Ryan White HIV/AIDS Program Part A Planning Councils: Addressing the Needs of Individuals Aging with HIV

This toolkit provides an overview of Ryan White HIV/AIDS Program (RWHAP) Planning Councils, how they function, how individuals can get involved, and how Planning Councils can be used to advance the priorities of individuals aging with HIV.
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What Is the Ryan White HIV/AIDS Program (RWHAP)?

The Ryan White HIV/AIDS Program (RWHAP) is a federal program that funds a range of medical care (including doctors’ visits and access to anti-retroviral treatment) and support services (including transportation, housing, case management, and food and nutrition services) for low-income people living with HIV. The program was first enacted in 1990, and today provides services to more than half of all people living with HIV in the U.S. every year. The program works to provide care and treatment to people who are uninsured and to provide access to services not covered by insurance for those who have public or private insurance. The examples below are some of the ways people use the RWHAP.

WHO DOES THE RWHAP HELP?

MIGUEL is 55 years old and has an income of $12,000/year, which is a little less than the federal poverty level. Miguel lives in a state that did not expand its Medicaid program under the Affordable Care Act (ACA). This means that unless Miguel is disabled or meets another narrow eligibility category, he cannot access Medicaid. He is also ineligible for any federal help to purchase private insurance. The RWHAP provides Miguel with medications for his HIV, doctors’ visits, and case management, transportation support, and other support services.

JOHN is 66 years old. He is currently on Medicare and has an income of $25,000/year. The RWHAP helps John with his Medicare medication co-payments, which can sometimes be expensive, and provides John with case management to help him navigate other services he might need.

SHARON is 50 years old and has an income of $12,000/year. She lives in a state that has expanded Medicaid and she is eligible and enrolled in that program. Her medications and most of her medical care (including doctors’ visits, lab services, and specialist access) are covered by Medicaid. The RWHAP provides Sharon with services not covered by Medicaid, including transportation, food and nutrition support, and case management.
The program is broken into five “Parts” and provides funding to states, cities, counties, and community-based organizations to improve health outcomes of people living with HIV and ultimately reduce HIV transmission.

The RWHAP is administered by the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) and received $2.69B in 2020. Because the focus of this toolkit is on RWHAP Part A Planning Councils, Appendix B provides a detailed breakdown of how funding flows from Congress to RWHAP Part A grantees, all the way to HIV service providers. HRSA/HAB has become more attuned to the needs of individuals aging with HIV, providing resources and guidance across all RWHAP Parts to adapt programs and prepare workforces to meet evolving needs of aging clients.

<table>
<thead>
<tr>
<th>THE RWHAP PROGRAM</th>
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<tbody>
<tr>
<td><strong>Part A</strong></td>
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<tr>
<td><strong>Part B</strong></td>
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<tr>
<td><strong>Part C</strong></td>
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<td><strong>Part D</strong></td>
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<tr>
<td><strong>Part F</strong></td>
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</tbody>
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Breaking Down RWHAP Planning Councils

The cornerstone of the RWHAP is meaningful engagement, input, and leadership from communities most impacted by HIV. From the inception of the program, RWHAP grantees have been required to include people living with HIV in state and local planning decisions.

As individuals living with HIV age, it is important to ensure that the make-up of planning bodies, their priorities, and the way they allocate funding reflect the changing needs of people living with HIV. One way that the program is required to engage community is through RWHAP Part A Planning Councils. Community engagement—through Part A Planning Councils in particular—is critical to ensure that the evolving needs of an increasingly older RWHAP population are front and center as program and funding decisions are made.

**WHAT IS A RHWAP PART A PLANNING COUNCIL?**

Jurisdictions receiving RWHAP Part A funds must have a Planning Council. The Planning Council assesses the needs of people living with HIV and helps to inform decisions about what funding allocations are needed to meet those needs. Planning Councils must include people living with HIV.

