



Follow the Leader: Shifting Power Through Patient-Directed Care

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Someday, the AIDS crisis will be over. Remember that. And when that day comes -- when that day has come and gone, there'll be people alive on this earth -- gay people and straight people, men and women, black and white, who will hear the story that once there was a terrible disease in this country and all over the world, and that a brave group of people stood up and fought and, in some cases, gave their lives, so that other people might live and be free. ~ Vito Russo, *Why We Fight* (1988)



Reflection

1. **Think of your last patient/client/consumer encounter.**
2. Who decided:
 - The agenda?
 - The goals?
 - The definition of success?
 - The next step?
3. Was the patient informed? Or were they directing?
4. Nothing About Us, Without Us (is for us)



Patient-Directed Care

- A model of healthcare where individuals are empowered with the authority, agency, and control to make decisions about their own healthcare, focusing on what matters most.
- Prioritizes the patient's personal values, goals, and desired outcomes rather than merely treating a specific disease.

Centers for Medicare & Medicaid Services. (n.d.). *Self-directed services*. Medicaid.gov. <https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services>

Tinetti ME, Naik AD, Dodson JA. Moving From Disease-Centered to Patient Goals-Directed Care for Patients With Multiple Chronic Conditions: Patient Value-Based Care. *JAMA Cardiol*. 2016 Apr 1;1(1):9-10. doi: 10.1001/jamacardio.2015.0248. PMID: 27437646; PMCID: PMC6995667.



TRADITIONAL APPROACH

Healthcare often asks:

“What is wrong?”



Focus on illness and symptoms



Provider defines the problem



Plan is provider-directed



Patient role: recipient



PATIENT-DIRECTED CARE

Patient-directed care asks:

“What matters to you?”



Focus on what matters most



Patient defines their priorities



Plan is collaborative and individualized



Patient role: partner and decision-maker

Well Intentioned
Data over Discussion
Maternal/Paternalistic
One “expert” in the room
The business of healthcare
Checklist Medicine



Better care starts when we move from fixing patients to **understanding people.**



Consultation →

Co-leadership

Professional authority →

Shared decision making

Care Recipient →

Subject Matter Expert

Core Shift in
Redistributing
Power

New York State Department of Health. (2026, May). *I deliver or oversee person-centered services*. New York State Medicaid Redesign Team. https://www.health.ny.gov/health_care/medicaid/redesign/person-centered_planning/i_deliver.htm

Element

Provider-Directed Care

Patient-Centered Care

Patient-Directed Care

Who sets the agenda?

Provider sets the agenda based on clinical priorities

Provider asks for patient input on the agenda

Patient sets the agenda; provider responds

Who makes decisions?

Provider makes decisions and gives recommendations

Decisions shared; provider recommends, patient agrees

Patient makes decisions with information & support

How are goals set?

Goals set by clinician (based on clinical standards)

Goals set together (provider + patient)

Goals set by patients with clinical guidance

Who defines Success?

Defined by clinical outcomes (e.g., viral load)

Defined by clinical outcomes and patient input

Defined by what matters most to the patient

Relationship Dynamic

Expert (Provider) → Recipient (Patient)

Expert (Provider) ↔ Partner (Patient)

Partner (Provider) ↔ Partner (Patient)

Focus

Disease and treatment

Whole person

What matters to the patient

Outcome

Compliance

Engagement

Self-determinant and optimal quality of life



Paving the Way to Patient Directed Care

- Participation is not the same as power.
- Shared decision making in:
 - Treatment planning
 - Medication decisions
 - Prevention choices
 - Care navigation
 - Referrals and Linkages

From Consultation to Leadership

Ascending Stair-Step Graphic

CONSULTED

Patient voice is heard, but not acted on

INCLUDED

Patient choice is possible, but authority is limited

LEADING

Shared agenda-setting, decision-making, and bodily autonomy

VOICE



CHOICE



AUTHORITY



Takeaway: Patient-directed care requires more than listening. It requires shared authority.





Taking Your First Steps

- Language
 - Medication Adherence → Medication Maintenance
- Comfortable in conversations with the “sex, drugs, and rock and roll” of HIV healthcare culture
- Centered in What Matters Most (to the patient)
- Decisional
 - While treatment choices may be limited by the complexity of the HIV virus, many of us are managing multiple comorbidities and psychosocial stressors with additional opportunities for choice and ownership

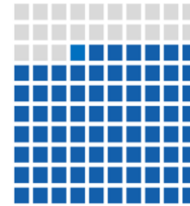


What Now and The Why of the Journey

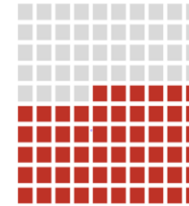
- Only People With HIV Can Stop The Spread of HIV
- We all have the right to make choices that are not in our best interest

Down the Road: Furthering the Why

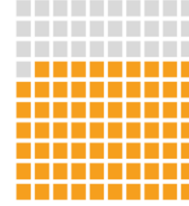
In 2024, for every 100 people living with diagnosed HIV in the United States



77
received
some HIV care



56
were retained
in care

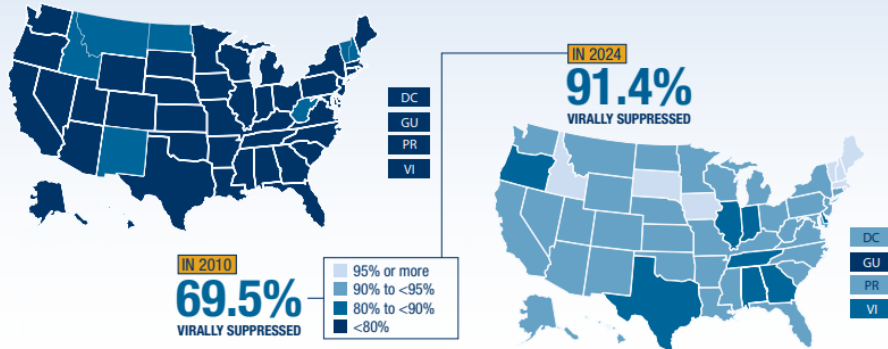


69
were virally
suppressed

Note. Data are presented for persons aged ≥ 13 years.



Figure 2
Viral Suppression^a Among Ryan White HIV/AIDS Program Patients, 2010 and 2024—United States and 3 Territories



Health Resources and Services Administration. (2025). *Ryan White HIV/AIDS Program annual client-level data report 2023* (Figure 2). U.S. Department of Health and Human Services. <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/2023-ryan-white-annual-data-report.pdf>

Centers for Disease Control and Prevention. (2026, May 18). *National HIV prevention and care objectives: 2026 update*. U.S. Department of Health and Human Services. <https://www.cdc.gov/hiv-data/nhss/national-hiv-prevention-and-care-objectives-2026.html>



Crossing The Finish Line

Where in my system or process could I give up power to create more space for patients to direct their own care?

- Be our educators
- Our cheerleaders
- Our advocates
- Our Partners

**Believe in us
and we'll
believe in you**



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