



BECOMING VISIBLE:

Addressing Stigma Experienced by
Older Adults Living with HIV.

**I AM
NOT...**

DIRTY AN ADDICT
DYING HELPLESS
BEING PUNISHED
A VICTIM
ALONE **SICK**
A STEREOTYPE
A WHORE **GUILTY**

**I AM
HIV
POSITIVE**

THE STIGMA PROJECT / LIVE HIV NEUTRAL

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OBJECTIVES:

1. Become familiar with End AIDS Washington 2020
2. Understand how HIV Stigma and Age are interrelated
3. Successful Aging – mastery, resilience, generativity, and social support
4. Become familiar with the U=U Campaign
5. Learn how peers impact this work



End AIDS Recommendations

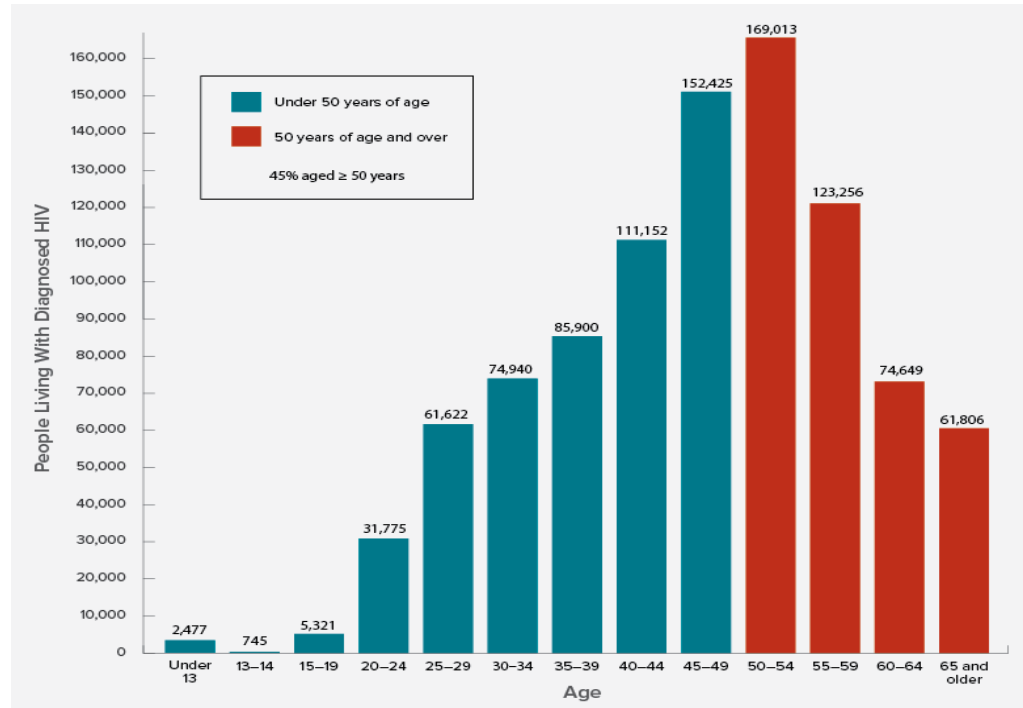
In 2015, people across Washington State completed surveys and participated in town halls and community conversations to make recommendations about how to End AIDS.

- Identify and reduce HIV stigma
- Reduce HIV-related disparities
- Implement routine HIV testing
- Increase access to pre-exposure prophylaxis (PrEP)
- Create health care that meets the needs of sexual minorities
- Improve HIV prevention and care for substance users
- Remove barriers to insurance and increase health care affordability
- Increase access to safe, stable, and affordable housing
- Deliver whole-person health care to PLWH
- Launch Healthier Washington for Youth
- Include meaningful community engagement and empowerment

DEFINITIONS

- **Stigma:** A mark of disgrace occurring within a power structure that is reinforced by labeling, stereotyping, separation, status loss, and discrimination.
- **Ageism:** Negative attitude toward aging based on the belief that aging makes people unattractive, unintelligent, asexual, unemployable, and mentally incompetent.

