Linkage and Retention in HIV Care: One Size Does NOT Fit All!
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Disclosures

Presenter(s) have no financial interest to disclose.

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Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Recognize the importance of tailoring strategies for retention in care for people living with HIV

2. Identify at least 3 retention strategies that would be effective for a particular target population

3. Describe benefits and drawbacks of at least 5 different retention strategies
Improving Retention in Care

Evidence-based strategies for improving retention in care are sorely needed.

The spectrum of engagement in HIV care in the United States spanning from HIV acquisition to full engagement in care, receipt of antiretroviral therapy, and achievement of complete viral suppression.

Only 50% of Americans diagnosed with HIV were retained in HIV care in 2011.

5 agencies, 5 approaches

Though there are some key similarities, there are many differences to these approaches.

Differences are based on:
- Population served
- Setting
- History
- Agency scope

Not everything looks like traditional “retention work”!
Women Organized to Respond to Life-Threatening Diseases (WORLD) Oakland, California

Kristina Wong
Program Supervisor
In 2014, WORLD served 209 unduplicated clients

- 204 of whom were women
- 5 were transgender
- 83% living below the federal poverty level (shockingly low figures given the cost of living in the San Francisco Bay Area)
- 76% stably housed (they owned or rented their home)
- 12% (26 people) were homeless (streets/emergency shelter)
WORLD Demographics, age and race

**Age**
- 65+ 52%
- 45-64 41%
- 25-44 6%
- 13-24 1%
- 13-24 1%

**Race/Ethnicity**
- Black 60%
- Hispanic 22%
- White 8%
- Other 10%
WORLD Demographics cont.

Insurance Status (n=46)

- Medicaid: 63%
- Medicare: 9%
- Private: 0%
- None: 11%
- Other: 17%

HAART Prescribed (n=59)

- Yes: 34%
- No: 66%
Among all people living with HIV in Alameda County in 2012, only about 28% were virally suppressed, compared with 51% of WORLD clients.
High-Touch, Women-Focused
Hiring the Right Person

- comfortable with and knowledgeable about HIV
- passionate about this work
- extremely reliable
- self-disciplined
- compassionate
- patient
- non-judgmental
- culturally sensitive
- humble
- comfortable with silence
- comfortable not always “fixing” everything
- communication savvy (understands street lingo and slang)
- discreet and sensitive to client confidentiality and stigma
- knowledgeable about the link between trauma and HIV
- aware of the intersectionality of HIV with other health and social determinates
- able to “meet a client where they’re at”
Points of Client Entry

1. Test for HIV at WORLD, linked same-day
2. Referred to WORLD by another testing organization
3. Referred to WORLD by a social worker at another organization
4. Referred to WORLD by a friend or acquaintance who is already a WORLD client
5. Linkage Specialist reviews charts of WORLD clients and calls those who appear to be out of care
6. Recruited via “street outreach”
7. Self-refer based on word of mouth, social media, or internet
Starting the Linkage Relationship

Having patience in beginning the client/specialist relationship is critical.

_It’s hard to be scared in front of a stranger. So, you can’t be a stranger. You have to give it time until you aren’t a stranger anymore. That’s when they’ll let you in and when you’ll finally really be able to make a difference._

The staff person must show that they truly have the client’s needs in mind, not the clinician’s needs or the organization’s needs.

_Nine times out of ten, it’s not HIV that starts the conversation. They know why I’m here. I want them to tell me what they want me to do for them. It doesn’t do any good for me to come in with my agenda and tell them it’s time for them to go to the doctor. That just won’t work._
Goals of Linkage & Retention Efforts

CD4 count or viral load is not a mark of the impact that the Linkage Specialist had on someone’s life. The impacts that we make with our clients before they even think about their medical care – those are the most meaningful things.

Concrete goals are:

1. Building Trust
2. Helping Clients Get to Appointments
3. Supporting Clients in the Exam Room
4. Advocating for Support Services on the Client’s Behalf
5. Building the Client’s Capacity for Self-Advocacy
Goals of Linkage & Retention Efforts

Ultimately there are three main types of clients served by WORLD, each of which require different approaches by Linkage Specialists:

**Scenario 1: Clients With Logistical Challenges To Care**

**Scenario 2: Clients Ashamed About Lack Of Follow-through**

**Scenario 3: Clients Who Fear Poor Treatment / Are Embarrassed**
The Bottom Line:

To be a leader in the area of client retention requires a whole-hearted commitment to the idea of retention services.

