Leveraging Health Information Exchanges to Help Re-engage People Living with HIV who are Lost to Follow-Up

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Learning Objectives

- Presentation 1: To describe the HASA-Healthix *Bottom-Up Project*, a unique collaboration between a Health Information Exchange (HIE) and organizations dedicated to re-engaging PLWH who have been *Lost to Care*
- Presentation 2: To recognize that the ability to find vulnerable out of care patients through technology is useful, but what is most crucial is being able to build and establish a relationship with them, and to understand stories of how transformative the Bottom Up program can be for these patients
- Presentation 3: To examine how organizational resilience and implementation science frameworks can be used to describe how partners have collaborated to overcome challenges experienced during implementation

Presentation 1: What is the *Bottom-Up Program?*

Presented by Peter Gordon, MD

PLWH Lost to Care – perhaps the Biggest Barrier to EHE

- The 2020 NYC HIV Care Cascade

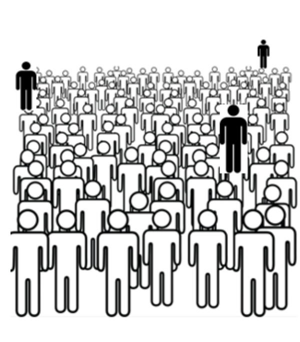
>10,000 PLWH Lost to Care

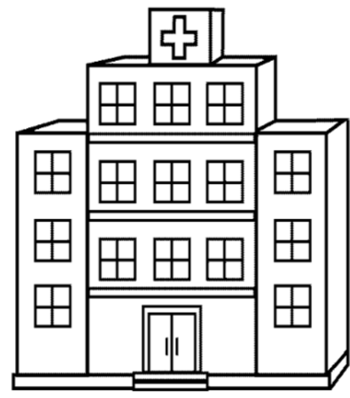
Limited Evidence-Based Interventions for Re-engagement

- Many HIV interventions show strong evidence of efficacy for improving linkage to care, subsequent retention in care and viral suppression
- Limited interventions have found strong evidence of efficacy for improving care re-engagement following a prolonged lapse in care
- **Data-to-care** represents a promising approach but often fails due to lack of basic or up to date contact information

The *Bottom-Up Project*

- **Maximizing linkage and re-linkage to care requires *both* an individual strategy and a population health strategy**
- They must work at multiple levels of care
  - Individual
  - Clinic
  - Population





Benefits of Health Information Exchanges (HIEs)

- **Health Information Exchanges (HIEs) are *ideal* partners for this challenge**
- Allows health care professionals and patients to appropriately access and securely share a patient's medical information electronically

Health Information Exchanges (HIEs)

- HIEs aggregate data in ways that no single institution, or EMR, can match

Healthix

> 20,000,000 patient records

> 8,000 contributing organizations

Healthix Data Sources

Hospitals & Health Care Systems

Independent Physician Practices of All sizes

Long-term Care, Nursing Facilities

Behavioral Health Facilities

Federally Qualified Health Centers (FQHCs)

Community Based Organizations

Home Care

EMS

Health Plans

PPS Leads

Medicaid Health Homes

Independent Pharmacies

Independent Labs & Radiology Centers

NYC Correctional Health Services

All Other Public HIEs in New York State

Medicaid Claims

The *Bottom-Up Project*

- Utilizes the reach of an HIE through 'event notification' to alert care navigators in real time to clients Lost-To-Follow-Up (LTFU)
- Can provide difficult to obtain and highly useful information – like updated contact information from housing agencies!

How Does This Work?

- HIV clients **LTFU ≥ 9 months** at NYP/CUMC
  - Traditional outreach (using contact information known to NYP/CUMC)
  - HIE-enhanced outreach (using contact data via the HIE portal)
  - HIE alerts (acting on real-time alert)
- Outreach team schedules appointments, provides visit reminders, conducts health promotion and offers Health Home enrollment

The Bottom-Up Project Partners and Steps

Project partners

- New York-Presbyterian
- Alliance for Positive Change
- Housing Works
- Healthix
- NYC HIV AIDS Service Administration
- CUNY Institute for Implementation Science in Population Health (CUNY ISPH)

NYP and HASA engage in efforts to consent clients to Healthix, although not a required step in program

STEP 1
NYP generates LTFU list and sends to Alliance & Healthix

STEP 2
Healthix programs notifications so alerts are sent to Alliance & NYP

STEP 3
Alliance uses Healthix and other data sources to search for clients

STEP 4
Alliance makes outreach phone calls and home visits to engage clients who are located

