in care. Diane Havlir, chief of the division of HIV/AIDS at SFGH, said the initiative aims to expand same-day treatment to all public and private providers citywide.

"Test-and-treat really means collapsing the care cascade," said Nancy Padian of the University of California at Berkeley, commenting on this and similar approaches at the conference's closing session. "When they're in your clutches, you put them on treatment."

Reference

Pilcher C et al. *Providing same day, observed ART to newly diagnosed HIV+ outpatients is associated with improved virologic suppression.* Eighth International AIDS Society Conference on HIV Pathogenesis, Treatment, and Prevention (IAS 2015), Vancouver, abstract WEAD0105LB, 2015.

You can download the slides of this presentation from the conference website.

A webcast of this presentation is available on the conference YouTube channel.

Where available, you can view details of sessions, view abstracts, download presentation slides and find webcasts using the conference <u>'Programme at a Glance' tool</u>.

You can also <u>download a PDF of the abstract book</u> from the conference website.

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The Information Standard Certified Member

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.

NAM's information is intended to support, rather than replace, consultation with a healthcare professional. Talk to your doctor or another member of your healthcare team for advice tailored to your situation.

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500 Lovett Blvd. Suite 100 Houston Texas 77006 April 6, 2017

To: Houston Ryan White Planning Council Houston Ryan White Grant Administration

Houston EMA/HSDA HIV Care Providers

Subject: AA recommendation per DSHS for Clinical-Based ADAP Enrollment Service Linkage Worker

Greetings,

This is the official notice from The Resource Group, Inc. (TRG), Ryan White Part B and State Services Grant Administration Agency, to recommend use of the additional DSHS State Services funding. DSHS is distributing its rebate funds to its AAs to expend under the label "State Services-Rebate(SS-R)". Each AA has the flexibility of distribution of the funding to ensure the continuous services and/or to fill any gaps in services. TRG is recommending use of these funds to support the ADAP/RW Eligibility Enrollment Network (RWAN) by co-locating a Clinical-Based ADAP Enrollment Service Linkage position at each Part A funded clinical site. TRG would like to recommend that \$375,000 be allocated to implement Clinical-Based ADAP Enrollment Service Linkage Workers for Ryan White primary care funded agencies in Houston EMA/HSDA.

Currently, the Ryan White Regional ADAP Liaison, Marcus Benoit, has created the RWAN through signed MOU's with all Ryan White Care sites and supportive service agencies in the 6 HSDAs including Houston throughout East Texas. Over the past 6 months TRG has collected data through informal ADAP site visits to assess the need for ADAP Enrollment Service Linkage workers at Ryan White Care sites in Houston EMA/HSDA. Results indicated that having a designated position to focus on ADAP applications would be beneficial to the clients, providers and the Texas HIV Medication Program. Through DSHS funding, this same process has been implemented in Texarkana HSDA, Tyler HSDA, Lufkin HSDA, Beaumont HSDA and Galveston HSDA where each DSHS funded clinic has hired an ADAP Enrollment Linkage position. This has resulted in much success and improvements in submitting completed THMP applications with accurate supportive documentation.

Please take this recommendation into consideration for the Houston HSDA, as many of the applications submitted to the Texas HIV Medication Program office comes from the Houston area.

Kind regards,

Yvette Garvin, Executive Director

713 526-1016 FAX 713 526-2369 www.hivtrg.org

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FY 2017 Houston EMA/HSDA State Services-R Service Definition					
AIDS Drug Assistance Program Enrollment Worker at RW Care Sites					
	(Created Date: 4/5/2017)				
DSHS Service Category Title: TRG Only	Referral For Health Care/Support Services				
Local Service Category Title:	A. Clinic-Based ADAP Enrollment Service Linkage Worker				
Budget Type: TRG Only	Categorical: 1 FTE per RW Care Site; unless advised otherwise				
Budget Requirements or Restrictions: TRG Only	Maximum of 10% of budget for Administrative Costs. A Full-Time Equivalent must be proposed at each clinic.				
DSHS Service Category Definition: TRG Only	ADAP Enrollment Worker Direct a client 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:	 C. PROPOSED: AIDS Drug Assistance Program (ADAP) Enrollment Service Linkage Workers (SLWs) are collocated at Ryan-White Part A funded clinics to ensure the efficient and accurate submission of ADAP applications to the Texas HIV Medication Program (THMP). ADAP enrollment SLWs will meet with all potential new ADAP enrollees, explain ADAP program benefits and requirements, and assist clients with the submission of complete, accurate APAP applications. ADAP enrollment SLWs will ensure annual re-certifications are submitted by the last day of the clients birth month and semi-annual Attestations are completed six months later to ensure there is no the lapse in ADAP eligibility and loss of benefits. Other responsibilities will include: Track the status of all pending applications and promptly follow-up with applicants regarding missing documentation or other needed information to ensure completed applications are submitted as quickly as feasible; 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; ADAP Enrollment workers will maintain relationships through the Ryan White ADAP Network (RWAN). 				
Target Population (age, gender, geographic, race, ethnicity, etc.):	HIV/AIDS infected individuals residing within the Houston HIV Service Delivery Area (HSDA).				
Services to be Provided:	 Meet with all potential new ADAP enrollees; explain ADAP program benefits and requirements; and assist clients with the submission of complete, accurate APAP applications, including but not limited to: Identifying and screening clients including screening for third party payer and potential abuse; completing the comprehensive THMP intake including determination of client eligibility for the ADAP program in accordance with the THMP eligibility policies including Modified Adjusted Gross Income (MAGI). Obtain, maintain, and submit the required documentation for client application including residency, income, and the THMP Medical 				

	Certification Form (MCF).
	 Certification Form (MCF). Conduct the 6-month attestations for all enrolled clients in accordance with THMP policies. Obtain, maintain, and submit to THMP any updated eligibility documentation. Conduct annual recertifications for all enrolled clients in accordance with THMP policies. Obtain, maintain, and submit to THMP any updated eligibility documentation. Proactively contact current ADAP enrollees 60-90 days prior to the enrollee's re-certification or attestation deadline to ensure all necessary documentation is gathered to complete the recertification/attestation on or before the deadline. Ensure annual re-certifications are submitted by the last day of the clients birth month and semi-annual Attestations are completed six months later to ensure there is no the lapse in ADAP eligibility and loss of benefits
	Provide initial education to applicants about the THMP including, but not limited to:
	• Discuss the confidentiality of the 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 client. Applicants should realize that their physician and pharmacist would also be aware of their diagnosis.
	• Discuss how applicants who have been approved by the THMP for assistance may be required to pay 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.
	• Discuss how applicants who are eligible for Medicaid assistance benefits must first utilize and exhaust their monthly Medicaid pharmacy benefits in order to be eligible to receive medications from the Program. Medicaid eligible applicants shall be assigned to the nearest available participating THMP pharmacy outlet to receive medication. The pharmacy will not charge the \$5.00 co-payment to the nearest
	 patient. Discuss the use of participating pharmacies and the procedure for how applicants will receive medications through the program.
	Submit completed applications via the most efficient method available (e.g. the Public Health Information Network or PHIN), including ARIES, once the document upload capability is rolled out.
	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.
	Participate in ongoing training and technical assistance provide by DSHS, THMP, or the RWAN.
Service Unit Definition(s): TRG Only	One unit of service is defined as 15 minutes of direct client services and allowable charges.

Financial Eligibility:	Adjusted gross income less than 200% of the Federal Poverty Level* (adjusted annually).
	* A spend-down calculation is applied to applicants' gross incomes to determine an adjusted gross income for eligibility screening.
	DSHS THMP Eligibility requirements https://www.dshs.texas.gov/hivstd/meds/
Client Eligibility:	Proof of Texas residency; Proof of being HIV-positive; Uninsured or underinsured for prescription drugs; and under the care of a Texas-licensed physician who prescribes the medication(s).
	DSHS THMP Eligibility requirements https://www.dshs.texas.gov/hivstd/meds/
Agency Requirements:	Agency will ensure documentation meets TDSHS and Agency requirements all activities performed on behalf of ADAP enrollees including re-certifications and attestations
	Agency will track the status of all pending applications and promptly follow-up with applicants regarding missing documentation or other needed information to ensure completed applications are submitted as quickly as feasible.
	Agency will ensure that completed applications undergo secondary review by a peer ADAP Enrollment Worker or Supervisor before submission. This peer or supervisor must meet all requirements of the ADAP enrollment service linkage worker, including required training.
	Agency will provide aggregated data regarding ADAP enrollment service linkage worker performance measures to TRG as directed.
Staff Requirements:	Education: To be defined locally, but must have at minimum a high school degree or equivalency;
	Experience:
	• Must have documented experience (paid, internship and/or as a volunteer) working with Persons Living with HIV/AIDS or other chronic health conditions.
	• Experience in performing intake/eligibility, referral/linkage and/or basic assessments of client needs preferred.
	Skills:
	• Must demonstrate proficiency in the use of PC-based word processing and data entry to ensure ADAP applications and re-certifications are
	 completed accurately in a timely manner; Must demonstrate the ability to quickly establish rapport with clients in a respectful manner consistent with the health literacy, preferred language, and culture of prospective and current ADAP enrollees;
	• Must demonstrate general knowledge of, or the ability to learn, health care insurance literacy (third party insurance and Affordable Care Act (ACA) Marketplace plans);
	Bilingual (English/Spanish) preferred;

	 AEWs working in care systems with a high prevalence of non- English speaking clients must be fluent in the preferred language of the high prevalence non-English speaking clients; Training:
	 Must complete all THMP ADAP training modules within 30 days of hire; Must complete all training required of Agency new hires, including any training required by TDSHS HIV Care Services Branch Standards of Care, within established timeframes; Must complete all annual or periodic training or re-certifications within established timeframes;
Special Requirements: TRG Only	There will be 1 FTE; unless advised otherwise, placed at each funded Part A primary care clinic.
	Meet the established guidance by DSHS for the ADAP Enrollment Worker. Follow the HHSC Uniform Terms and Conditions.
	THMP regards all information in the application as confidential. No information that could identify a client (including 11-character codes) will be released, except as allowed by law or as specifically designated by the client. THMP regards the information in the application as part of the applicant's medical record. Funded agencies should have physical security and administrative controls to safeguard the confidentiality of the applications and other means of identifying the individual.
	Applications can be expedited for pregnant women, post- incarcerated persons, minors, those with CD4 counts under 100, and other special circumstances. Eligibility and access to medications for newborn infants and pregnant women is considered a program priority.
	 Required Performance Measures Enroll all ADAP-eligible clients in Texas HIV Medication Program (THMP) within 30 days of initiation of care. Recertify all existing clients in THMP without lapse in coverage. Maintain 95-100% approval rate for initial application submissions Maintain 100% Ryan White Eligibility for all Ryan White clients at the contracted agency. Ensure that up-to-date eligibility information (in compliance with established guidance) is maintained for all clients served. Maintain relationships through the Ryan White ADAP/Eligibility Network (RWAN) to ensure all clients on ADAP in the HSDA are submitting accurate application Utilize CPCDMS and Texas PHIN databases.