1. Hiring and training full-time staff to focus on retention; sufficient numbers to keep caseload <50, or ideally 20-30

2. Giving Linkage Specialists leeway to provide what the client truly needs – might include “non-traditional” things

3. Supporting Linkage Specialists with clinical consultations, encouragement to have strong work/life boundaries and practice good self-care
ACQC Demographics, breakdown

As of 2010 there were 15,980 people living with HIV/AIDS in the borough of Queens (679 infections per 100,000 people).

- 71% were male and 29% female
- 41% were Black and 37% Hispanic
- 35% were men who have sex with men
- 18% people who inject drugs.
- 27% of people newly diagnosed with HIV infection were concurrently diagnosed with AIDS
ACQJC Demographics

Retention in ACQC Mental Health Services
- Not retained: 16%
- Retained: 84%

Retention in ACQC Harm Reduction Services
- Not retained: 13%
- Retained: 87%
ACQD Demographics cont.

Referral from ACQC to Medical Care
- Not referred: 6%
- Referred: 94%

Case Management Clients Retained in Medical Care
- Not retained: 17%
- Retained: 83%
A “One-Stop Shop”

ACQC administers their program as a “one-stop shop” with essentially all services available in their main Jamaica location (or in a building down the street), and satellite services extending to Far Rockaway and Woodside. Staff move fluidly between each of these locations. ACQC tries to create a client-centered atmosphere for clients to feel right at home.
Creating a Client-Centered Atmosphere

- Receptionist
  - Testing
  - Education
  - Linkage & Navigation Case Management
  - AHF Liaison or Linkage Specialist
    - Pharmacy
    - Clinic
    - First Step to Health

AHF
ACQC Fundamentals

1. Respect the client, and each other.

• Many clients are chronically disrespected in their lives
• Receptionist knows client’s names – all are greeted with a smile
• Assume the best of clients
• Dress professionally
• When a client is ready to receive help, set aside anything that’s not urgent
• This extends beyond clients, more importantly within staff
ACQC Fundamentals

2. The door is always open...literally.

- Very little is done by appointment
- When a client shows up at the office for services, give them *all* the services they can, before the window closes again
- “Open-door policy”
ACQC Fundamentals cont.

3. Coordination through collaboration.

- In many organizations with multiple services, care is coordinated through a central staff role (i.e. Health Home Care Manager).
- At ACQC, every staff member is expected to be familiar with complete service offerings, and working with the client in front of them to assess their other needs.
- As a staff member, your door is the right door.
ACQC Fundamentals continued

4. Casual Fridays are for self-care.

• Dressing down: wearing jeans to work and being comfortable.
• There are team huddles to discuss updates and changes
• Staff and colleagues are supported by management to provide assistance when needed
ACQC Fundamentals, 5.

5. Basic needs come first!

- Focusing on basic needs such as housing, food, clothing, and safety is the foundation of everything
- Challenging in a metrics-driven environment
- Need to build resources that help collect and track health outcome-related metrics, even while meeting basic needs
The Bottom Line:

4 things set the ACQC model apart:

1. Our peer model: the best client volunteers become “peers”, who are frequently promoted to regular staff positions

   Many of our peers have never worked before. No one has really given them the chance. It is amazing the commitment that you get from someone when they feel like you believe in them! No one is more committed...than the peers. They assume you’ll be judgmental and then you’re not? They will give back 200%.
The Bottom Line:

4 things set the ACQC model apart:

1. Our peer model: the best client volunteers become “peers”, who are frequently promoted to regular staff positions

2. Non-reliance on appointments, and open door policy

3. Decentralized structure (your door is the right door)

4. Serious commitment to staff self-care
AID Atlanta
Atlanta, Georgia

Johnny Rogers
Case Manager
AID Atlanta Demographics

Atlanta, GA MSA, 2000-14
Haven of Hope Demographics

Atlanta, GA MSA, 2000s
AID Atlanta Demographics, gender

AID Atlanta Clients by Gender, 2015 (n=521)
- Male: 439 (84%)
- Female: 68 (13%)
- Transgender: 14 (3%)