**RWHAP CLIENTS**

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>2010</th>
<th>2018</th>
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<tbody>
<tr>
<td>&lt;13</td>
<td>2.1%</td>
<td>0.8%</td>
</tr>
<tr>
<td>13-24</td>
<td>6.6%</td>
<td>4.1%</td>
</tr>
<tr>
<td>25-34</td>
<td>15.0%</td>
<td>17.9%</td>
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<tr>
<td>35-44</td>
<td>25.8%</td>
<td>19.3%</td>
</tr>
<tr>
<td>45-54</td>
<td>33.9%</td>
<td>26.8%</td>
</tr>
<tr>
<td>55-64</td>
<td>13.7%</td>
<td>23.5%</td>
</tr>
<tr>
<td>≥65</td>
<td>2.9%</td>
<td>7.6%</td>
</tr>
</tbody>
</table>

Source: HRSA/HAB, Ryan White HIV/AIDS Program Clients, by Age Group, 2010 and 2018—United States and 3 Territories
HEALTH CARE AND SOCIAL SERVICES CHALLENGES FOR PEOPLE AGING WITH HIV

- Increased social isolation and associated mental health issues
- Housing instability
- Financial management challenges, including navigating Social Security benefits
- Discrimination in nursing homes or other congregate living facilities
- Hearing decline/loss
- Premature aging of immune system
- Cognitive impairment
- Multiple medications
- Lack of knowledge about services

What (and Why) Is a RWHAP Part A Planning Council?

The RWHAP legislation is groundbreaking in many ways, including its commitment to ensuring that people most impacted by HIV have a voice in how funding is used. There are a number of community engagement and planning requirements attached to both RWHAP and HIV prevention funding. This toolkit focuses on RWHAP Planning Councils that are required for RWHAP Part A grantees (hardest hit cities and counties).

The RWHAP statute itself requires Part A grantees to have Planning Councils to identify service needs and resource priorities for the area. For example, the City of New Orleans is one of the RWHAP Part A grantees in Louisiana, meaning that the city receives federal funding to provide HIV services in the New Orleans area. The city—working closely with its Planning Council—provides its Part A funding to hospitals, clinics, and community-based organizations. These providers are then able to provide services to low-income people living with HIV who otherwise could not afford them. The Planning Council must reflect a range of different voices, including voices of individuals living with HIV. At least 33% of voting members must be consumers of RWHAP Part A services who do not have a conflict of interest, meaning they are not affiliated in any way (as staff, consultant or Board member) with a RWHAP Part A funded agency.

Who makes up a planning council?

- Health care providers
- Community-based organizations
- Social services providers
- Mental health and substance use service providers
- Hospital planning agencies
- Affected communities, including people living with HIV and RWHAP Part A consumers
- Community leaders
- State agency representatives (e.g., Medicaid)
- RWHAP Part B, C, and D grantees and other non-RWHAP HIV federal grantees
- Representatives of justice-involved or formerly incarcerated individuals

The Planning Council works closely with the Part A grantee, but has a slightly different role. The Part A grantee is the recipient of federal funding and is responsible for contracting with providers for services, but the Planning Council provides input into what needs rise to the top in the community and what kinds of services should be funded.

The Planning Council typically establishes permanent or ad hoc committees to carry out core functions (e.g., a “Membership Committee,” “Service Standards Committee,” or “Needs Assessment Committee”).
### KEY PLANNING COUNCIL RESPONSIBILITIES

| Identify needs of the community | Assess the needs of people using Part A services (e.g., through needs assessments)  
  |  | Focus on identifying needs of historically underserved populations |
| Establish service and funding priorities | Establish service category priorities and guidance for Part A allocation of funds in the area based on identified needs and other data available (e.g., rates of new HIV cases and geographic disparities)  
  |  | Take into account capacity building needs for communities experiencing HIV disparities |
| Provide “directives” to the Part A grantee on how to meet identified priorities | Provide “directives” or formal guidance to the Part A grantee on how best to meet the needs of the community |
| Participate in state and local planning processes | Develop a Comprehensive Plan to meet the priorities the Planning Council identifies and participate in the RWHAP Part B Statewide Coordinated Statement of Need process |
| Develop service standards | Provide expectations for providers on how to best carry out the RWHAP services they are funded to provide (e.g., staffing qualifications and client rights and responsibilities) |
| Assess how well the Part A grantee administers Part A funding | Evaluate how efficiently the grantee selects providers and how well provider contracts and HIV service quality are monitored |