<i>FY 2018 RWPC</i>	"How to	Best Meet	the Need'	'Decision	Process
0 _ 0 0					

Step in Process: Co	Date: 06/08/17		
Recommendations:	endations: Approved: Y No: If approve Approved With Changes: below:		
1.			
2.			
3.			
Step in Process: Ste	eering Committee		Date: 06/01/17
Recommendations:	Approved: Y No: Approved With Changes:	If approved below:	with changes list changes
1.			
2.			
3.			
Step in Process: Qu	uality Assurance Committee		Date: 05/18/17
Recommendations:	Approved: Y No: Approved With Changes:	If approved below:	with changes list changes
1.		<u> </u>	
2.			
3.			
Step in Process: H	TBMTN Workgroup		Date: 04/17/17
Recommendations:	Financial Eligibility:		
1.			
2.			
3.			

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DRAFT

2016 Proposed Idea

(Applicant must complete this two-page form as it is. Agency identifying information must be removed or the application will not be reviewed. Please read the attached documents before completing this form: 1.) HRSA HIV-Related Glossary of Service Categories to understand federal restrictions regarding each service category, 2.) Criteria for Reviewing New Ideas, and 3.) Criteria & Principles to Guide Decision Making.)

THIS BOX TO BE COMPLETED BY	RWPC SUPPORT STAFF ONLY
# 2 Control Number	Date Received_ <u>02/13/17</u>
Proposal will be reviewed by the:	Quality Assurance Committee on: $\frac{D2}{16}/17}$ (date) Priority & Allocation Committee on: $\frac{D2}{23}/17}$ (date)

THIS PAGE IS FOR THE QUALITY ASSURANCE COMMITTEE (See Glossary of HIV-Related Service Categories & Criteria for Reviewing New Ideas)

SERVICE CATEGORY: Transportation (Medical Transportation) 1.

(The service category must be one of the Ryan White Part A or B service categories as described in the HRSA Glossary of HIV-Related Service Categories.)

unknown will need staff assist

This will provide clients with units of service.

2. ADDRESS THE FOLLOWING:

- A. DESCRIPTION OF SERVICE: Cab Vouchers to access transportation for PLWHA with safety issues such as Trans-gender, Homeless, people experiencing domestic violence and others, as determined by case manager or Dr.
- B. TARGET POPULATION (Race or ethnic group and/or geographic area): See above.
- C. SERVICES TO BE PROVIDED (including goals and objectives): To eliminate barriers to accessing HIV core Medical Service providers in the EMA/HSDA. This services can only be used to travel to/from HIV medical services.
- D. ANTICIPATED HEALTH OUTCOMES (Related to Knowledge, Attitudes, Practices, Health Data, Quality of Life, and Cost Effectiveness):Lack of transportation is the 5th most commonly-cited barrier among PLWHA Rank #2 w/in the 5 support services, most commonly-cited was lack of transportation (trans. study 2013) Transportation eliminates barriers to care, thereby supporting PLWHA in continuous care Transportation supports linkage to care, Maintenance/retention in care, and viral suppression.
- 3. ATTACH DOCUMENTATION IN ORDER TO JUSTIFY THE NEED FOR THIS NEW IDEA. AND, DEMONSTRATE THE NEED IN AT LEAST ONE OF THE FOLLOWING PLANNING COUNCIL DOCUMENTS: Paragraph: 1/Tab1 Current Needs Assessment (Year: 2016 Page(s): Х
- Current HIV Comprehensive Plan (Year: 2017) х
- Page(s): 81 Paragraph: 1/Tab2 Health Outcome Results: Date: FY 2017 Serv. Cat. Info. Page(s): 1 Paragraph: * X
- Other Ryan White Planning Document: Х
 - Name & Date of Document: Transgender Study 2013 Page(s): ⁶ Paragraph: 1&2/tab³

RECOMMENDATION OF QUALITY ASSURANCE COMMITTEE: Not Recommended Sent to How To Best Meet Need Recommended

REASON FOR RECOMMENDATION:

(Continue on Page 2 of this application form)

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DRAFT

Proposed Idea

THIS PAGE IS FOR THE PRIORITY AND ALLOCATIONS COMMITTEE

(See Criteria and Principles to Guide Decision Making)

THIS BOX TO BE COMPLETED BY RWPC SUPPORT STAFF ONLY AND INCLUDE A BRIEF HISTORY OF RELATED SERVICE CATEGORY, IF AVAILABLE.

CURRENTLY APPROVED RELATED SERVICE CATEGORY ALLOCATION/UTILIZATION: Allocation: \$527,362 Expenditure: \$183,376 Year-to-Date as of 10/27/16

Utilization: 3,374 Unduplicated Clients Served Year-to-Date as of 06/08/16 N/A Units of Service Provided Year-to-Date

AMOUNT OF FUNDING REQUESTED:

<u>\$</u> Unsure ______ This will provide funding for the following purposes which will further the objectives in this service category: (describe how):

PLEASE STATE HOW THIS IDEA WILL MEET THE PRIORITY AND ALLOCATIONS CRITERIA AND PRINCIPLES TO GUIDE DECISION MAKING. SITE SPECIFIC STEPS AND ITEMS WITHIN THE STEPS: Principles: A,C,D,

Criteria STEP 1: A,F Criteria Step 2: D,E,F

RECOMMENDATION OF PRIORITY AND ALLOCATIONS COMMITTEE:

__ Recommended for Funding in the Amount of: \$_____ __ Not Recommended for Funding

____ Other:

REASON FOR RECOMMENDATION:

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2016 Houston HIV Care Services Needs Assessment

A collaboration of:

Houston Area HIV Services Ryan White Planning Council Houston HIV Prevention Community Planning Group Harris County Public Health, Ryan White Grant Administration Houston Health Department, Bureau of HIV/STD and Viral Hepatitis Prevention Houston Regional HIV/AIDS Resource Group, Inc. Harris Health System

People Living with HIV in the Houston Area and Ryan White HIV/AIDS Program Consumers

Approved: December 8, 2016

Chapter 2: Service Needs and Barriers

• •

Descriptions of Barriers Encountered

All funded services were reported to have barriers, with an average of 33 reports of barriers per service. Participants reported the least barriers for Hospice (two barriers) and the most barriers for Oral Health Care (86 barriers). In total, 525 reports of barriers across all services were indicated in the sample.

(Table 1) Within education and awareness, knowledge of the availability of the service and where to go to access the service accounted for 82% barriers reported. Being put on a waitlist accounted for a majority (66%) of wait-related issues barriers. Poor communication and/or follow up from staff members when contacting participants comprised a majority (51%) of barriers related to staff interactions. Almost all (86%) of eligibility barriers related to participants being told they did not meet eligibly requirements to receive the service or difficulty obtaining the required documentation to establish eligibility. Among administrative issues, long or complex processes required to obtain services sufficient to create a burden to access comprised most (59%) the barriers reported.

Most (84%) of health insurance-related barriers occurred because the participant was uninsured or underinsured and experiencing coverage gaps for needed services or medications. The largest proportion (81%) of transportation-related barriers occurred when participants had no access to transportation. It is notable that multiple participants reported losing bus cards and the difficulty of replacing the cards presented a barrier to accessing other services. Inability to afford the service accounted for all barriers relating to participant financial resources. The service being offered at a distance that was inaccessible to participants or being recently released from incarceration accounted for most (77%) of accessibility-related barriers, though it is worth note that low or no literacy accounted for 14% of accessibility-related barriers. Receiving resources that were insufficient to meet participant needs accounted for most resource availability barriers. Homelessness accounted for virtually all housing-related barriers. Instances in which the participant's employer did not provide sufficient leave for sick/wellness attend appointments comprised most (60%) employment-related barriers.

Education & Awareness	%	Wait-Related Issues	%	Interactions with Staff	%
Availability (Didn't know the service was available)	50%	Waitlist (Put on a waitlist) 66% Communication (Poor correspondence/ Follow up from staff)		51%	
Definition (Didn't know what service entails)	7%	Unavailable (Waitlist full/not available resulting in client not being placed on waitlist)	15%	Poor Treatment (Staff insensitive to clients)	17%
Location (Didn't know where to go [location or location w/in agency])	32%	Wait at Appointment (Appointment visits take long)Resistance (Staff refusal/ resistance to clients)		(Staff refusal/ resistance to assist	13%
Contact (Didn't know who to contact for service)	11%	Approval (Long durations between application and approval)			7%
				Referrat (Received service referral to provider that did not meet client needs)	17%
Eligibility	%	Administrative Issues	%	Health Insurance	%
Ineligible (Did not meet eligibility requirements)	48%	Staff Changes (Change in staff w/o notice)	12%	Uninsured (Client has no insurance)	
Eligibility Process (Redundant process for renewing eligibility)	16%	Understaffing (Shortage of staff)	2%	Coverage Gaps (Certain services/medications not covered)	319
ocumentation	38%	Service Change (Change in service w/o notice)	10%	Locating Provider (Difficulty locating provider that takes insurance)	139
		Complex Process (Burden of long complex process for accessing services) Dismissal	59%	ACA (Problems with ACA enrollment process)	179
		(Client dismissal from agency) Hours (Problem with agency hours of	4% 16%		
Transportation		operation) Financial	%	Accessibility	%
No Transportation (No or limited transportation options)	81%	Financial Resources (Could not afford service)	100%	Literacy (Cannot read/difficulty reading)	149
Providers (Problems with special transportation providers such as Metrolift or Medicaid transportation)	19%			Spanish Services (Services not made available in Spanish)	99
				Released from Incarceration (Restricted from services due to probation, parole, or felon status) Distance	329
				(Service not offered within	459
Resource Availability	%	Housing	%	accessible distance) Employment	%
Insufficient (Resources offered insufficient for meeting need)	56%	Homeless (Client is without stable housing)	100%	Unemployed (Client is unemployed)	40
Quality (Resource quality was poor)	44%	IPV (Interpersonal domestic issues make housing situation unsafe)	0%	Leave (Employer does not provide sick/wellness leave for appointments)	60'

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Houston Area Comprehensive HIV Prevention and Care Services Plan 2017 - 2021 Capturing the community's vision for an ideal system of

Capturing the community's vision for an ideal system of HIV prevention and care for the Houston Area

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monthly household income of at least \$6,000 or greater (n=349, 43.8%), and even more participants reported living in a house or apartment paid for by self (n=635, 79.7%).