Client engages by enrolling in Alliance program

Client does not agree to engage

STEP 5
Client Engagement Activities

receives supportive services

attends 2 medical appointments

Client graduates from program

STEP 6
Monthly, Alliance returns NYP data tracker with process and outcome data on clients

Presentation 2: What it Takes to Find Clients

Presented by Sharen Duke, MPH and Terriell Peters

Alliance-NYPH Bottom-Up Pilot Collaboration with HASA & Healthix

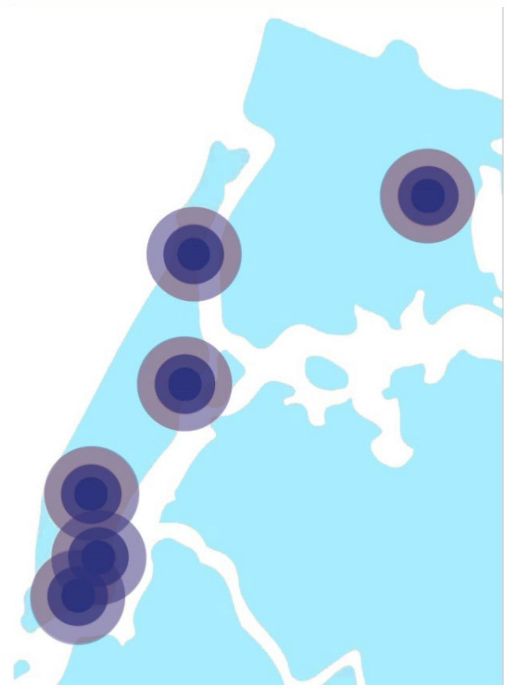
New York Presbyterian Hospital's HIV Center for Excellence and Alliance for Positive Change have created a partnership with HASA, Healthix and CUNY ISPH to design, implement and evaluate a peer-delivered linkage to care program, informed by multiple data sources, that locates and engages hundreds of HIV-positive Medicaid-eligible individuals who have fallen out of medical care, and/or are not virally suppressed.

Alliance for Positive Change

Alliance for Positive Change helps New Yorkers affected by HIV and other chronic illnesses make lasting positive changes towards health, housing, harm reduction, recovery, workforce development, and self-sufficiency.

Each year, we help New Yorkers:

- Get tested for HIV, HCV, COVID
- Manage substance use & recovery
- Train individuals to become Certified Peer Workers
- Access medical care to take charge of their health
- Escape homelessness
- Rejoin the world of work
- Replace isolation with community
- And lead healthier and more self-sufficient lives



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Program Components

- Leveraging technology – Healthix / Medicaid portal –to find vulnerable out of care patients is useful
- Building and establishing a relationship with vulnerable out of care patients is crucial
- Stories and experiences of patients and peer navigators provide insight to some of the powerful transformations that have occurred through the Bottom Up program interventions

Quote From Program Staff

"The finding of the client is the hard part, but getting the client engaged is the hardest part."

-Alliance Linkage to Care Specialist

Quote from Program Participant

“They don’t overwhelm you. They meet you where you are. They will say here are the tools, and we are going to teach you how to build with these tools… up to you to learn to build or learn to keep destroying….. I built myself with sticks and twigs, they taught me to build with stones and metal so my foundation is going to stick and I don’t have to worry about my house caving.”

–Linkage to Care Client

Role of Alliance

Alliance for Positive Change

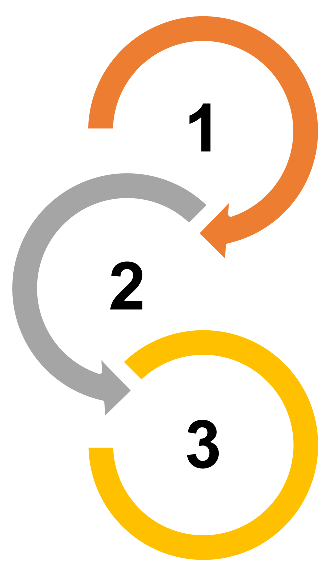
- Utilize Peer Navigators to find and re-engage NYP patients on the "Lost-to-Follow-Up" list with a goal of consent, enroll and link patients to:
  - Medical care within 2 months of program enrollment
  - Health Home Care Management
  - Treatment Adherence Services
- Utilize technology (i.e., Healthix demographic information and alerts) to supplement traditional "feet on the ground" outreach methods
- Document patient re-engagement with medical provider within 2 months of enrollment; enroll in Health Home care management

Data Points Provided by NYPH

NYPH generates a monthly list of people living with HIV (PLWH) who have received been lost-to-follow-up (LTFU), defined as having no visits in the prior 9+ months.