Haven of Hope Clients by Gender, 2015 (n=408)
- Male: 277 (68%)
- Female: 126 (31%)
- Transgender: 5 (1%)
AID Atlanta Demographics

**AID Atlanta Clients by Race/Ethnicity, 2015 (n=521)**
- Black/AA (69%)
- Latino/a (13%)
- White (15%)
- Oth/Unk (2%)

**Haven of Hope Clients by Race/Ethnicity, 2015 (n=408)**
- Black/AA (64%)
- Latino/a (5%)
- White (30%)
- Oth/Unk (<1%)
AID Atlanta Demographics, age

AID Atlanta Clients by Age, 2015 (n=521)
- 19-24 (6%)
- 25-34 (36%)
- 35-44 (26%)
- 45-54 (25%)
- 55-64 (7%)
- 65+ (1%)

Haven of Hope Clients by Age, 2015 (n=408)
- 19-24 (3%)
- 25-34 (19%)
- 35-44 (23%)
- 45-54 (35%)
- 55-64 (15%)
- 65+ (3%)
AID Atlanta Demographics, race ethnicity

VL Suppression by Race/Ethnicity

- **AID Atlanta (2015)**
  - Black/AA: 40% Suppressed, 61% Unknown, 25% Not Suppressed
  - Latino/a: 25% Suppressed, 74% Unknown, 73% Not Suppressed
  - White: 50% Suppressed, 50% Unknown, 0% Not Suppressed

- **Haven of Hope (2015)**
  - Black/AA: 31% Suppressed, 69% Unknown, 25% Not Suppressed
  - Latino/a: 18% Suppressed, 82% Unknown, 25% Not Suppressed
  - White: 67% Suppressed, 33% Unknown, 0% Not Suppressed

- **State of Georgia (2012)**
  - Black/AA: 50% Suppressed, 50% Unknown, 14% Not Suppressed
  - Latino/a: 53% Suppressed, 47% Unknown, 9% Not Suppressed
  - White: 46% Suppressed, 54% Unknown, 7% Not Suppressed
  - Oth/Unk: 43% Suppressed, 57% Unknown, 11% Not Suppressed

*Unknown: No VL data from 2012, presumed fallen out of care*
Intensive Case Management

People here are so stigmatized, they are so afraid of people finding out, they don’t talk to anybody. They suffer alone, and then they die. We have to reach out to them. Help them be connected. That’s how we keep them alive.

- Stigma has been shown to cause social isolation.
- People with “concealable stigmas” such as HIV infection sometimes avoid entering into close relationships, for fear of discovery and rejection.
- Earning and keeping someone’s trust allows them to be less isolated, and better able to care for their health.
AID Atlanta Fundamentals pt. 1

1. Go in and blend in.

• Different parts of the community have different needs
• Actively seek out underserved communities
• Work with them to find out exactly what is needed
• Built strong relationships with stakeholders and other respected people (including church leaders) who can act as facilitators
• Instead of a vividly marked “HIV testing van,” we do venue-based testing inside settings with good community relationships
2. Go beyond where everyone else goes.

We’re all fishing in the same pond here, so we want to go beyond where everyone else goes. They may have less population, but they have an incidence rate that we need to pay attention to.

- Go beyond the neighborhood, or even the metro area.
- Many patients in Georgia are only able to receive health services within a certain catchment area – which causes a major problem if they want to remain anonymous.
- Haven of Hope will see anyone who lives in the State of Georgia.

As long as they’re getting the care, and getting their medicines, that’s what matters. There are enough barriers out there. We ourselves shouldn’t be adding barriers to care on top of that.
3. Every client is an individual, with individual needs.

- Case managers start by identifying this client’s priorities
- Address those first
- Then identify barriers to entering and remaining in treatment, and do what needs to be done to overcome those
  - Could be transportation
  - Could be comfort with a provider
  - Could be something else entirely
3. Every client is an individual, with individual needs.

When they go home, they live with their mommas, their sisters, whatever. They keep themselves so closed down. They had a taste of the city life but now they’re back in the country. They can’t be themselves. So it really mentally drains them…Coming and talking to me, I’ve been able to bridge that gap. I don’t use big words. When I need to go hood, I go hood. When I need to clean it up, I clean it up…They want to be talked to in layman’s terms. Doctors have their things they always say… Reality ain’t happening that way.
4. Education as Prevention.