Transportation has consistently been a known limitation to fluid mobility within the Houston Area given its significant geographic spread and limited public transportation system, often creating a barrier to accessing HIV care because of the difficulties in navigating this distance. For the sample population, the majority reported owning a vehicle (n=487, 61.1%) while 236 respondents reported relying on public transportation (29.6%). However, 12 participants in the sample reported having no transportation available to them (1.5%) (**Table 2**).

Description	No. (%)	Description	No. (%)
Birth sex		Employment status	
Male	498 (62.5%)	Full-time employment	302 (37.9%)
Female	245 (30.7%)	Part-time employment	192 (24.1%)
Intersex	13 (1.6%)	Temporary, contractual, or other work	162 (20.3%)
No response	41 (5.1%)	Student	26 (3.3%)
Race/Ethnicity		Retired	18 (2.3%)
Black or African American	396 (49.7%)	Disabled	48 (6.0%)
Hispanic	267 (33.5%)	Unemployed	16 (2.0%)
White	57 (7.2%)	No response	33 (4.1%)
Other/Multiracial	77 (9.7%)	Household monthly income	
Age Group		< \$1000	34 (4.3%)
<18	8 (1.0%)	\$1000-\$1999	15 (1.9%)
18-24	188 (23.6%)	\$2000-\$2999	72 (9.0%)
25-34	175 (22.0%)	\$3000-\$3999	89 (11.2%)
35-44	240 (30.1%)	\$4000-\$4999	45 (5.6%)
45-54	110 (13.8%)	\$5000-\$5999	135 (16.9%)
55+	76 (9.5%)	\$6000+	349 (43.8%)
Education		No response	58 (7.3%)
Post-secondary degree	437 (54.8%)	Housing status	
Technical/vocational degree	44 (5.5%)	House/apartment paid by self	635 (79.7%)
High school diploma	188 (23.6%)	House/apartment paid by other	87 (10.9%)
GED	63 (7.9%)	Subsidized housing	38 (4.8%)
Less than high school	59 (7.4%)	Stay with others	12 (1.5%)
No response	6 (0.8%)	No response	25 (3.1%)
Health Insurance		Transportation	•
Private insurance	199 (25.0%)	Own vehicle	487 (61.1%)
Medicaid/Medicare	112 (14.1%)	Public transportation	236 (29.6%)
Harris Health System	60 (7.5%)	No transportation	12 (1.5%)
COBRA	67 (8.4%)	No response	62 (7.8%)
VA	11 (1.4%)		
Ryan White only	38 (4.8%)		
Self-pay	178 (22.3%)		
No response	340 (42.7%)		

Source: 2016 Houston HIV Prevention Services Needs Assessment

Of the total sample population, 493 identified as a man in their current gender identity or expression, with about 253 reporting woman and 5 reporting part-time as man and part-time as woman. Forty-six participants provided no response, total, for current gender identities or expression. About 473 participants reported a birth sex of male and a current gender identity of man (59.3%). Of those with a current gender identity or expression of man, 350 persons reported a sexual orientation of gay (43.9%), with the next highest percentage identifying as straight/heterosexual (n=121, 15.2%) followed by bisexual (n=20, 2.5%) and pansexual (n=1,

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Same Charles Margins Palling Say million Tiplice NA-65 ASSESSING SAF Part A: Van Based: This service aligns with the following goals: Needs Assessment Rankings:a 2.700 National HIV/AIDS Strategy (NHAS) Updated for FY98: \$488.405 Following van based Transportation was defined as "Transportation to/from 2.450 2020 (2015) FY99: \$580.909 transportation services: your HIV medical appointments on a van or with a FY00: \$838,460 Increase the percentage of persons with 2.200 69% of clients accessed HIV Metro bus card" in the 2014 Needs Assessment. diagnosed HIV infection who are retained in FY01: \$912.947 primary care at least once: Results as defined are below: served 1.950 HIV medical care to at least 90%. FY02: \$1,015,666 72% accessed LPAP at least 50% 44% Increase the percentage of persons with 1.700 FY03: \$945.743 once: and 35% 40% # of clients diagnosed HIV infection who are virally FY04: \$598,816 74% accessed oral health 1.450 30% suppressed to at least 80%. FY05: \$570,000 services at least once. 20% The Continuum of Care 11% 11% Transportation 1.200 FY06: \$570,000 · Increase the percentage of those aware of 10% (Untargeted & olal Bus Pass: FY07: \$512.000 950 their H/V+ status retained in HIV care 0% Rural) Following bus pass transportation FY08: \$654,539 Increase the percentage of those aware of Did not Did not Needed Needed 700 (Van & Bus services: their HIV+ status with a suppressed viral load know need the the Pass) 450 77% of clients accessed a RW Part A/B: about service service. servicè. The Texas HIV Plan Update for 2014-2015 service of some kind at least difficult to FY09: \$654,539 service easy to (2013) 200 CY10 CY13 CY11 CY12 CY14 CY15 access access Ensure continuous participation in systems FY10: \$595.366 once: 598 394 322 478 611 754 - 36% accessed HIV primary -----Van Based of care and treatment 89%-Bus Increase viral suppression 2.628 2.592 2.342 care at least once; Part A: Bus Pass 1.725 2.406 2.263 11%-Van 20% accessed LPAP at least Comprehensive HIV Plan (2012-2014): FY11: \$625.366 Increase the percent of RW clients in FY12: \$543,459 once: and 55% of respondents reported a need for <u>Source:</u> RWGA and The Resource Group, 4/25/16 continuous HIV care to 80% 25% accessed oral health Transportation services, tying this service with FY13: \$543,459 Reduce the proportion of diagnosed services at least once. Housing as the 5th highest ranked need. FY14: \$527,361 individuals who are not in HIV care by 0.8% The most common barrier reported for FY15: \$527.362 each vear Transportation Services was lack of transportation Source: RWGA FY 2013 Final Year Outcomes Reports FY16: \$527,362 Increase the proportion of RW clients with (18% of all reported barriers to this service).* UVL by 10% Males, African American PLWHA, and PLWHA age. Source: PROPOSED FY 2016 45+ reported the least difficulty accessing Recommendations from the SIRR Study: Allocations - Level Funding Transportation services Distribute bus passes through EIS at Scenario Based upon FY15 Actual Awards - as of discharge for use as transportation to a Homeless PLWHA, out-of-care, and recently ¥ 06/24/15 community-based HIV care provider. released had the most difficulty accessing × Recommendations from the Transgender Transportation services. Special Study: *Anecdotally, the initial transportation gap in accessing Transportation Lack of transportation was cited most often services, and the angoing gap of refilling bus cards was noticed during data collection for the 2011 and 2014 Needs Assessments, and the I/RR and ⊁ (44%) by transgender consumers as a barrier Transgender special studies. However, this particular issue has not been to HIV care, it is recommended that the formally measured. workgroup explore ways to reduce Source: 2014 Houston Area HIV/AiDS Needs Assessment, Located al: transportation barriers for this Special Population. http://www.rwpchouston.org/Publications/2014%20Needs%20Assessment %20-%20FINAL%203-13-14.pdf

FY2017 Service Category Information Summary - Part A, MAI, Part B, SS

J:ICommittees/Quality improvement/FY17 How To Best/Service Category Summaries/CHART - All FY 2017 Service Category Info Summaries - FINAL- 04-25-16.docx

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Last Updated: 2/13/17

Access to HIV Care among Transgender and Gender Non-Conforming People in Houston

A Special Study of the Houston Area Ryan White Planning Council Approved March 14, 2013

BACKGROUND

The <u>Houston Area Ryan White Planning Council</u> is responsible for designing HIV care, treatment, and support services for people living with HIV/AIDS in the Houston Eligible Metropolitan Area (<u>EMA</u>). The Planning Council uses several sources of information in order to meet this mandate, including epidemiological profiles, service-utilization reports, and a community-wide <u>needs assessment</u> of HIV-positive individuals conducted every three years. When specific populations are underrepresented in current data sources, the Planning Council may also commission a special data collection effort, or *Special Study*, to fill data gaps.

In 2012, the Planning Council released its <u>comprehensive HIV prevention and care services</u> <u>plan</u> for the Houston Area. In it are the specific HIV-infected populations in the Houston EMA with insufficient data for assessing their current level of access to HIV services. In response, the Planning Council commissioned a series of Special Studies to gather data on each underrepresented group. This article presents the results of the Planning Council's first Special Study in the series, focused on transgender and gender non-conforming people living with HIV/AIDS in the Houston EMA.

INTRODUCTION

Transgender individuals are among the highest risk for HIV infection in the U.S. today.¹ Moreover, the challenges often faced by transgender individuals in regards to discrimination, stigma, lack of resources, and other social determinants can make it difficult for them to access HIV services.¹ One study of transgender people living with HIV/AIDS showed a statistically lower rate of HIV treatment when compared to nontransgender people.² For these reasons and others, transgender communities are a high priority for HIV prevention, linkage, and retention in care efforts both nationally and in the Houston EMA.³

However, relatively little is known about the specific needs, gaps, and barriers to HIV care among transgender people in the Houston EMA. Transgender individuals are less than 1% of all Ryan White HIV/AIDS Program clients in the EMA,⁴ and only 22 transgender-identified individuals participated in the EMA's most recent community-wide needs assessment of people living with HIV/AIDS.⁵ This Special Study sought to describe the HIV service utilization patterns of transgender people living with HIV/AIDS in the Houston EMA, including socio-economic or behavioral factors that may be influencing their use of services, and to establish baselines for core HIV prevention and care indicators, including linkage to care and unmet need.