DEMOGRAPHIC OF PEOPLE LIVING WITH HIV



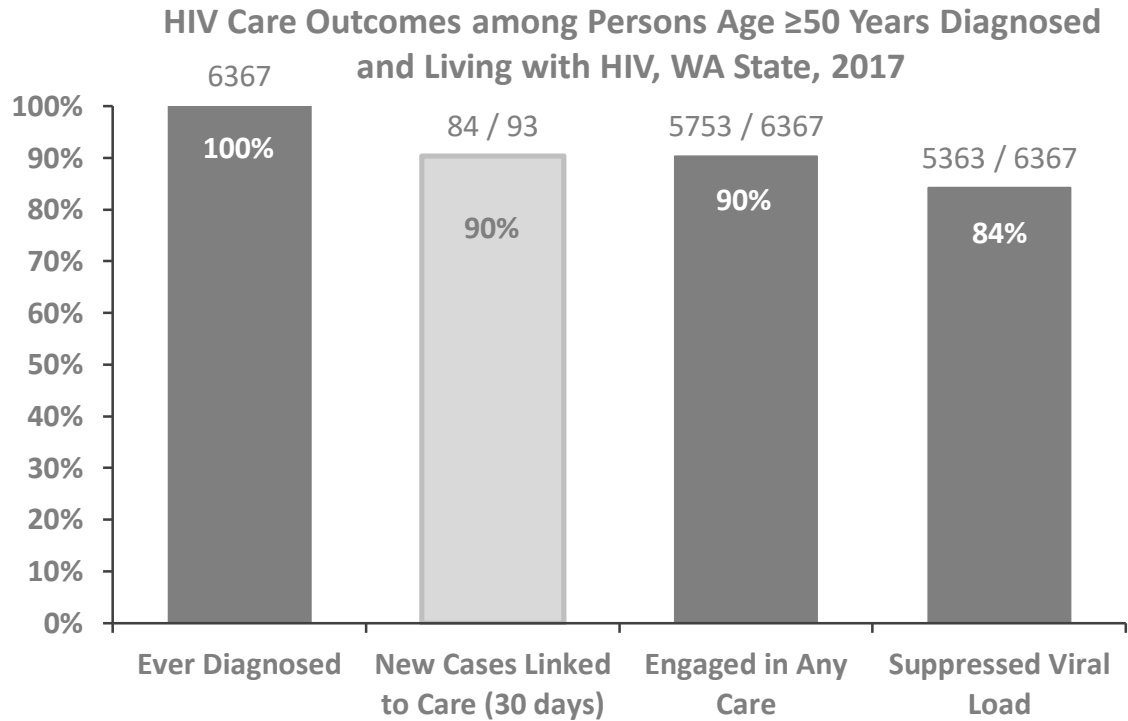
45% OF PEOPLE LIVING WITH HIV ARE AGED 50 OR OLDER

CDC (2015)

HIV Over 50 in Washington State

- Persons age ≥ 50 years account for 49% of all persons living with HIV in Washington
- Persons age ≥ 50 years account for more than 20% of all new HIV diagnoses in Washington

What's working...



Types of Stigma

- **Anticipated**
- **Enacted**
- **Internalized**

What does HIV stigma and ageism look like?

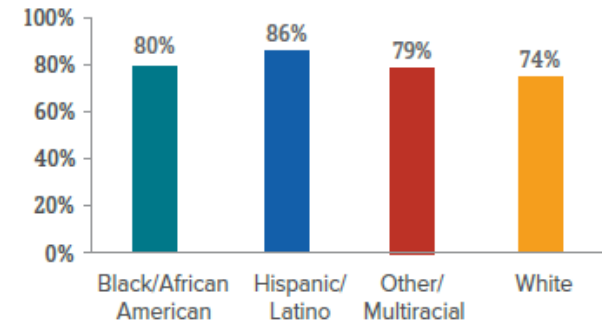
- “I was called an AIDS infested old bitch” – survey respondent
- *Fear of contagion or passing on HIV to a loved one – Emlet et al., (2006)*
- “I am ashamed that I am HIV-positive” – MMP, CDC
- *“Invisible in the gay community” – survey respondent*
- “I live in assisted living—the owner was talking with me and when I told him I had AIDS he backed up 10 feet and said he was afraid of getting it from me.” –survey respondent
- *Feeling the need to hide your HIV status*

Internalized HIV Stigma

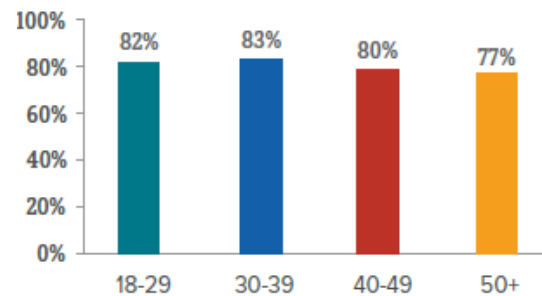
Which groups are most affected by internalized HIV-related stigma?

Percentage reporting internalized stigma:

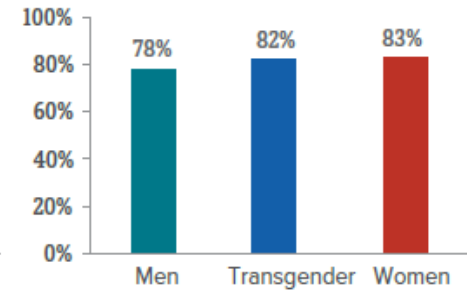
By Race/Ethnicity



By Age



By Gender



STIGMA: WHAT NOT TO SAY

Protective Factors

MASTERY:

The sense that someone has control over their own situation (including managing their HIV disease) and future.