- The CDC notes that the same cultural factors that lead to higher levels of stigma in the South also limit access to accurate sexual health information.
- AID Atlanta’s robust education program aims to combat this:
  - Evolution Project
  - AIDS 101
  - Speakers Bureau
  - RightTRACK
  - Comprehensive Risk Counseling and Services (CRCS)
  - Healthy Relationships
The Bottom Line:

We can’t counteract all the stigma that our clients experience, but we can give them a place to be safe and take care of their health.

We do this by:

• Flying under the radar
• Going beyond the usual
• Building relationships at every turn

You’ve got to have some place in this world where you can be open, and let it all out. That’s the way I can help you.
SSHC Demographics

SSHC is located in Roseland, a Chicago Community Area with more than 20,000 families and 279 people living with HIV, with an HIV infection case rate of 44.8 per 100,000.

It borders Pullman, which has one of the highest infection rates in the entire city.
During 2015, SSHC renovated its mobile testing unit (MTU)

- Added two testing rooms
- Outfitting the van with an outside surround sound audio system, to draw in potential testers.

- 883 rapid HIV tests just in the first quarter of 2016
- On track to provide more than 3,500 tests this year
- Identified 6 people who were HIV-positive
- These tests were almost exactly evenly split between MSM (49.6%) and high-risk heterosexual females (50.4%)
SSHHC Demographics cont.

In addition to testing, HIV Prevention Program staff provided:
- 377 HIV presentations to over 2000 community residents in 2015
- Hosted community forums
- Held various fundraising and awareness-raising events

We also offer 3 kinds of case management:
- **Division of Rehabilitative Services (DRS),** for disabled clients
  - 112 active clients
  - 49% male, 46% female, and 5% transgender; 99% African-American
- **Supportive/Medical**
  - 42 active clients
  - 79% male, 21% female, 88% African-American
- **Corrections**
  - 45 active clients (normal caseload is 30)
  - 93% male, 7% female, 98% African-American
Collaborating for Success

We have an unflinching commitment to collaboration.

Not just a “buzz word”!

We weave it through all of our work, which is one of the major reasons SSHC is able to serve the people of Chicago’s South Side so well.
SSHC’s Keys to Collaboration, 1

1. Recognize the impact of disparities and scarce resources.

On the North Side of Chicago:
- 96,541 residents live in an area that is 3.1 sq. miles (31,142 people per sq. mi).
- Residents are 87% White, and 4% African-American.
- Only 11.4% of residents live below 100% of the Federal Poverty Level (FPL).
- 30% of residents over age 25 have a graduate-level degree.

On the South Side of Chicago:
- 44,495 residents live in an area that is 4.8 square miles (9270 people per sq. mi)
- Residents are 1.5% White, and 98.3% African-American.
- 23.2% of residents live below 100% of the Federal Poverty Level (FPL).
- Only 6% of Roseland residents over age 25 have a graduate-level degree.
SSHCC’s Key to Collaboration, cont.

1. Recognize the impact of disparities and scarce resources.

• Many South Side residents — particularly African American MSM — travel North for fun. Many test while they are on the North Side, which exacerbates the disparity in HIV-related funding that goes up North.

• When they come home to the South Side, there aren’t the same types of billboards or information; not the same types of education or resources.

• South Side works to fill that gap, and work with other organizations to fill the gap together.
SSHC’s Keys to Collaboration cont.

1. Recognize the impact of disparities and scarce resources.

We really are the “Help Center,” not just in name. With the MTU, we’re literally IN the community. Night and day, it doesn’t matter. We’ve been able to provide so much more than HIV prevention. We’ve become everything. We have to be a referral source for the community. Most of the things people ask? We’ve got somebody on the MTU that can give you some kind of direction, connect you with the help you need.

• Sometimes we do classic HIV prevention work
• Sometimes what we do is non-traditional!
  • Haunted House
  • Camping (the “Black Boy Scouts”)
  • Drumline
2. Foster good will with others.

Sometimes, potential clients come in for case management, but they already have a case manager somewhere else.

In those cases, we refer them back to their original case manager, but offer to support them in advocating for themselves to get the services they really need.

*There’s enough work for us in this community – we don’t have to try to take work from other organizations. I’m really big on collaborations and partnerships. I really believe that in order to create a more healthy community, we have to partner. We have to work with other providers and other organizations in the community. That’s really my biggest push for making sure that clients’ needs are met: working more collaboratively with other agencies.*

—Vanessa Smith, Executive Director
2. Foster good will with others.