Contact Information	Demographics	Patient ID #'s	Medical Contact	Viral Load Information
Name	Date of Birth	Medical Record Number	HIV/Primary Care Provider	Last Viral Load Date
Address	-	Insurance Identification Number	Last Visit Date	Last Viral Load Result
Cell/Home Phone Number	-	-	-	-

Alliance Data Utilization Strategy



Alliance **utilizes numerous data sources** to locate hard to reach clients:

1. Medicaid Portals—Healthix & MAPP

- Updated address and phone number
- Insurance Eligibility
- Last billing date and/or site

2. Google Maps

- Cluster addresses by zip codes to maximize outreach efficiency

3. Criminal Justice Databases

Successful Outreach & Engagement Techniques

Mapping: Utilize Google Maps to organize outreach activities by neighborhood-- helps to increase the number of home visits in one day. This strategy enables Peers to make up to 15 home visit attempts in one day.

Matching: Try to match the Peer to the demographic characteristics/life experience of the client (e.g., pair women with female Peer Navigator)

Motivational Interviewing: Meet the client where they are, to create trust and engagement in medical and social support services, with Peer as health coach

Personal Experiences: Shared lived experiences of Peer Navigators help the client to open-up

Whole Person: Focus is broader than HIV diagnosis. Clients feel more comfortable when you speak about their life in general, and offer help to overcome barriers

Confidentiality: Speak in code when you are around family members/roommates, or public spaces

Incentives: Help to open the conversation and build trust

Role of Alliance Peer Navigators

- Shared Lived Experience
  - Culturally
  - Linguistically
  - Socially
  - Economically
- Reduce Barriers to Care
- Foster Trust
- Promote Long-term Engagement
- Guide Patients Toward Health and Stability

Photo: David Nager/Alliance

Role of Alliance Peer Navigators

Linkage to Care Service Strategies:

- Peer outreach and connection to care
- Peer coaching and motivational interviewing
- Reminder calls and accompaniment to clinic and specialty appointments
- Conduct home visits and community field work
- Address social determinants of health
- Provide COVID education & vaccine access
- Conduct Treatment Adherence Coaching
- Enroll in HH care management and provide "warm hand-off"

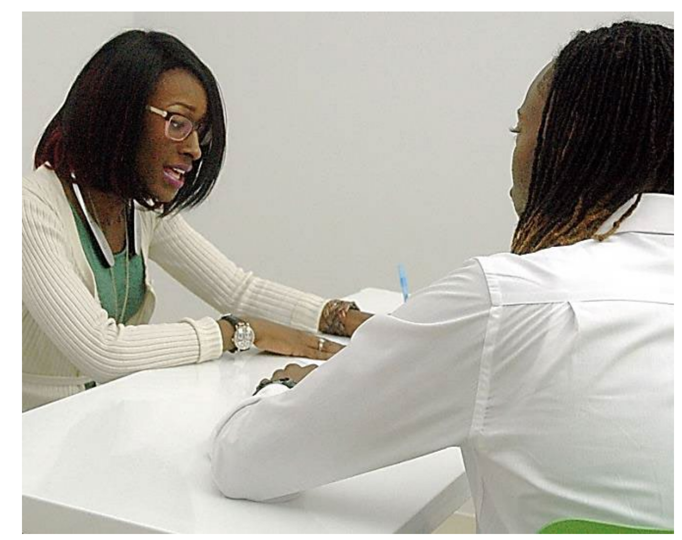


Photo: David Nager/Alliance

Role of Alliance Peer Navigators

Outreach:

- Utilize the demographic and contact information contained in the LTFU file to attempt to contact the client telephonically and via field-based outreach
- Utilize Healthix portal to obtain new/updated demographic information
- Respond to Healthix alerts
- Educate clients on different Alliance programs and supportive services

Engagement:

- Consent clients to Alliance, NYP, Health Homes and Healthix
- Initiate the linkage to medical care process by identifying preferred medical site and scheduling an appointment
- Accompany client to first medical appointment, as needed
- Provide Treatment Adherence coaching, as needed

Alignment:

- Documentation of minimum one medical appointment within two months of program enrollment