METHODS

Participants were self-selected, self-identified transgender HIV-positive adult residents of the Houston EMA. Because many individuals may not identify with the term "transgender," inclusion screening questions used the broader terminology of "transgender or gender non-conforming" and offered both a definition of the term and examples along a broad continuum of gender expression. The text for the transgender inclusion screening question for the study was:⁶

"Do you consider yourself to be transgender or gender non-conforming in any way? Transgender/gender non-conforming refers to people whose gender identity or expression is different, at least part of the time, from the sex assigned to them at birth

RESULTS

HIV Testing, Diagnosis, and Linkage to Care

The first topic we wanted to address through this study was what motivates transgender people in the Houston EMA to test for HIV and where they test. In our sample, the most commonly-cited reason for testing was feeling sick (25%), followed by receiving an HIV test as part of a routine health check-up (21%). Three percent (3%) of the time the reason for testing was the recommendation of a medical provider, and another 3% was in response to community advertising, The most common location for HIV testing was a dedicated HIV clinic (34%), followed by an ER or hospital (17%). Thirteen percent (13%) said they were tested at a health department, and 9% were tested in jail or prison.

Because treatment for HIV can extend life expectancy and quality of life for those infected, length of time for linkage to care post-diagnosis and current care status are used as indicators of community health related to HIV both nationally and locally.^{3,9} At the time of this study, baselines were missing for both of these measures for the transgender population in the Houston EMA. Therefore, the next topics we sought to address in the study were linkage to care and patterns of care. We asked respondents when they first saw a doctor for HIV following their diagnosis (either within three months or more than three months, per the federal benchmark⁹) and if they were currently meeting the national definition of being in care, which is defined as completing at least one of the following in the last 12 months: (1) seen a doctor for HIV, (2) taken HIV medications, (3) had an HIV viral load test, or (4) had a CD4 count test.¹⁰

(See Table 2) The majority of the transgender people in this study was linked to care within three months of their HIV diagnosis (76%). This percentage is comparable to current estimates for the Houston EMA as a whole (77%), ¹¹ though lower than both local and national goals.^{3,9} For those in the sample who did report delayed care, the most commonly-cited reason was denial about being HIV-positive (80%). However, 16% of the time the reasons were lack of knowledge about where to go for HIV services,

fear about how the medical staff would react to their gender variance, and fear about how other clients would react. Twelve percent (12%) of the time the reason for delayed care was having to disclose their gender variant status to providers and staff.

The majority of the people in

TABLE 2-Linkage to Care among Participating Transgender People

 Who Are HIV Positive (n=133) Compared to the General HIV-Positive

 Population in the Houston Area and Local and National Goals

	General		
	Transgender	HIV+	Goal⁵
	Participants	Population ^a	
Linked to HIV Care within 3			
Months of Diagnosis	75.9%	77.4%	85.0%

this study was also currently in care (97%). This percentage far exceeds estimates for the general HIV-positive population in the Houston EMA (75%).¹² This is most likely a bias in our sample, rather than a true unmet need result, due to study recruitment taking place at HIV clinics and HIV group homes. Therefore, no additional analysis was performed on this data point.

HIV Care Service Utilization, Barriers to Care, and Service Needs

(See Table 3) Another topic we wanted to explore in this study was the use of specific HIV care, treatment, and support services by transgender people in the Houston EMA. To do this, we

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·	Reporting Use of Service		Reporting Barrier to Use
Service Category (in order)	# (%)	Service Category (in order)	# (%)
Primary HIV care	113 (85.6)	Oral health care	28 (21.2)
X Transportation	76 (57.6)	Primary HIV care	23 (17.4)
Case management	64 (48.5)	Case management	23 (17.4)
Oral health care	60 (45.5)	Transportation	18 (13.6) -
Mental health counseling	59 (44.7)	Medical nutritional therapy	15 (11.4)
Medical nutritional therapy	51 (38.6)	Mental health counseling	13 (9.8)
HIV medication assistance	46 (34.8)	Legal services	8 (6.1)
Substance abuse treatment	28 (21.2)	Health insurance assistance	7 (5.3)
Health insurance assistance	25 (18.9)	Hospice care	7 (5.3)
Legal services	21 (15.9)	HIV medication assistance	6 (4.5)
Day treatment	19 (14.4)	Day treatment	6 (4.5)
Language services	14 (10.6)	Substance abuse treatment	4 (3.0)
Hospice care	9 (6.8)	Language services	4 (3.0)

TABLE 3-HIV Care Services Used and Barriers Reported by Participating Transgender People Who Are HIV Positive (n=132) in the Houston Area

asked each respondent if, in the past 12 months, they had used each of the services that the Planning Council had prioritized for funding through the Ryan White HIV/AIDS Program and if they had experienced any difficulties accessing each of the services, regardless of recent use. Primary HIV care (86%), transportation (58%), and clinic-based case management (49%) were the most used services in past 12 months. The services cited most often as having difficulties to access were oral health care (21%), primary HIV care (17%), and clinic-based case management (17%). These findings are consistent with the general population of HIV-positive people in the Houston EMA.¹³

(See Table 4) Specific barriers faced by this population when seeking HIV services were also

explored. When asked what barriers, if any, respondents had faced at any time since their diagnosis, the most commonly-cited was lack of transportation (44%). Also high on the list was being treated poorly by staff due to gender variance (29%), lack of funds to pay for services (28%), and denial about being HIV-positive (24%). In addition, 19% of respondents reported lack of provider familiarity with transgender needs as a barrier to care. Twenty-two percent (22%) reported no barriers. When compared to

TABLE 4-Most Commonly-Cited Specific Barriers to HIV Care Reported by

 Participating Transgender People Who Are HIV Positive (n=105) Compared to the

 General HIV-Positive Population in the Houston Area

		Rank among	
	# (%)	General HIV+	
Specific Barrier Experienced (in order)	Reporting	Population ^a	-
No transportation	46 (43.8)	6	¥
Treated poorly by staff due to being transgender	30 (28.6)		1
No money, the services cost too much	29 (27.6)	11	
Fear or denial about being HIV-positive	25 (23.8)	14	
Wait times for services were too long	20 (19.0)	3	
Hard to get an appointment for HIV services	20 (19.0)	5	
Providers are not familiar with transgender needs	20 (19.0)		
A problem with drugs or alcohol	18 (17.1)		
Lack of housing	18 (17.1)		
Felt fine, not sick, "didn't think I needed HIV care"	16 (15.2)		
HIV care a low priority	16 (15.2)		
No Barriers Experienced	30 (22.2)		_

*2011 Houston Area HIV/AIDS Needs Assessment, April 2011 (n=924). Ranking is for core and support services combined; no distinction between type of service was made in our study.

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Priority and Allocations FY 2017 Guiding Principles and Decision Making Criteria

(Priority and Allocations Committee approved 02-25-16)

Priority setting and allocations must be based on clearly stated and consistently applied principles and criteria. These principles are the basic ideals for action and are based on Health Resources and Services Administration (HRSA) and Department of State Health Services (DSHS) directives. All committee decisions will be made with the understanding that the Ryan White Program is unable to completely meet all identified needs and following legislative mandate the Ryan White Program will be considered funding of last resort. Priorities are just one of many factors which help determine allocations. All Part A and Part B service categories are considered to be important in the care of people living with HIV/AIDS. Decisions will address at least one or more of the following principles and criteria.

Principles are the standards guiding the discussion of all service categories to be prioritized and to which resources are to be allocated. Documentation of these guiding principles in the form of printed materials such as needs assessments, focus group results, surveys, public reports, journals, legal documents, etc. will be used in highlighting and describing service categories (individual agencies are not to be considered). Therefore decisions will be based on service categories that address the following principles, in no particular order:

Principles

- A. Ensuring ongoing client access to a comprehensive system of core services as defined by HRSA
- B. Eliminating barriers to core services among affected sub-populations (racial, ethnic and behavioral) and low income, unserved, underserved and severe need populations (rural and urban)
- C. Meeting the needs of diverse populations as addressed by the epidemiology of HIV
- D. Identify individuals unaware of their status and link them to care and address the needs of those that are aware of their status and not in care.
- E. Expressing the needs of the communities with HIV for whom the services are intended

Allocations only

- F. Documented or demonstrated cost-effectiveness of services and minimization of duplication
- G. Availability of other government and non-governmental resources, including Medicaid, Medicare, CHIP, private insurance and Affordable Care Act related insurance options, local foundations and non-governmental social service agencies

Criteria are the standards on which the committee's decisions will be based. Positive decisions will only be made on service categories that satisfy at least one of the criteria in Step 1 and all criteria in Step 2. Satisfaction will be measured by printed information that address service categories such as needs assessments, focus group results, surveys, reports, public reports, journals, legal documents, etc.