Emlet et al., 2017

RESILIENCE:

A pattern of positive adaptation in the context of past and present adversity.

Emlet et al. 2017

Protective Factors

GENERATIVITY:

The desire to give back to your community.

Emlet et al., 2017

SOCIAL SUPPORT:

Strength in community, sense of belonging, and often shared experience.

Emlet et al. 2017

What we're concerned about...

Mental Health:

- Social isolation
- AIDS Survivor Syndrome
- Loss of Purpose
- Caring for partner, friends, & family
- Depression

Physical Health:

- Pulmonary
- Cardio
- Metabolic
- Renal
- Multi-morbidities

Sexual Health

- People over 50 still have sex!

UNDETECTABLE = UNTRANSMITTABLE



“People who take ART daily as prescribed and achieve and maintain an undetectable viral load have effectively no risk of sexually transmitting the virus to an HIV-negative partner”
- CDC, 2017

“Stigma is a public health crisis and the greatest challenge to ending the epidemic”

– Bruce Richman, MEd., Prevention Access Network



- Reduces the shame and fear of sexual transmission and opens up possibilities for conceiving children without alternative means of insemination.
- Dismantles HIV stigma on the community, clinical, and personal level.
- Encourages testing, treatment uptake, adherence, and retention in care.
- Offers a strong public health argument for universal access to diagnostics, treatment, and care to save lives, bringing us closer to ending the epidemic.

DOH Funded Peer Navigation (CHW)

Peer Navigators (Community Health Workers) are often HIV-positive, medication adherent role models, living with a shared experience as well as a shared community membership with the populations they work with.



PEER NAVIGATOR

WHAT DOES A PEER
NAVIGATOR DO?



I define the scope of my position with the 3 points of END AIDS WA

REDUCE NUMBER OF NEW DIAGNOSES

LINK AND MAINTAIN TO HEALTHCARE

OVERALL VIRAL SUPPRESSION

Working with HIV positive individuals

- Talk to them about importance of medication adherence and avoiding drug resistance.
- Numbers i.e. CD4s, Viral loads
- Answer questions about sexual health and HIV.
- Access to healthcare and medications
- STIGMA (who and how to tell about status) U=U
- SUPPORT (share my status and some of my story)
- Social opportunities/ Community events, volunteer opportunities etc.
- Medical Case Management

Madison Clinic at KPHD

- Check in with clients and also people not in case management
- Ask about any problems with adherence and general health
- Do follow up for providers
- Advocate for clients
- Talk about support and social opportunities
- Share new HIV information
- Promote U=U
- Transportation
- Promote Medical Case Management Program

Work with high acuity clients

- Check in about adherence
- Phone calls
- Make sure they have access to medical care and medication
- Coach on medication adherence and importance of VL and CD4 testing
- Case managers will give me heads up on clients that may need my support
- Advocate

COMMUNITY

- Support community and volunteer activities (monthly Red Ribbon Dinner, Pride Booth, World AIDS Day, WSCE, HIV Quality Improvement group).
- Inform HIV community about any program issues or changes.
- Develop, print and distribute brochures, newsletter and other information
- Promote HIV Medical Case Management Program with community resource partners.
- Voting member of the State HIV Planning Steering Group (HPSG)

Information

- HIV news and information
- Drug updates
- PrEP and PEP (Pre Exposure Prophylaxis and Post Exposure Prophylaxis) information
- Activities and opportunities
- U=U
- Quarterly newsletter (contribute and distribute)

Work with Case Managers

- Assist with intake and meet new clients
- Accompany caseworkers to home visits
- Home inspections
- Fill in when case manager is out of office

Miscellaneous

- Client rides to medical appointments when applicable
- Syringe Exchange
- Run errands for Case Management i.e. pick up prescriptions or needed supplies for clients
- Accompany client to medical procedures (surgery)
- Troubleshoot
- Challenges....

Next steps...

Community Listening Sessions

- First one was held in Spokane, WA (Oct, 2018)
- More sessions will be planned monthly beginning in February and ending in June.

Formation of Special Emphasis Workgroup

- Consisting of community partners and providers who currently work with high numbers of 50+ individuals (including HIV specialists, gerontologists, and community liaison).

Creation of email for communication

- HIVover50@doh.wa.gov

DOH Program Update:

1. DOH has funded 10 peer navigators in 8 agencies!
2. DOH has partnered with DOC to fund 2 peers that work with justice-involved clients!
3. DOH is providing additional technical assistance for CBO's that already have peers in place (i.e. Lifelong's HART program and BABES)
4. Several peers were able to attend either USCA or Ryan White Conference, which provided unique opportunities for networking and professional development.

Questions?

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