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**How Does Someone Become a Member of a Planning Council?**

Each Planning Council must have a process for nominating and adding new members. Planning Council vacancies and qualifications are publicly posted. Nominated individuals (either nominated by themselves or another person) are reviewed by the Planning Council and members are then recommended to the city or county official who is legally responsible for the Part A grant to make the final decision. New members are typically provided with an orientation and mentorship opportunities to help get them up to speed on how to meaningfully participate in Planning Council activities. There is no professional requirement to be a part of a Planning Council. Individuals living with HIV who receive RWHAP Part A services are critical members of the Planning Council and provide valuable leadership to ensure that Part A services are meeting the needs of the community.

**TIP: HOW TO FIND RULES FOR APPLYING TO JOIN A PLANNING COUNCIL**

To see your Planning Council’s process for adding new members, consult the Planning Council’s bylaws (either on the website or by requesting them from a Planning Council member). The bylaws provide information on how the Planning Council functions and rules for membership, managing conflicts of interest, leadership, and decision making. Most Planning Councils have public websites that are easily found on the internet.
Can Community Members Participate in Planning Council Meetings and Activities Even If They Are Not Members?

Planning Councils typically follow the state or local government’s “open meetings” requirements. This means that Planning Council meetings are open to the public and agendas, meeting minutes, and other documents reviewed at the meetings are posted publicly. Each meeting generally allows for some form of public comment to solicit input from non-Planning Council community members. Planning Councils also have discretion to be creative with how they structure meetings and other opportunities for engagement of non-members in discussions and planning. For instance, some Planning Councils engage non-Planning Council community members to participate in discrete projects, workshops, or town halls on an ad hoc basis, usually addressing a specific topic or population.

How Are Part A Planning Councils Different from Other HIV Planning Groups?

A core function of Planning Councils is to develop a plan to meet the needs of people living with HIV in the Part A jurisdiction. However, in addition to Planning Councils, there are many planning and community engagement requirements across HIV federally funded programs. Over the years, there has been an effort at the federal level to support a more integrated approach to planning across HIV Care and Prevention. As a result, many RWHAP Part A Planning Councils have merged with HIV Prevention Planning Groups to form integrated Care and Prevention Groups. With the Ending the HIV Epidemic (EHE) federal initiative, there may be additional changes ahead across RWHAP and HIV Prevention planning processes. There are several major plans that intersect with RWHAP Part A Comprehensive Plans.

While the multitude of different plans can be daunting, engaging in the state and local planning processes is critical to ensure that on-the-ground perspectives are taken into account and that the priorities and goals reflect the voices of those most impacted by the epidemic. Depending on the jurisdiction, the planning landscape may look different. For instance, some jurisdictions still carry out separate plans across Care and Prevention and across RWHAP Parts A and B. Other jurisdictions combine their planning processes into one statewide plan that incorporates all of the required federal elements. Every jurisdiction, regardless of how they structure their planning, must ensure that the plans are responsive to the federal Integrated HIV Prevention and Care Plan requirements. These integrated plans cover the time period 2017-2021. Federal guidance on what these plans will look like after 2021 is forthcoming. Finally, the federal EHE initiative also
includes a planning requirement. Every EHE Phase 1 jurisdiction (48 counties, Washington, D.C., San Juan, Puerto Rico, and seven states that have a disproportionate occurrence of HIV in rural areas—Alabama, South Carolina, Oklahoma, Mississippi, Arkansas, Missouri, Tennessee). These plans were due at the end of 2020 and it is likely that future iterations of these plans will align with the integrated Care and Prevention plans discussed above.

**HIV Planning: A Complex Landscape**

- **RWHAP Part B Statewide Coordinated Statement of Need (SCSN)**
  HRSA/HAB required plan that identifies funding priorities, unmet needs, and sets forth goals for addressing them. RWHAP Part B grantees are required to engage all RWHAP Parts in the development of the plan (state/territory).