(Continued)

DECISION MAKING CRITERIA STEP 1:

- A. Documented service need with consumer perspectives as a primary consideration
- B. Documented effectiveness of services with a high level of benefit to people and families living with HIV infection, including quality, cost, and outcome measures when applicable
- C. Documented response to the epidemiology of HIV/AIDS in the EMA and HSDA
- D. Documented response to emerging needs reflecting the changing local epidemiology of HIV/AIDS while maintaining services to those who have relied upon Ryan White funded services.
- E. When allocating unspent and carryover funds, services are of documented sustainability across fiscal years in order to avoid a disruption/discontinuation of services
- F. Documented consistency with the current Houston Area Comprehensive HIV Prevention and Care Services Plan and the Continuum of Care and their underlying principles to the extent allowable under the Ryan White Program: to build public support for HIV services; to inform people of their serostatus and, if they test positive, get them into care; to help people maintain their negative status; to help people with HIV improve their health status and quality of life and prevent the progression to AIDS; to help reduce the risk of transmission; and to help people with AIDS improve their health status and quality of life and, if necessary, support the conditions that will allow for death with dignity

DECISION MAKING CRITERIA STEP 2:

- A. Services are effective with a high level of benefit to people and families living with HIV, including cost and outcome measures when applicable
- B. Services are accessible to all populations infected, affected, or at risk, allowing for differences in need between urban, suburban, and rural consumers as applicable under Part A and B guidelines
- C. The Council will minimize duplication of both service provision and administration and services will be coordinated with other systems, including but not limited to HIV prevention, substance use, mental health, and Sexually Transmitted Infections (STIs).
- D. Services emphasize access to and use of primary medical and other essential HRSA defined core services
- E. Services are appropriate for different cultural and socioeconomic populations, as well as care needs
- F. Services are available to meet the needs of all people and families living with or at risk for HIV infection as applicable under Part A and B guidelines
- G. Services meet or exceed standards of care
- H. Services reflect latest medical advances, when appropriate
- I. Services meet a documented need that is not fully supported through other funding streams

PRIORITY SETTING AND ALLOCATIONS ARE SEPARATE DECISIONS. All decisions are expected to address needs of the overall community affected by the epidemic.

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Trans* Folks in Motion: Transgender and Gender Nonconforming Individuals' Experiences of Transit and Transit Spaces

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Trans* Folks in Motion: Transgender and Gender Nonconforming Individuals' Experiences of Transit and Transit Spaces

by

Jade Benner

An undergraduate honors thesis submitted in partial fulfillment of the

requirements for the degree of

Bachelor of Arts/Science

in

University Honors

and

Sociology

Thesis Adviser

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Portland State University

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INTRODUCTION

In recent decades, much of social science theorizing has seen an influence and shift, both substantively and methodologically, toward the spatial aspects of society. These attempts to reconcile space and society reconceptualize human life and social organization as not only temporal, as conventionally held, but also spatial (see Lefebvre 1991). This reconceptualization requires integration of the spatial into the social and vice versa. Within sociological theorizing, this has resulted in an emerging "mobilities" paradigm. Mobilities examines the sociologically patterned movement of people, ideas, and goods and encompasses the study of such diverse social phenomena such as economic migration, vacationing, telecommuting, and transportation. A focus within the field of mobilities is on the "experience, practice, and symbolism of [people's] daily movement," which Vannini calls *mobile culture*. This leads us to fuller examination of (social) spaces hitherto undertheorized such as the transit spaces of the present study. Far from being merely a means of moving from point A to point B, we examine transportation as a rich site of this mobile culture, worthy of study in its own right.

In this paper I use several terms relating to space. Consistent with the integration of the social and spatial, I use "space" to refer to a generic physical and social location, with all its physical and social contents and dynamics (see Neal 2010). Public space is simply a space that is in principle open to all members of society. For the transit spaces of the study, I am referring to the physical and social spaces of bus stops, light rail train and streetcar platforms, as well as inside buses, light rail trains, and streetcars. Based on how the study participants responded, much of the focus of this paper will be on the inside of buses and the social experiences people have there.

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As with mobilities, the field of transgender studies has greatly evolved in the last several decades. Though "transgender" saw its first academic blow up in the 1990s (Stryker & Whittle 2006), the 2014 founding of the first transgender journal, *Transgender Studies Quarterly*, and the 2016 announcement of the world's first Chair in Transgender Studies, seems to signal a new era in the field, with transgender perspectives and issues being examined from a multitude of angles, both academically and in terms of policy. Moreover, a recent explosion of media attention on transgender individuals like Laverne Cox and Caitlyn Jenner, as well as national debates sparked by controversial "bathroom bills" seeking to restrict transgender and LGBT access to public accommodations, have brought transgender civil rights to popular awareness.

While these more accessible media images of transgender individuals have been essential in moving popular conversations forward, they are far from representing all transgender and gender nonconforming people, particularly those of concern in the present study. In the pioneering Transgender Studies Reader (Stryker & Whittle 2006), Whittle's foreword to the compilation project proclaims that "a trans identity is now accessible almost anywhere, to anyone who does not feel comfortable in the gender role they were attributed at birth" (ibid: xi). Thus, Whittle and other transgender studies scholars are concerned with not only people like Cox and Jenner who are recognized by audiences as the gender they identify as (this is commonly called "passing"), but also with transgender men and women who are not always recognized for the gender they identify as (similarly, "not passing"), as well as individuals who do not identify with the gender binary at all and may or may not intentionally elude any sort of recognition. In other words, they might not be concerned with, or be trying to "pass" as a man or woman. These individuals may variously identify as transgender, non-binary (not identifying within the binary

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categories of man and woman), gender non-conforming (not adhering to traditional gender roles or presentation), or something else.

While the wide variation in usage and the multiple meanings of many transgender terms can quickly confound and overwhelm those new to the field, some useful distinctions have emerged. In this paper I will use the term trans*, written with an asterisk to denote inclusivity, as Stryker and Whittle do above without the asterisk¹. This umbrella usage seeks to include all the participants of our study and serves as the lens through which I attempt to understand their experiences. Other important terms include cissexism and heterosexism, which refer to systemic patterns of discrimination towards trans* folks and gay or lesbian folks, respectively. Heterosexism was often reported in participants' experiences, as other passengers and passersby might have read them as gay or lesbian rather than trans*. Transmisogyny is the particular discrimination, often more severe, that trans women and trans femme folks experience, as a matter of being perceived as both transgender and female/feminine.

It is essentially at the crux of these two interdisciplinary fields of study, sociological mobilities and transgender studies, that the present study was undertaken. In my paper I seek to answer two main questions: What are some of the general experiences of trans* individuals on public transit, and second, How do spatial characteristics of public transit, including the openness of bus stops and the tight confines of crowded buses, affect how trans* individuals experience transit?

First I present key findings from our study's interviews with 25 trans* regular users of public transportation regarding their everyday experiences, including everything from hostiles stares, to, as was the case with one participant, a stabbing. I recount the range and types of situations trans* riders encounter, and how they interpret and react to these situations, as they

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appear in the interview data. Subsequently I utilize the literature from an array of disciplines such as feminist geographies and urban sociology to interpret and discuss the interview data and its implications. In particular I intend this paper first to amplify the stories of transgender individuals and advocate for trans-inclusive approaches in transportation planning and policy, and second to contribute to the complexification of theorizing gender in public spaces.

TRANS* EXPERIENCES OF DISCRIMINATION

Across many cultures, places, and times, humans have honored and lived out a plentitude of various gender identities. In fact, Susan Stryker (Stryker & Whittle 2006) traces gender nonconformity in Western society (and what we may now categorize as transgender) back to the Greeks and Romans. Geographically and culturally distinct nonbinary identities and roles are found across every inhabited continent in the world, from the hijra of India, to the muxe of Oaxaca, to the Maori whakawahine. In the individualistic United States, though transgender and nonbinary identities have long existed, neological terms to describe one's gender identity have recently proliferated. Terms like genderqueer, agender, androgyne, femme, boi, demigirl, and neutrois can refer to gender identities that exist either along a spectrum of masculine to feminine, or outside of this binary framework altogether. Because there are multitudes of terms which vary in usage and often overlap, the term *trans** (again, see ¹) has become a sort of umbrella term to describe all identities that do not adhere to the traditional male/female binary, which I will continue to use in this paper. Other studies may look at different subsets of trans* populations, or use different catchall terminology, and I will distinguish this where I feel it is relevant.

It is well documented that transgender and gender nonconforming individuals experience significant discrimination, verbal harassment, and physical violence, including murder, due to

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their identity or presentation (Grant et al 2011; Jauk 2013; Miller et al 2015; others). The National Transgender Discrimination Survey (n=6450) found that 53% of respondents were verbally harassed or disrespected in a place of public accommodation such as a restaurant, store, hotel, bus, or government agency (Grant et al:5). Another sizeable study (n=402) found that 60% of respondents had experienced violence or harassment (Lombardi et al 2001). Viviane K. Namaste's seminal work on genderbashing (2000) adds to theorization of anti-transgender violence by suggesting that a primary factor in all anti-LGBT violence is visible gender nonconformity. In this sense, gaybashing can also be understood as a form of gender violence, insofar as the victimized individual is targeted due to gender-atypical presentation or behavior.

Moreover, there are many studies showing the link between anti-trans* discrimination and negative health outcomes. At least one study has linked personal experience of discrimination with an increase in health-harming behaviors such as smoking and drug or alcohol abuse (Miller et al), and links between discrimination and negative health outcomes have been attested among other marginalized groups. Miller et al also noted a link between visible level of gender nonconformity and risk of discrimination, and thus health-harming behaviors. Nadal et al (2012) also linked microaggressions (slights, insults, and subtle or indirect discrimination and hate) with diminished mental health and Miller et al linked everyday anti-trans* discrimination, as well as major discrimination, with elevated rates of attempted suicide.

GENDER AND PUBLIC SPACE

Along with the women's movements of the 1960s and 70s many academic disciplines began to consider for the first time the unique perspectives and concerns of women. Feminist critiques and takes on geography, sociology, city planning and urban studies contribute much to

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our understanding of gender in urban public spaces. These scholars have analyzed extensively how patriarchy has shaped the city and metropolitan regions and discuss how urban material and spatial reifications of patriarchy contribute to women's oppression. In other words, the city is inherently sexist. Theorists like Nancy Duncan, Clara Greed, and Susan Gal have highlighted the gendered nature of the public/private divide and explain how assumption of who should be in what space and when have served to subjugate and constrain women. Sue Hendler suggests that cities hoping to address their sexist nature would implement gender equity planning practices, including a particular attention to availability and accessibility of childcare, robust public transportation with crosstown service, affordable housing, and personal safety design.

Similarly, scholars of sexuality, queer, and trans geographies such as C.J. Nash and Gill Valentine discuss how different urban lesbian, gay, and transgender communities have disrupted the heterosexual and cisgender assumptions inherent in urban spaces. They suggest that explicitly queer spaces have a mutual relationship with queer identities, each supporting and/or transforming one another. For example, Nash (2010) recorded how some trans men went through a spatial transition from frequenting lesbian spaces to frequenting exclusively straight spaces and exclusively (gay or straight) male spaces as part of establishing their new identity. This mutual relation between gay, lesbian, and trans individuals and the spaces they inhabit suggests that the nature of public space has an effect on transgender individuals, including their identity and behavior.