Photo: David Nager/Alliance

Linkage to Care Service TARGETS

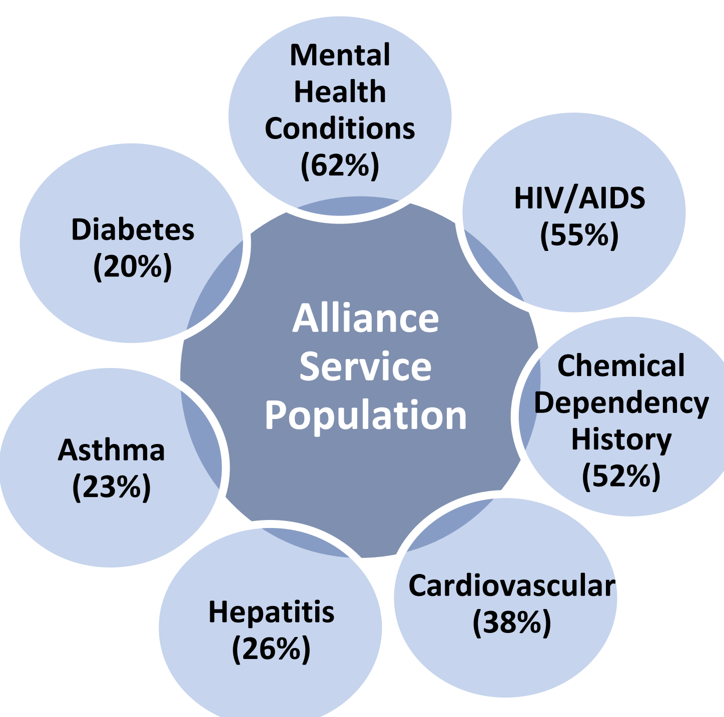
- **Outreach** 100% of all referred Patients who are lost to care (Annual Projection of 300 Patients)
- **Find/Locate** 40% (120) of referred Patients
- **Obtain Consent** for 33% (40) of Found Patients
- **Conduct Social Determinants of Health & COVID Education** for 33% (40) of Found Patients
- **Re-engage** 60% (24) of Consented Patients into medical care
  - Successful re-engagement includes visit with HIV Specialist and completion of viral load and syphilis test
- **Enroll** 10% of Consented Patients into Medicaid Health Homes

NYPH/Alliance Patient Demographics

Most NYPH/Alliance patients have multiple chronic illnesses.

We address *Social Determinants of Health* to enhance access to needed care and support:

- **Housing:** unsafe, unstable, threats of eviction, rent arrears, needed repairs
- **Mental Health / Substance Use:** depression, anxiety, addiction
- **Food Insecurity**
- **Entitlements:** undocumented, Medicaid reactivation, spend-downs



Peer Navigation: Outreach to Found

Demographics: N = 221
July 2021 – May 2022

Sex at Birth
- 19% Female
- 81% Male

Age
- 8% 20-29 years
- 33% 30-39 years
- 19% 40-49 years
- 21% 50-59 years
- 12% 60-69 years
- 8% > 70 years

Boro of Residence
- 46% Manhattan
- 38% Bronx
- 9% Brooklyn
- 2% Queens
- 1% Staten Island
- 5% Outside of NYC