- **Integrated HIV Prevention and Care Plan**
  HRSA/HAB and CDC required plan that may combine the RWHAP Part B SCSN, RWHAP Part A Plan, and HIV Prevention Plan (statewide).

- **HIV Prevention Comprehensive Plan**
  CDC required jurisdictional HIV prevention plan created by the HIV Planning Group identifying priorities and strategies to implement High Impact Prevention strategies (states and CDC directly funded cities).

- **RWHAP Part A Comprehensive Plan**
  HRSA/HAB required plan that identifies needs, funding priorities and an action plan to improve access and outcomes for RWHAP Part A jurisdictions (cities and counties).

- **Ending the HIV Epidemic (EHE) Jurisdictional plans**
  CDC required plan for EHE Phase 1 jurisdictions, including goals to address the four pillars of the EHE initiative (mix of states, cities, and counties).
How Can Planning Councils Address the Needs of Individuals Aging with HIV?

The role that Planning Councils play in needs assessment, priority development, and resource allocation guidance makes them important entities to engage to ensure that the needs of individuals aging with HIV are being met in RWHAP Part A jurisdictions. Research is building that shows that people over 50 living with HIV have specific needs that may not be adequately addressed by the current RWHAP workforce and service delivery models. People over 50 living with HIV may have increasing comorbidities and increasingly need both HIV and geriatric medicine expertise and interventions. They may face increased social isolation that negatively impacts physical and mental health, particularly those who are long-time HIV survivors. And finally, social services needs—especially access to stable housing and service coordination—may be more acute for this population.

The following considerations may be useful in engaging Planning Councils to become more active in this area:

1. Tell the Story with Data

The first step in identifying actions a Planning Council should take to better meet the needs of people aging with HIV is to understand the data in the RWHAP Part A jurisdiction. RWHAP client level data is available from the Part A grantee and can be disaggregated by age (i.e., broken down into age groups).

HOW TO ACCESS RWHAP DATA

RWHAP data for the Part A jurisdiction is found in what is called an “epidemiologic profile.”

The profile includes:

- Race/ethnicity data for people living with HIV
- Number of new HIV cases in the area
- Percentage of people living with HIV who are virally suppressed (broken down by demographic information, including age)

Epidemiologic data for the state can usually be found on the state health department HIV program website. The Part A grantees also collects data on RWHAP services and clients.
bands to focus on RWHAP clients over the age of 50. This data may reveal trends in service utilization for this older age cohort as well as any disparities in outcomes, including viral suppression rates. Planning Councils can also look to epidemiologic data from HIV surveillance programs to show new diagnoses by age.

Another way to collect data on the needs of this population is to incorporate specific questions into a community needs assessment. Questions can address comorbidities, commonly utilized services, social determinants of health (e.g., neighborhood safety, housing, and financial stability), and identified service needs. If a separate needs assessment cannot be administered, it may be possible to disaggregate existing needs assessment data by age to specifically look at individuals over 50. Pointing to epidemiologic data and information on unique needs can help to shape more specific program and resource recommendations, for instance, Planning Council directives discussed in more detail below.

2. Engage External Stakeholders

Planning Councils can use their meeting time to engage new stakeholders and voices and spend focused time on certain issues. For instance, Planning Councils could invite representatives from local Councils on Aging (also called “Area Agencies on Aging”), clinical experts specializing in HIV and aging, or Medicare experts to provide information and resources to inform Planning Council activities. Engaging different stakeholders can also help to identify education and training needs. For instance, the Planning Council may identify workforce education and training needs to ensure that broader systems—including nursing homes and assisted living facilities—have the resources necessary to provide culturally competent care to people living with HIV.

WHAT IS A COUNCIL ON AGING AND HOW DO I FIND ONE NEAR ME?

Throughout the country, there is a network of local agencies focused on meeting the needs of older individuals. These agencies provide resources and information on how to navigate social services and public programs and may be an important partner to Planning Councils. Find your local agency or council on aging here.