This leads to another emphasis in the gendered nature of public spaces. Documentation on gender and safety in public spaces is prolific, both in how these spaces *evoke* feelings regarding one's (lack of) safety and are *navigated* with regard to one's feelings of safety. Fear of crime and violence is consistently documented as more pronounced among women (Madriz

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1997; Pain 2001; Ratnayake 2016; others). This is despite the greater likelihood of victimization among men, and is often called the fear-safety paradox. Initial theorists thus called the fear irrational and unfounded, but studies have since attempted to explain this fear-safety discrepancy among women. One study cites gendered differences in vulnerability in the actual case of victimization (regardless of likelihood), as well as socialization of fear and risk perception in order to elucidate the significance behind the paradox (Smith and Torstensson 1997). May et al (2010) also highlight the elevated *perception* of risk in addition to fear of crime among women when compared to men. Additionally, Brownlow's (2004) study suggests that women consciously monitor the public spaces they navigate for environmental cues of danger and differentiate which spaces are generally safe and which generally are not. All of this appears to suggest that women's risk assessment has a particular spatial component to it. Men's evaluations of safety in public spaces, in contrast, are more independent of location or space. In other words, their "level of concern is constant across situation and context," even while it may be lower generally (ibid:589). Thus gender is a clear factor in shaping feelings of safety and resulting behavior in public spaces. This research is in line with feminist urban planners' calls for policies that include personal safety as a key factor in design and planning (see Ratnayake 2016).

In addition to the gendered nature of feelings of safety in public spaces, scholars have documented how women change their behavior in response to these feelings of (un-)safety. Some examples of these modifications of behavior in public include avoidance of particular spaces or at particular times, travelling with company, keeping a friend updated on their whereabouts, and carrying personal safety devices such as pepper spray. In fact, May et al have demonstrated that women also change their behavior in relation to their fear and evaluations of risk including usage of avoidance and defensive behavior. Other scholars (Skogan & Maxfield 1980) confirm that

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women modify their behavior in public spaces in response to fear of crime more frequently than men.

This fear of victimization and resulting behavior modification has also been studied within the context of transit. One study suggested that gender was a key factor explaining fear of crime on public transit (Yavuz and Welch 2009), while earlier studies have established that fear of crime in general affects transit usage and avoidance (Lynch and Atkins 1988). Another scholar even cites gender as "the most significant factor related to anxiety and fear about victimization in transit environments," effecting what modes, routes, and times women utilize for their personal transportation (Loukaitou-Sideris 2008). While the explanations for the fear-safety discrepancy are still evolving, the fact that gender plays a huge role in perceptions of safety, fear, and subsequent behavior in public in general and on transit in particular is virtually uncontested. In this paper I seek to complexify the understanding of gender in public space by adding the voices of trans* individuals regarding their experiences of public transit.

In one of the few studies to highlight trans* individuals' perceptions of urban space, 14% said they felt their city was unsafe for trans* people, 48% said tolerable, and 38% said their perception of safety was good (Doan 2007). Additionally respondents reported they felt threatened in their city in the last twelve months by hostile stares (32.7%), hostile comments (21.8%), and physical harassment (17.1%). In light of the evidence that fear and perception of safety can alter women's behavior, it may seem natural that trans* individuals also engage in similar avoidance and defensive behavior in reaction to evaluations of safety. In fact, one study has shown how trans men feeling a lack of safety are compelled to alter their behavior, to perform defensive masculinities that uphold the gender binary (Abelson 2014). These dynamics

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are also likely to extend to how trans* individuals intellectually interpret, and emotionally and behaviorally react to their experiences on public transit.

TRANS* FOLKS IN MOTION

The 2011 report of the National Transgender Discrimination Survey (Grant et al) is the most comprehensive publication to date on the experiences of discrimination of trans* individuals in the United States. In the report, several questions were asked relating to transportation (p130). Verbally harassment or disrespect on a bus, train, or taxi was reported by 22% of respondents. After physical assault by a police officer (6% of respondents), the most commonly reported occurrence of physical assault happened on a bus, train, or taxi (4% of respondents). In addition, 9% of respondents were denied equal treatment or services on a bus, train, or taxi, and 26% reported experiencing any of the above three on a bus, train, or taxi.

It is clear by this point that trans* individuals face various forms of discrimination in various places, including public transportation. However, the experiences of trans* individuals on public transportation has never been studied in depth. This study aims to aggregate and interpret a diverse set of experiences, supplementing and adding depth to the above NTDS statistics. In addition, I have presented the literature establishing a clear relationship between gender and key aspects of the experience discrimination, including the perception of risk, fear of victimization, sense of vulnerability, and subsequent behavior modification. As the research on (binary) gender in (public) space abounds, studies that highlight the unique nature of *nonbinary* gender in public space number only a few, while no major studies have ever before theorized nonbinary conceptions of gender in transit spaces. I hope to contribute to the continuing evolution of theorizing gender and space.

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METHODS

The rich voices in this study come from 25 interviews with trans* individuals regarding their experiences on public buses, light rail trains (MAX), and streetcars in Portland, Oregon. The regional public transportation service provider, TriMet, offers residents of the greater Portland metro area various modes of transportation, including 78 bus lines, 5 light rail or Metropolitan Area Express (MAX) lines with 97 stations, and 2 streetcar lines. Service hours are approximately 5am until 2am. The city itself is notable in that it boasts the second highest percentage of self-identified LGBT adults according to a 2015 Gallup poll, and prides itself on having a quirky, liberal culture. This may have had an effect on the experiences of trans* interviewees, as some even noted differences from other cities they'd lived in. Interview topics included gender identity and history, public transit usage (including time of day, mode, route, and purpose of travel), typical experiences and emotions on transit, particularly positive and negative experiences, barriers and challenges in using transit, suggestions for change, and comparison to non-transit public spaces.

These interviews were conducted and transcribed by co-researchers. Study advertisements called for transgender and gender nonconforming individuals (who I refer to as trans* in this paper) who rode public transit at least three times per week. All participants have been given a pseudonym as a measure of confidentiality. Effort was made to retain the gender or "flavor" of participants' real names in order to respect the significance of many trans* individuals' names in their identity. I then participated in a workshop style approach to organizing, categorizing, and interpreting the interview data, guided by a general inductive approach (Thomas 2003). This approach seeks to define emerging patterns in the data and interpret them in relation to the research question(s). Together we created a coding scheme that

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captured important emerging themes, coded all the transcripts using qualitative data analysis software, and then summarized each of the thematic codes in code memos. Thus, in this paper I draw from my co-researchers' work on compiling the literature, and categorizing, interpreting, and analyzing the interviews, while all of the writing and discussion remains my own. I used the above methods to answer my research questions regarding the general experiences of trans* users of public transit as well as how the nature of various transit spaces, including the enclosed, confining nature of the bus and the openness of the bus or MAX stop affected riders.

FINDINGS AND DISCUSSION

Many of the themes that emerged from our interviews that we found significant were given a code. These include type of discrimination (major and everyday), source of discrimination (off-transit passersby, on-transit passengers, and TriMet staff including drivers), positive experiences, discussion of police, discussion of intersecting identities on transit, gendered experiences (transmisogyny and FtM male privilege), discussion of gender nonconformity, strategies for managing discrimination (both at the personal and institutional levels), and discussion of the nature of the transit space itself. Below I only summarize the findings most relevant to my research questions, organizing summaries by thematic groupings.

Experiences of Discrimination: Type, Source, and Nature

The National Transgender Discrimination Survey was first to gather statistics on the rates of harassment and discrimination that trans* folks experience in public transit. The responses of the participants in our study add some depth to these statistics. I summarize the frequency of both everyday and major discrimination, describe who is discriminating against trans*

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passengers, and what this discrimination may look like. We found that discrimination occurs in a range of ways, and that overall most discrimination is coming from other passengers and passersby at bus and MAX stops rather than TriMet staff.

Everyday discrimination is any incident that occurred on transit that was harassing or discriminatory in nature, but did not seem to have gravely impacted the participant. This type of discrimination included everything from passengers taking pictures and laughing at participants to passengers moving seats as to not sit near a trans* person. Looks and stares were the most common form of discrimination. Some looks were described as disgusted, while other participants reported experiencing hostile or even sexually objectifying stares. Other common discriminatory interactions included cissexist and heterosexist language and slurs, challenges of the participant's gender identity, and invasive questions about the participant's anatomy, sexual practices, and gender identity. Kacey recounted the distress of having her gender identity drawn to attention and questioned:

[W]e were waiting for the bus to go home and I think this guy came up asking if we had a cigarette he could spare...[and] I responded to him. The moment he heard my voice he asked what gender I was. I'm just kind of like, I don't want to deal with this right now. So, I just sort of buried my head in my partner's shoulder and she got rid of him.

Major discrimination would be any discriminatory incident where the participant described or implied the severity of the event and how it affected them or their ability to ride transit. This comprised a much smaller portion of the reported incidents, but still was alarmingly common, at 10 out of 25 participants. One of the participants, Trysta, was stabbed at a MAX platform and how that affected her. She also described another recurring situation of men ostensibly accidentally slamming into her when the MAX would lurch that got so bad she started carrying Mace and making it visible to the men who pushed her. Other participants described physical

confrontations and assaults that forced them to change the bus stop they would use or what time of day they would ride transit. Enid reported,

I had a lady that I would prefer to say was under the influence of cocaine- decided I was too effeminate and punched me. So, I've ridden the bus with that woman before and every time I'm around her I'm very on edge...even though it's right there on my main ride, so obviously I'll schedule around from that, or get off when I see her get on.

As for where the discrimination was coming from, the majority of the incidents that participants spoke of were from other passengers. The most severe incidents often happened on the MAX platforms and at bus stations where other denizens and passersby would verbally harass or physically attack trans* individuals waiting for transit.

Gendered Experiences: Transmisogyny, FtM Male Privilege, and Gender Nonconformity

While some participants in our study simply identified as (binary) trans men or trans women the majority of participants claimed at least in part a nonbinary identity, or in a number of ways described their gender identity with varying degrees of fluidity. For example, one participant, Luke, identified himself as both "transgender female to male" and "genderqueer," using he/him/his pronouns. Another participant, Jordan, consciously subverted gender norms, considering their nonbinary identity political.