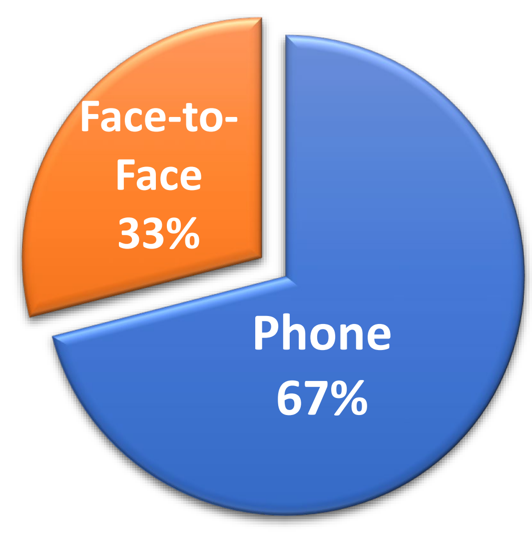
Peer Navigation: Outreach to Found

Alliance conducted 4,181 outreach activities

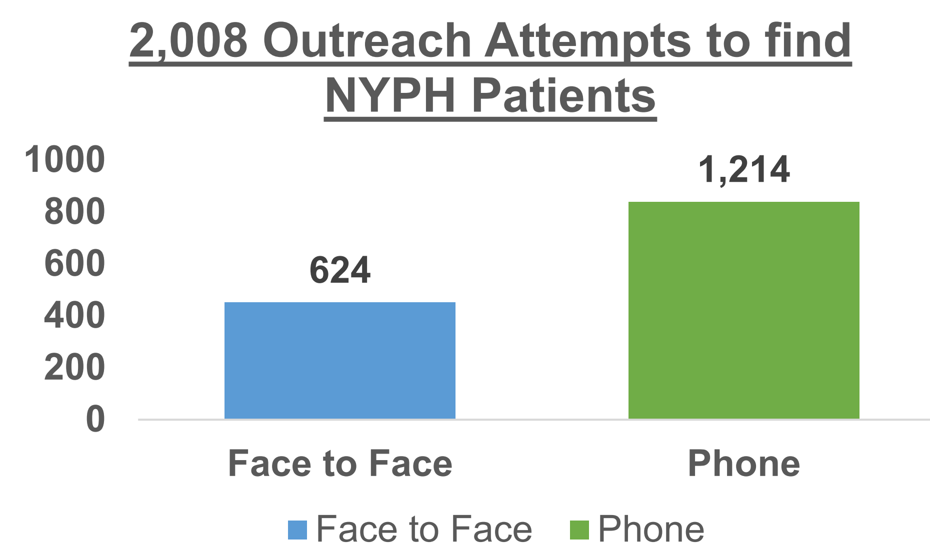
- **Phone: 1,341**
- **Face to Face: 667**
- **Healthix/MAPP: 2,173**
  (internet search)

Alliance found 116 out of 221 (52%) NYPH HIV-positive patients who were chronically lost-to-care (> 9 mos.)

July 2021 – May 2022



Methods Used to Locate Members



SUCCESSFULLY LOCATED 116 OUT OF 221

# **NYPH OUTREACH** Located **N=221**	# **OUTREACH Activities**	# NYPH Patients FOUND	% NYPH Patients FOUND
Face to Face	**624 (33%)**	**43**	**25%**
Phone	**1,214 (67%)**	**127**	**75%**
Total Outreach	**2,008**	**170**	**100%**

Average Outreach Attempts Per Patient = 11

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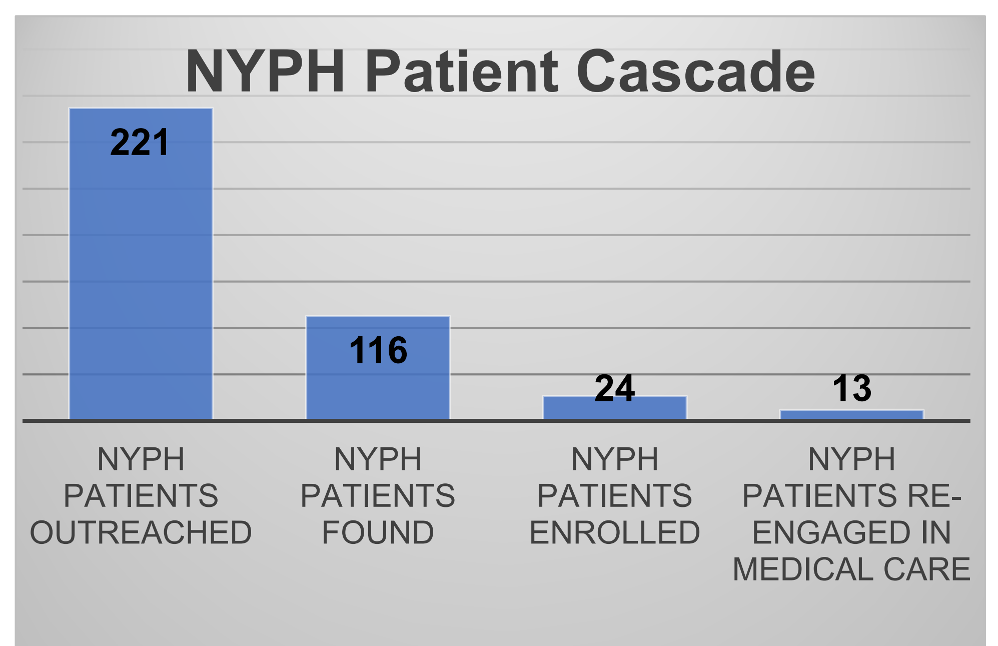
2022 Program Outcomes