3. Ensure Services Most Utilized by Individuals Over 50 Are Included in Priority Setting

Planning Councils must provide the RWHAP Part A grantee with priorities for services, usually in the form of a list of critical service categories, including resource allocation recommendations, and a detailed justification of the need. The Part A grantee uses this information to make decisions about how to allocate resources across different services. Using data from the needs assessment (particularly a focused needs assessment on HIV and aging), the Planning Council could ensure that services used
more heavily by individuals over 50 are prioritized. This could include prioritizing housing, food bank/home delivered meals, or insurance assistance depending on what local data indicates. For instance, some Planning Councils assess all funded service categories and rank them in order of importance.\(^9\) Ensuring that services most important to individuals living with HIV over 50 have a high ranking will help inform the Part A grantee to make decisions that prioritize the needs of this population.

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4. Use Planning Council Directives to Prioritize HIV and Aging

Planning Councils use “directives” to provide the RWHAP Part A grantee with guidance to recommend action on identified priorities. Planning Councils could use a directive to elevate the needs of individuals aging with HIV and make recommendations for investment in services that better meet these needs. A directive focused on HIV and aging could include specific recommendations to invest in workforce development (e.g., a broader provider network that includes HIV and geriatric expertise), pilot new service delivery models\(^9\) to assess what works best for an aging population, or allocate additional funds to social services identified in needs assessments of this population, including food and nutrition and housing.

**SAMPLE DIRECTIVE FOCUSED ON HIV AND AGING**

**Priority population:** RWHAP Part A clients over the age of 50

**Goal:** Improve health outcomes of individuals living with HIV over the age of 50 by improving retention in care

**Directive:** The RWHAP Part A grantee should partner with the State Health Insurance Assistance Program (SHIP) for Medicare

**Performance measure:** Reduce gaps in access to care for individuals living with HIV aging into Medicare

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5. Ensure HIV and Aging Issues Are Included in Broader HIV Plans

Planning Councils can also help to elevate HIV and aging priorities through their participation in broader HIV planning activities, including the RWHAP Part B SCSN and the EHE initiative plans discussed above. Inclusion of individuals over 50 as a priority population in statewide plans is essential to increasing awareness of this growing population. Setting forth broad goals that include this population helps to catalyze the political action and investment needed to reconfigure services and funding to better address the needs of individuals living with HIV over the age of 50.
Conclusion

RWHAP Part A Planning Councils play an important role in ensuring that the needs of individuals aging with HIV are met. This toolkit should serve as a resource to help empower and guide individuals to participate in the Planning Council process, whether by pursuing formal membership on a Planning Council or by participating in a more informal manner as a non-voting community member.
Appendix A: Glossary

ADAP: AIDS Drug Assistance Program, funded through RWHAP Part B, provides medication access and insurance assistance to low-income individuals living with HIV.

Administrative agent: the organization, agency, or entity that assists the RWHAP grantee to carry out administrative activities (e.g., developing and fielding requests for proposals, disbursing funds, and monitoring contracts).

AETC: AIDS Education and Training Centers are regional technical assistance providers that provide education and training for primary care providers and other members of the HIV workforce. AETCs are funded through RWHAP Part F.

CBO: Community based organizations provide services to a specific community or geographic location and make a large portion of the HIV provider network.

CDC: The Centers for Disease Control and Prevention is the federal agency that administers HIV Prevention and Surveillance funding.

CEO: The Chief Executive Officer is the official recipient of RWHAP Part A funds, usually the mayor or chair of the county board of supervisors.

Core Medical Services: medical services including: ADAP treatments, AIDS pharmaceutical assistance, Early Intervention Services (EIS), health insurance premium and cost-sharing assistance, home and community-based services, home health care, hospice, medical case management, medical nutrition therapy, mental health services, oral health care, outpatient/ambulatory health services, substance abuse outpatient care. For definitions of each RWHAP service see HRSA/HAB Policy Clarification Notice 16-02. Unless they have a waiver, Part A grantees must spend at least 75% of funds on core medical services.

EHE: The Ending the HIV Epidemic Initiative is a federal initiative launched in 2019 that provides targeted funding to jurisdictions with the highest demonstrated need to end new HIV infections.

EMA: Eligible Metropolitan Areas are eligible for RWHAP Part A funds and are defined as metropolitan areas with a certain number of new and cumulative AIDS cases based CDC data.