In any case, an even greater number of participants recounted experiences in which they were perceived as transgender or gender nonconforming, often attributing the discrimination to this perception. For example, Felix contemplated, "I've noticed on days that I'm far more masculine I tend to get less looks or whatever, versus days that I'm a little more androgynous." Here Felix is explaining how they get more stares when they are visibly nonconforming, but fewer when they adhere to stricter masculine standards of presentation. Many instances of

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discrimination or microaggression were linked to misrecognition (sometimes referred to as not passing) and/or intentional gender nonconformity among participants. In some situations, it was clear that being read as transgender or gender nonconforming immediately preceded and gave rise to discrimination. This was often the case in the widely reported othering glances and hostile stares. In any case, for some, the simple act of misrecognition or repeated misrecognition constituted a negative transit experience.

In addition, the male privilege of the four binary-identified trans men was strikingly clear. Their interviews were shorter, with fewer incidents to tell of, and several of them were conscious of the fact that they didn't have much to say. Jackson explicitly reflects on the privilege of being male in comparison to before:

I have recollection prior to transition to having some times where I felt very uncomfortable with people looking at me, commenting about "hey are you a dyke?" ... I feel like prior to transition I got more looks and more comments directed to my weight. Now that I'm male people don't bug me about being "hey fatto." Whereas before it was definitely an issue people focused on, or commented on, or felt it was appropriate to comment on, or had no filter about it.

After transition he reports not having any safety concerns or anything that makes him uncomfortable on transit. When a trans man reported concerns or fears on public transit, they had to do less with gender, for example, Tucker's occasional claustrophobia on crowded rides.

This sharply contrasts to the experience of trans women and other participants identifying and/or presenting feminine of center (which I will refer to inclusively here as transfeminine). The transmisogyny experienced by these participants is distinguished by its severity and frequency. Transfeminine participants experienced the most severe, invasive, and frequent forms of discrimination, harassment, and violence, including a stabbing, sexual objectification and harassment, and unprovoked physical fights. Piper recounted one particularly invasive and distressing incident: I was riding the max home... and some rider... wanted to make me out to be some kind of male in a dress or something like that, they were actually literally asking me to pull down my pants to the point where I was in tears.

Transmasculine and nonbinary-identifying participants also reported invasive anatomical questions. Janelle, who identifies as "genderqueer" and presents "androgynous, masculine of center" reported:

What I often get is a staring contest with folks who will stare me down, and quietly murmur to whoever they're talking with, up to like, people asking me if I'm a man or a woman, asking me if I have a vagina or a dick, people sitting really close to me and asking invasive questions.

While participants of multiple identities and presentations received such invasive questions and challenges to their bodily sovereignty, the severity of physical attacks and the frequency of harassment and microaggressions toward transfeminine participants distinguished the pattern of transmisogyny.

Personal Strategies for Managing Discrimination

With all the discrimination participants faced, everyday and major, many had developed distinct coping techniques and strategies for mediating potential and actual discrimination. Behaviors such as wearing headphones or reading a book while on the bus or MAX were ways that several participants described ensuring that no one attempted to bother them. Tucker explained, "For me, [headphones are] a symbol; don't talk to me, leave me alone." At least one participant, Enid, preferred to strike up conversation with other riders, and other participants recounted friendly conversation as part of a sign of a safe or enjoyable ride. Trysta described once displaying a can of Mace as a deterrent to the threat of another passenger. She also touched on how strategies for managing discrimination and violence must be conjured up to

suit the environment:

I have my no bullshit face when I'm going—when I'm walking around out in public the boots I'm wearing make a serious click. You're hearing this [pounding sound] everywhere I'm going. I have to do this; otherwise I will be victimized by any number of people. None of this will work on the train because I can't move.

This reveals that managing discrimination for some riders is a conscious, sometimes burdensome

process. Shannon adds:

If I'm going comfortably on the MAX or on the bus I am definitely thinking "how do I look?" If I'm gonna pass—how well do I pass? If I don't pass, well how non-binary do I look in this moment, and therefore how much attention do I think I will attract? If I go as a boy, if I go in boy mode, I'm fine. If I go in girl mode and wear my sunglasses and I'm cute, I'm usually okay. If I'm non-normative then I'm hitting everybody with a double whammy: black is different and non-normative is different. We don't know which box to put you in....Trans women don't always last very long, especially trans women of color, so passing is something that I've definitely had to incorporate into some of my work life.

Other participants similarly report planning or modifying their gender presentation while on public transportation in order to mediate harassment or discrimination. Other common strategies participants employed included avoiding a particular mode of transit (some preferred the bus over the MAX and vice versa), avoiding certain travel times, particularly when high school students use the bus, avoiding certain bus lines which they often had a prior negative experience on, and avoiding a part of town associated with crime in popular conception but not necessarily because of prior experience. Perhaps in one of the most striking examples of the above list of strategies, Sam described how they were verbally and then physically harassed at a bus stop. After the incident Sam described being so shaken up, and their wife so worried, that they agreed on a plan of what particular bus stops were safe to use, being chosen in part for the presence of other pedestrians. This example also clearly shows the role of prior experience in shaping one's subsequent transit behavior.

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[Not sure if I want to add Institutional Practices to my findings and discussion or a separate policy discussion section, and instead focus more intently here on gender, gender identity, gender presentation, personal strategies and transit spaces]

Spatial Factors in the Experience of Transit

Feminist, sexuality, queer, and trans geographers and urban theorists have shown gender and sexuality to play out uniquely in space and that space is uniquely shaped by gender and sexuality. An emerging theme participants kept mentioning had to do with the particular effects of the captive space encountered aboard the buses and light rail MAX trains, so I decided to include it as a thematic code. Here I summarize all the various excerpts I understood to have a spatial component. The data I coded under this theme included talk of crowded rides, attacks at bus stops, male privilege of others respecting personal space, and the metaphorical violation of personal space in the objectifying gaze. To make a sort of sense out of these diverse responses, I categorized them into two basic somewhat overlapping categories of Responses on Space and Safety and Responses on Space and Gender.

Physical/social space and safety

Many of the responses fitting under the "discussion of transit spaces" theme were discussion of various safety concerns faced in transit physical-social spaces. Many comments existed along the line of feeling that the specific layout of the transit space was confining or restraining, thus affecting their ability to escape danger or an undesirable situation. This feeling

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of being trapped most frequently applied to riding the bus, and, to a lesser extent, riding the MAX. Talia explained the predicament unique to transit:

Sometimes the nature of public transit causes more problems because anyone who wants to be an asshole to the people around them has a captive audience that cant or doesn't want to get off immediately. If you're on the street its easier to get away from people you don't want to be around.

While many participants spoke of discomfort and feeling trapped on the bus or MAX, at least two participants, Teagan and Christine, both described situations where they were forced to choose their personal safety and disembark the bus over their right to use public transportation. Other participants such as Nico spoke of other factors that weigh in when a threatening situation arises: "Especially since I'm going to and from work. I don't have an option without big consequences in my life of exiting from a negative bus or train type of situation." This may be a particularly troubling situation for low-income and transit-dependent riders, as well as riders with a different ability. Tucker also spoke to the increased feelings of fear of something going wrong on public transit, pointing out that you're trapped.

In addition, Piper felt quite literally trapped when a passenger tried to remove the headphones she was wearing in an attempt to make her listen to him. She said, "[C]onsidering I was trapped between him and the window I kind of had no other choice. I'm like, okay, I'll wait a couple of stops after the one I'm going to get off just so he doesn't follow me." Alternatively, Sam prefers to remain hypervigilant, in a way, constantly mapping out escape routes and eyeing out public venues along the bus line where they could stake out refuge from a perpetrator. All this demonstrates the effect of the enclosed space of a bus or MAX light rail train on trans* participants' feelings of

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safety, fear of riding transit, and coping strategies such as disengaging and disembarking or practicing hypervigilence.

Another trend in comments about Safety and Space on public transit had to do with the new or additional safety and discrimination risks that transit spaces bring, mostly having to do with being in close quarters with many strangers, often for a long period of time. In contrast other public spaces like streets, restaurants, and parks, where people are less confined and restrained and there are many other distractions, the opportunities for strangers to grope, bump into, or otherwise violate someone's personal space may be far fewer. As Trysta alludes to, the violation of boundaries can be constant in these spaces. On a crowded train rides, "some cis male, when the train lurches, he'll slam up against my backside. The first time, I was like, 'Oh it's because of the train.' The fiftieth time, I was like, 'Fuck you,' out loud, right?" Other transit-unique risks include exceptionally long and intense sexually objectifying or hostile stares and scrutiny of appearance and unwanted sexual advancements. These spaces might make some onlookers feel as though they have a right to study other riders, and subsequently ask invasive questions about anatomy or sexual activity. Several participants recalled such invasive questions, not the least of which demanded Piper to pull down her pants and reveal her body. In addition to this unique risk of examination and interrogation, Piper also briefly demonstrated the fear of being followed home above. Shannon further elucidates this particular additional risk of being in transit spaces:

[T]here's a very real danger just being in public and then in an enclosed space on public transit stuck with someone who might have clocked you and now dislikes you and might be staring at you and you don't know— does this mean you're waiting to see where I get off the train or the transit or the bus? 'Cause I've done that, I've waited, I've gone long past my stop until someone who was staring me or made me uncomfortable got off first.

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I was not gonna let them get off after me, was not gonna let them follow me.

Though being followed can occur anywhere, Shannon highlights how a long, intimate transit ride can multiply the risk of being followed. In addition, transit allows potential stalkers not only the chance to follow, but also the chance to discover an individual's particular schedule, or exact home or work address. These spatialized fears and safety concerns comprise the first set of findings on trans* individuals' experiences of transit spaces.

Physical/social space and gender

Some of the most obvious examples of the intersection of space and gender have to do with male passengers' aggressive spatial entitlement on transit, in contrast to trans* (particularly nonbinary and transfeminine) senses of being squished, groped, examined, and all around having their personal space violated. Teagan reflects on several types of violation:

[N]egative riding experiences are always just someone who feels entitled to my space. And imposes their space upon me whether that's through verbal abuse, whether that's improper questioning, whether that's just physical manspreading. It's always about inserting their space into my space.