Another example:

One weekend, SSHC was sponsoring a Gospel Fest. A colleague from another agency asked if they could do hepatitis C (HCV) testing.

SSHC is doing HIV testing, and has the capacity to do HCV testing as well – but the Executive Director said, “Sure, let’s work together.”

It’s critically important for SSHC to have good relationships with their colleagues, and that “we actively work to build good will with people whenever we can. That’s how you maintain a good reputation.”
SSHC’s Keys to Collaboration part 2 cont.

2. Foster good will with others.

This type of mutual respect and leveraging of reputation works in less formal situations, too: SSHC works with local gangs to ensure their own safety and the safety of clients.

*Those gangs, they are very violent, and they will stop what they’re doing. We’re given 5 minutes to safely give their guys the condoms, and then we have to keep it moving. They give us safe passage.*

Mr. Cherry, Outreach Supervisor

*I was able to talk with the gang members, and we gave them dinner, and we said, “Please don’t mess with our gay kids.” And it worked. They agreed to leave our kids alone.*

Charles Nelson, MSM Project Director
SSHC’s Keys to Collaboration, 3.

3. Build provider capacity whenever you can.

- Even though we’re usually not funded to do it, SSHC believes that building capacity of others is critical – it helps the people we’re trying to serve.
- We are in demand because we understand the importance of being engaged in your community.

There are usually 1 or 2 organizations that get funding [from CDC] to do work on the South Side of Chicago. One of them, a person who wasn’t African-American, came on the bus, and came to ask us how to do outreach efforts, because they were failing. And I was like, “How do you think you’re going to do outreach [here] on the bus?” A lot of large organizations get funded to try to provide services in a community...but they do not hire from the community, and they are not familiar with the community. We help where we can, but sometimes it’s just further evidence of why we are so successful.
4. If you don’t have it, find it.

- The benefit of a strong commitment to successful collaboration is that one agency doesn’t have to provide all the services that clients need.
- Many of the clients served by SSHC are those that have been rejected by other agencies.
- Many of them have significant mental health challenges, yet SSHC doesn’t offer mental health services on-site.
- Staff handle this through strong partnerships with agencies that do offer high-quality mental health services.
SSHC’s Keys to Collaboration, 5.

5. Keep learning and growing.

• “Clarity is our friend. If you don’t understand something, ask.”

• All staff are required to take 12 trainings every year, including trainings on cross-cultural work and self-care.

_I also think it’s about challenging staff. Keeping them engaged. Keeping them challenged with new programs, new projects to keep them really working on self-improvement. When we allow people to work on self-improvement, they stay. That’s part of the self-care, if they have time to work on themselves. This means trainings, support groups, mental health days. Sometimes the focus has to be on you. That’s a definite benefit to us._

—Vanessa Smith, Executive Director
The Bottom Line:

SSHC is able to be so collaborative with external agencies because staff have learned to be collaborative with each other.

Family-oriented closeness within the agency isn’t there by accident – it’s been created.

By collaborating with others, we serve our clients best. They know we are here for them, and care about them, and will do whatever’s needed to help them stay retained in care, living healthy and long lives.
AIDS Task Force of Greater Cleveland
Cleveland, Ohio

Robert Candage, LISW-S
Director of Clinical Services
ATGC Demographics, map

HIV Prevalence Rates (cases per 100,000 population) as of December 31, 2018

Prevalence by ZCTA (zip code boundaries)
- 1 - 50 per 100,000 (0.05%)
- 51 - 250 per 100,000 (0.05% - 0.25%)
- 251 - 500 per 100,000 (0.25% - 0.5%)
- 501 - 1000 per 100,000 (0.5% - 1.0%)
- 1001 - 1500 per 100,000 (1.0% - 1.5%)
- 1501 - 2056 per 100,000 (1.5% - 2.06%)

ATGC

CDPH

File: HIVPrebyZCTA07032014_zonprev.mxd
Date: July 7, 2014
Cleveland Department of Public Health
Source data: CDPH Confidential Surveillance Registry
Scale: 1:125,000
ATGC Demographics, breakdown

As of May 17, 2016, there were 670 active clients of ATGC.