Epidemiologic Data/Profile: A description of the status and distribution of an infectious disease in a specific geographic area, usually drawn from health department HIV surveillance data. For HIV, includes description of burden of HIV in the population of an area in terms of socio-demographic, geographic, behavioral, and clinical characteristics of persons newly diagnosed with HIV, people living with HIV, and persons at higher risk for infection.

HRSA/HAB: The Health Resources and Services Administration HIV/AIDS Bureau is the federal agency that administers the RWHAP.

HOPWA: The Housing Opportunities for People with AIDS program is a federal program that provides funding to support housing for people living with HIV and their families.

Medicaid: State program (with a combination of state and federal funding) that provides health insurance to low-income individuals.
APPENDIX A: GLOSSARY
continued

**Medicare:** Federal program that provides health insurance to individuals over the age of 65 and individuals living with a disability.

**RWHAP:** Ryan White HIV/AIDS Program, a federal program created to address the health care and service needs of people living with HIV.

**SCSN:** The Statewide Coordinated Statement of Need is a written statement of HIV service needs for the state and includes input from all RWHAP Parts.

**Support Services:** RWHAP non-medical services including: childcare services, emergency financial assistance, food bank/home delivered meals, health education/risk reduction, housing, legal services, linguistic services, medical transportation, non-medical case management, other professional services, outreach services, and permanency planning. For definitions of each RWHAP service see HRSA/HAB Policy Clarification Notice 16-02. Unless they have a waiver, Part A grantees may spend no more than 25% of funds on support services.

**TGA:** Transitional Grant Areas are eligible for RWHAP Part A funds and are defined as metropolitan areas with high new and cumulative AIDS cases (but slightly lower than EMAs) based on CDC data.
Appendix B: RWHAP Part A Funding: From Congress to Service Delivery

CONGRESS
Appropriates (or allocates) money for the Ryan White HIV/AIDS Program (RWHAP), including Part A

HRSA HIV/AIDS BUREAU
Applies statutory funding formula based on HIV/AIDS cases for RWHAP Part A grantees and disburses funds to EMAs and TGAs

MAJOR CITY OR COUNTY GOVERNMENT (PART A GRANTEE)
The chief elected official (CEO) in the major city or county government in the EMA or TGA is the official Part A grantee; the CEO may designate a lead agency to administer the grant.

EMAs (eligible metropolitan areas) = metropolitan areas with a certain number of new and cumulative AIDS cases based on Centers for Disease Control and Prevention (CDC) data.

TGAs (transitional grant areas) = metropolitan areas with high new and cumulative AIDS cases (but slightly lower than EMAs) based on CDC data.

Do I live in an EMA or TGA?

HIV SERVICE PROVIDERS
The Part A grantee, with resource allocation input from the Planning Council/Body, disburses funding to HIV providers (e.g., clinical providers, community-based organizations, support services) through competitive process and monitors sub-recipient activities and quality of services. Unless they have a waiver from HRSA/HAB, Part A grantees must spend at least 75% of funding on core medical services and no more than 25% on support services.

PLANNING COUNCIL/BODY
The planning council or planning body works with the Part A grantee to identify service needs and priorities and inform resource allocation to RWHAP providers.
NOTES


2 The RWHAP statute requires Part A EMAs to have planning councils. The law does not specify that TGAs follow the same legislative requirements when it comes to planning councils, but TGAs are required to have a process for seeking input and engagement from communities impacted by HIV. Many TGAs voluntarily follow the planning council requirements. For the purposes of this toolkit and for the sake of simplicity, reference to planning councils also includes TGA planning bodies.


Mission Statement
For 40-plus years, SAGE has worked tirelessly on behalf of LGBT older people. Building off the momentum of the Stonewall uprising and the emerging LGBT civil rights movement, a group of activists came together to ensure that LGBT older people could age with respect and dignity. SAGE formed a network of support for LGBT elders that’s still going and growing today. SAGE is more than just an organization. It’s a movement of loving, caring activists dedicated to providing advocacy, services, and support to older members of the LGBT community. LGBT elders fought—and still fight—for our rights. And we will never stop fighting for theirs.