Teagan uses the word space here to refer not only to the physical space occupied by and immediately surrounding her and other passengers' bodies, but also the social space that our bodies inherently inhabit. Janelle, Trysta, and Piper were asked invasive questions about their bodies, another imposition of social space. Another example of the maledomination tendency in transit space can be seen in Janelle's reflection of when they were on a mostly empty MAX and a drunk man sat right next to them, pressing his shoulders into theirs, asking Janelle if they were "a dude or a chick." This double imposition of male space over trans* space may have been assisted by a substance, but is

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consistent with the everyday impositions seen in stares, glares, and gazes. The men slamming into Trysta opportunistically as the train lurched is another example of male spatial entitlement, including into the personal spaces of trans women and nonbinary trans* individuals.

A second subtheme of gender in transit spaces that may be seen as a hopeful corollary or compliment to the first, was that of resistance, and attempts to stake one's own trans* claim in the transit space. This can be seen in Trysta's reaction to the man slamming into her by shouting, "Fuck you!" and in subsequent incidents, brandishing a can of Mace. The difficulty and risk of staking one's own claim can also be seen in how Trysta admits she doesn't know if its legal for her to openly wield the Mace like that, and that it would likely affect "half the train."

Another reportedly successful attempt of defending herself on the street, the clicking of Trysta's boots contribute to her serious "no bullshit" demeanor. But she admits that this act of resistance and reclaiming public space doesn't translate to the bus or MAX. These two actions of Trysta's to reclaim a tiny, safe trans* piece of space on public transit demonstrate the challenge of resisting the patently harsh assaults on the spaces of trans* individuals (and trans women like Trysta in particular) without inciting the backlash from the cisnormative space all around.

Teagan, Christine, and Sam faced similar difficulties in resisting domination by male and cisnormative space. For example, when Teagan tried to stand up to the cis white man who was using gay and trans slurs on the bus and it escalated, Teagan felt the need to back down and exit the bus after "the entire bus looked at me like I was the aggressor." After seeing the loss of her male privilege after transition, Christine wanted to resist and

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"kept resolving, I'm just not going to stand for this. I'm going to push right up to the counter. I'm going to push right up to the entrance. Do whatever I need to do," but soon realized, "That's just what we do [as trans women]. If we act as a man, that just confuses people. It serves to alienate people." And so she capitulated to the continued male domination of space perhaps because she knew it could undermine her recognition as women or distress her relationships.

Sam contemplated a time when a man came up to them expressing sexual interest and getting all close. Rather than carve out a safe trans* space for herself, she moved seats, fearing what might happen if she was not all smiles with this man. These examples show the difficulty in claiming even the smallest personal trans* space of safety within hostile, cisnormative and patriarchal spaces.

Another response exemplifying the relations between gender and space is Talia's contemplation on how transit differs from other public spaces. She reports when she is dressed more feminine on public transportation, she is more likely to get harassed than on the street, but if dressed masculine, she wouldn't have a problem. Others also report this interplay of gender and space aboard the bus. Talia's experience exemplifies how a trans* identifying and at least partially gender nonconforming individual can manipulate the reactions she gets both by type of dress and type of space.

POLICY SUGGESTIONS

The experiences that the trans* participants in our study endure surely concern researchers such as myself. By collecting the stories offered by our participants, we hope to contribute to more informed urban policies. One of the interview questions asked participants to

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ponder what TriMet could do to improve the experiences of trans* riders. The suggestions I give are a synthesis of what participants reported and my own analysis of what might be helpful.

In the state of Oregon, gender identity is in fact a protected class, as declared in 2009 by the Oregon Equality Act. TriMet nondiscrimination policy as found on their website, however, does not explicitly include gender identity. Many participants noted this and suggested that TriMet update their language to include trans* folks as a protected class. Though riders can theoretically seek recourse at the state level in the case of an event, increased visibility and recognition of trans* riders could go a long way in demonstrating their commitment and making trans* users feel safer in the first place. For example, several riders experienced harassment on the bus or MAX but did not report it, and some who reported incidents to TriMet received little or no follow-up. Other ways to affirm and support trans* riders would be to increase representation of visibly trans* folks in their ads and placards, as some participants suggested. Shannon sums up the enormous work that affirmation and representation can do to start making transit safer and more comfortable for trans* riders:

[S]eeing [signage] that reflects that trans people exist even, and are probably on this bus with you would make me feel so much better about whether or not the people around are aware of the fact that I might exist...And that, while it's not their responsibility to have to care about me, they do have to see me as a member of their community.

While both the findings of the overall study and the participants' observations themselves support the fact that most of the discrimination in transit is being perpetrated other passengers, there can still be a productive role for TriMet staff. In any case, they can keep an ear, and, when appropriate, an eye, out for interactions which threaten the safety of

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passengers. Though, as many participants agreed, it is not the operator's job to mediate interactions at the back of the bus, nor should it be for reasons of driving safety, they should at the very least respond to passengers' solicitations for help. Teagan, for instance, attempted to report to a bus driver another passenger who was making inappropriate and offensive suggestions about her anatomy, yet the driver decided not to intervene. Teagan assessed that this was likely because the driver was unaware of trans*-specific issues and did not recognize how the situation Teagan reported was threatening.

One measure that could address this issue is a gender and LGBT sensitivity training for all staff, such as the Bridge 13 training that is offered to organizations all around Portland. This was in fact one of the most repeated suggestions for TriMet, along with a policy of using gender-neutral pronouns such as singular 'they' to refer to all passengers who the staff person does not know. Christine also added that such trainings can alert operators that just because a trans* person is involved in an altercation on transit does not mean they are to blame. They may in fact be in need of support from TriMet staff, and staff should act accordingly. Several participants experienced situations on transit and other places of public accommodation where employees intervened, but only to remove the trans* person from the vehicle or business. This only furthers the discrimination that trans* individuals experience on transit and further reduces their ability to ride, and do so safely. Not only do trans* riders need operators and other staff to intervene, they also need them to have the appropriate knowledge to intervene supportively.

One participant, Janelle, while recalling a positive experience on transit, expressed a simple solution of positive authority presentation that could be employed to

reduce instances of discrimination without asking an operator to divert too much attention

from the road:

Usually they'll introduce themselves, and I take a seat, and they immediately address us with a friendly, respectful authority. So some of those drivers will say things like "hold on everybody, we're moving pretty fast." I notice when they have a verbal confirmation to the entire bus and when they're constantly aware of their surroundings, my experience is more positive because their authority is being presented in a respectful manner. So folks don't usually try anything when an operator is that present. There have been a couple times when folks were disgruntled or whatever, and they've immediately jumped out and said, "Please don't do that, please don't swear on my bus, if you cannot correct your behavior I'm going to have to ask you to leave." That will immediately stop anything from happening.

In addition to the threatening interactions with other passengers that can make riding public transit unsafe and distressing, passengers did have a few instances where TriMet staff were responsible. One of the most repeated concerns regarded TriMet transit police. Several participants noted that, due to their marginalized identity(-ies), the unprofessional, aggressive, and intentionally intimidating behavior of transit officers was particularly distressing, making them feel unsafe. Other instances included drivers snickering, whispering 'freak' at a passenger, and denial of service, as when a bus driver took one look at Christine, shut the door on her, and drove off. At the same time, Christine evaluated that this type of discrimination on part of the driver was the exception, and restated her positive experiences with staff. In any case, the above listed measures could vastly reduce the occurrence of drivers directly discriminating against trans* passengers, all the while creating a supportive environment that addresses the discrimination occurring at the hands of other passengers.

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SUMMARY AND CONCLUSION

Thanks to a rich dataset provided by participants, many examples and patterns of trans* individuals' experiences on public transit are easier to examine. Some of these key findings include that trans* individuals face both major and everyday harassment and discrimination on public, the bulk of which comes from other passengers, with these patterns differing by gender. Binary-identifying trans men reported next to no transit issues, while trans feminine individuals experienced the most severe attacks and frequent microaggressions. The plurality of participants (11 of 25) identified as a nonbinary identity and the majority included some sense of fluidity in their identity.

In response to anti-transgender violence and discrimination, participants employed a range of personal strategies to mediate the effects of such discrimination or prevent it from occurring again. They include wearing headphones, modifying one's gender presentation, and avoiding particular routes or transit hours.

In exploring trans* individuals' experiences of transit spaces, several key findings emerged relating to the unique social nature of transit spaces, particularly on the bus. Trans* users of public transit expressed safety concerns, pointing to the restraining nature of public transit, as well as the potential to expose users to unique forms of harassment. Other spatial themes regarding other male passengers' attempts to dominate trans* riders spaces, the often difficult attempts at trans* spatial resistance, and the role of gender nonconformity in transit spaces fall under the Gender and Space side of participants' responses to experiences of transit spaces.

In sum, trans* riders face many challenges that ask them to use personal coping strategies and stake out a trans* micro-refuge within the cisnormative space of the bus or light rail train.

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As trans* riders express fear of crime, sense of vulnerability, and gender- or genderidentity based discrimination, it may well be worth including the experiences of trans* transit users alongside those more well-documented experiences of women, in order to understand broader gender-based issues. Other issues trans* individuals face in regard to getting around their city or town may need to be studied in greater detail. For example, as one participant noted, some trans* folks use transit differently, needing to take it to multiple different doctors, to work, and home. Other studies could look at transit dependency among trans* riders, transit routes, and experiences in other public places to support endeavors to improve policy and expand protections.

NOTES

1. As terminology and usage greatly varies, I have found some distinctions useful. I stubbornly include the asterisk in each deployment of trans*, simply in order to clarify the diverse range of nonbinary and gender nonconforming identities are to be included. Sans asterisk, trans may or may not be interpreted to include the individuals of our study. The many ins and out of transgender terminology and distinctions such as the one I use continue to be the matter of debate. The usage I prefer for this one paper is in no way an attempt to conclude this discussion/debate. In fact, the evolution and fluidity of terms and concepts may even be considered a hallmark of transgender studies, which Stryker & Whittle in fact consistently refer to as "trans studies."

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