- 459 (68.5%) were African American
- 10 (1.5%%) were Hispanic
- 185 (27.6%) were White
- The rest were another ethnicity (or did not note an ethnicity)

- This mirrors the HIV epidemic in Cleveland pretty closely: in 2012 PLWH for Cleveland as a whole were 72.3% African American, 16.8% White, and 7.8% Hispanic.
ATGC Demographics, gender

ATGC clients compared with Cleveland PLWHA overall, by gender

ATGC Clients

- Female: 26%
- Male: 73%
- Transgender: 1%

Cleveland PLWHA

- Female: 23%
- Male: 77%
- Transgender: (not tracked)
ATGC Demographics, age

ATGC clients compared with Cleveland PLWHA overall, by age

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<th>Age Group</th>
<th>ATGC Clients</th>
<th>Cleveland PLWHA</th>
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ATGC Clients | Cleveland PLWHA
ATGC Demographics, facts

• Only 4 ATGC clients lived in zip code 44114 (most-impacted)

• 17 clients (17%) lived in one of the four zip codes next-most-impacted by HIV

• The remainder of clients lived in areas outside of that most heavily-concentrated part of the epidemic

• ATGC draws from the entire Cuyahoga County region, not just those parts closest to the clinic and office
1. Care for the community.

_We are really attached to this community. We are more than a safe haven – we’re actively supporting people. We have a strong commitment to bettering the community and the people in it._

Sometimes, caring for the community simply means acting toward clients in ways that let them know they’re seen, and heard, and someone cares for them.

_When I first got diagnosed in ’07 I was nervous and upset. My doctor referred me to the Taskforce. When I got there I was crying, and the lady behind the desk came out from behind the desk and took my hand and said, “We’re here to help you.” I knew it was going to be ok._

–Toni, Receptionist and Client
ATGC Fundamentals, pt 2

2. Reflect the community and engage in diversity work.

- We have the ability to relate to the clients
- We meet the clients where they are
- We hire staff that reflects demographics most at risk
- It reflects the community we serve
- Many of them are living with HIV
2. Reflect the community and engage in diversity work.

We do diversity really well [here]. We do really frank discussions here about sex, race, all sorts of things. We don’t let things fester; we put it on the table and speak clearly and sort it out. Being willing to talk about it, being willing to be educated about it, being willing to call someone on it – this is the key. We check intent here, not just the value of the words that are being said. Intent is worth more than just the surface value of the words. So, in doing that, we recognize and call out unintentional bigotry. We can work with that. The real question is, do you have the capacity to gain insight? If yes, we will work with you. If no, then you have to go. One of the things we screen for when we hire folks is this capacity for insight. I don’t know if we do that consciously, but...you can be a highly religious person, and work very well in this agency, if you have insight into what your religion is doing and how to use that in the process. If you don’t have that insight, it’s going to get in the way.
3. Empower the clients to care for themselves.

If the client’s capable of doing 51% and you’re only letting them do 49%, then that’s a disservice. You need to recalibrate. It’s our rule that you don’t take over until you have to.

- Bob, Director of Clinical Services

Sometimes I get flustered. Nervous. Sometimes I think “OK, if someone else asks me a question...I swear...” They’re always on you. They don’t give you no room to slack, no room to stop doing anything. But, it’s one of the best things they do: staying on top of us. Once they feel like we’re not giving the most effort we can, they stay on us. They are always making sure that I’m 10 steps ahead of myself. They’re very trusting. They have trusted me with many things. That’s a big step. It’s hard to get trust from people. So that’s a big deal.

– Herman, Client and Volunteer
4. Create a safe space.

- Clients don’t have to have a “good reason” to be at ATGC
- They can hang out (e.g. in the computer lab) without time limits or expectations for action
- This helps clients know they are valued, and gives them the opportunity to grow and try new things
- This is especially evident with our youth program.
ATGC Fundamentals, pt 5

5. Take care of yourself, too.

• “Fun Committee” (help maintain staff morale)
• We take time to celebrate milestones and accomplishments
• We try to have a brown-bag lunch together at least once a week
  • “Everybody eats together, and we ask questions and get answers. We laugh and tell stories. We clear the air, and discuss where we’re headed.”
• We are a “work family”
• Personal days are supported – staff are expected to take them
• We hold “Open Houses” for staff and debrief when needed
5. Take care of yourself, too.

We’re caregiving, not caretaking. You can’t have a large ship on the Cuyahoga River. So, you don’t drive the large ship, you be the tugboat. Staff stay here for a long time because we help them be the tugboat. We remind them that they are here to support clients, but they can’t take on responsibility that doesn’t belong to them.
The Bottom Line:

Support clients and staff, to make sure no one falls through the cracks.

Doing so while honestly and boldly engaging in tough conversations about difference is what allows the staff to work together closely while embracing the diversity that makes them stronger.

We’re really, really good at taking care of people. It stems from leadership. We have an amazing leadership team that really gets humanity. The leadership has a high level of understanding that shit happens, and we support one another. The leadership gets that for staff, but gets it from a client perspective as well. Some of our clients have to decide between buying toilet paper or getting their meds; there’s no judgment about what people do. Everybody does everything they can to make sure that all the resources are brought to the table. The question is, how do we help this person, and not let them fall through the cracks?
Review of Main Points
Bottom line:

Retention work is often not traditional work.

Sometimes, retention work means appointment reminders or arranging transport.

But sometimes, it’s helping a client get to the laundromat before an appointment, or spending time walking with them around the lake.

(Ryan White may not explicitly pay for these things, per se...)
Similarities

All these programs:

1) work to empower clients and build their capacity to take control of their own lives and health.

2) understand that fostering strong relationships between staff and clients based on trust and consistency is a key to success.

3) recognize that self-care for staff prevents burnout, reduces turnover, and ultimately benefits clients.
Similarities, continued

All these programs:

1) work to empower clients and build their capacity to take control of their own lives and health.

2) understand that fostering strong relationships between staff and clients based on trust and consistency is a key to success.

3) recognize that self-care for staff prevents burnout, reduces turnover, and ultimately benefits clients.

BENEFITS:
• An empowered client is far more likely to thrive.
• Most clients won’t need you forever!

DRAWBACKS:
• It can be hard to recalibrate your desire to help.
• Sometimes you can feel helpless.
Similarities, cont.

All these programs:

2) understand that fostering strong relationships between staff and clients based on trust and consistency is a key to success.

BENEFITS:
• Trusting you can help build trust in others.
• Strong relationships feel good for both parties.

DRAWBACKS:
• This takes a lot of time! Slow, and not easily counted.
• Being hurt by others can damage the relationship with you.
Similarities, cont.

All these programs:

3) recognize that self-care for staff prevents burnout, reduces turnover, and ultimately benefits clients.

BENEFITS:
• Low turnover is a huge asset to a small organization.
• Happy staff make happy clients!

DRAWBACKS:
• Self-care means setting boundaries – and living with them.
• Staff self-care can take time away from service provision.
Differences

Some agencies try to be as comprehensive as possible: “one stop shops”

- Clients don’t have to travel all the time
- Once they build a relationship with one person, they are golden!
- Staff and resource intensive
- Hard to have expertise in so many areas at once

Some agencies stay lean, and make referrals to external resources

- Staff and expertise can be small/focused
- Collaborations can make your organization stronger!
- May not be as “easy” for clients
- Your success with helping clients relies on the conduct of others
Differences, cont.

Some agencies work hard to “blend in” when they work

- Good for clients who might not seek services for fear of stigma
- Can be less expensive this way!
- Might be hard to promote your services and/or be “found”
- Reliant on venues of others

Some agencies go for fancy signs, lights, and visibility

- Helps normalize HIV in the community
- Can be really effective at drawing in potential clients who are simply curious
- Might scare some people away
- Can involve moderate capital expenditures in some cases
Your Turn!
Take a handout.

Think of a challenging client who struggles to be retained in care.

Take about 3 minutes to write a basic description (nothing confidential):

- Gender
- Age
- Situation
- Major complicating factors
- Top 3 reasons you think they struggle to stay engaged in care.
Take a handout., cont.

Now, find a partner you don’t know, and trade worksheets.

Spend the next 5 minutes or so coming up with at least 2 suggestions for things this client’s agency might be able to do to help them stay engaged in care.

➢ Think outside the box.

➢ Try to be realistic! Ask questions if you need.
Take a handout, continued

Trade back your worksheets and spend 5 minutes discussing.

What is an idea you think could work?

Would you have thought of that?

What do you think simply won’t work?

Why? Explain (politely).
Questions and Discussion
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