- **In 11 months, Alliance conducted outreach and Linkage to Care services for 221 NYPH patients who were lost-to-follow-up (out of care for > 9 months)**
- Of the 221 ***OUTREACHED*** members, **52% (116)** of members were ***FOUND***
- Of the 116 ***FOUND*** members, **21% (24)** of members were ***ENROLLED*** in Alliance's LTC program
- Of the 24 ***FOUND*** members, **54% (13)** of members were ***RE-ENGAGED*** in medical care

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Peer Navigation: Linkage to Care IMPACTS

In 2021-22:

- Alliance **successfully located – *FOUND* – 52% of NYPH patients living with HIV who were lost to follow-up** (116 out of 221 NYPH patients)
- **21% of *FOUND* patients were enrolled in linkage to care services** (24 out of 116 NYPH patients)
- **54% of PLWHA patients enrolled in the LTC program were successfully re-engaged in medical care** (13 out of 24 pts)
- Successful engagement took an average of **11 attempts per patient**
- **Staff Pattern**: One Program Manager, Two Peer Navigators, plus Supervisor @ Alliance and NYPH

Photo: David Nager/Alliance

Peer Navigation: Linkage to Care IMPACTS

- **Individual Impact:** Alliance Peers consistently attest to the program's impact in enabling them to strengthen their recovery efforts, increase their commitment to HIV risk reduction, improve their access to services, and rebuild their self-esteem. These factors directly support the Peers' ability and motivation to maintain healthy behavioral changes over time.
- **Community Impact:** Peers act as role models for positive behavioral change and have an overwhelmingly positive impact on the communities they serve. Peer navigation and peer support services help increase health care utilization, connection to recovery and supportive services, reduced hospitalizations, reduced emergency room utilization, and improved health outcomes, such as viral load suppression and reduced rates of new HIV infections.

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Collaboration in Action

- **Partnership** weekly planning calls to develop the evaluation and refine program protocols, attended by stake holders from each program
- **Cooperation** around data points and reporting metrics
- **Teamwork** in ensuring all data teams are trained to properly document and utilize each data system

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Presentation 3: Exploring Implementation Processes and Organizational Resilience: Implementing in challenging times

Presented by Abigail Baim-Lance, PhD

Presentation Objectives

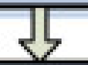
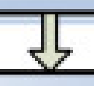
- To examine how organizational resilience and implementation science frameworks can be used to describe how partners have collaborated to overcome challenges experienced during implementation.

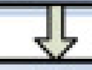
Times of Challenge and Organizations Carrying On

The Consolidated Framework for Implementation Research (CFIR)

Implementation

Characteristics of the Invervention	Inner Setting	Outer Setting	Individuals involved	Implementation Process
- Intervention source - Evidence strength and quality - Relative advantage - Adaptability - Trialabiliy - Complexity - Design quality - Cost	- Structural characteristics - Networks and communications - Culture - Implementation climate	- Patient needs and resources - Cosmopolitanism - Peer pressure - External policies and incentives	- Knowledge and beliefs about the intervention - Self-efficacy - Individual stage of change - Individual identification with organisation - Other personal attributes	- Planning - Engaging - Executing - Reflecting and evaluating



CFIR Model: Damschroder et al, 2009

Our Organizational Resilience (OR) Framework

system's ability to continue to perform and meet its objectives in the face of challenges (Barasa)

Challenges by Type

Resilience By Type

Organizational Characteristics/ Dynamics

Challenges by Type using Resiliency Concepts

Acute: sudden and transient in nature

- public health emergencies like COVID-19

Chronic: everyday issues

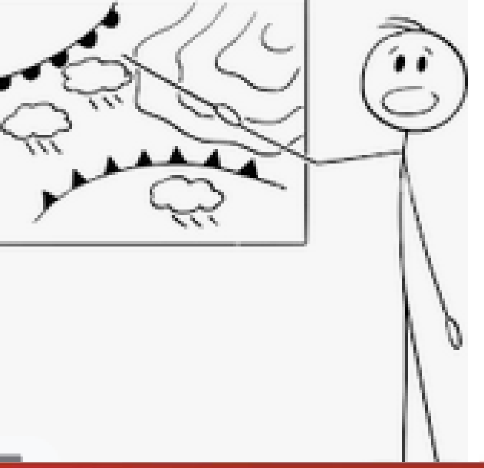
- funding cuts, staff shortages

Barasa et al, 2018

Resilience by Type

Increasing intensity of change

ABSORB	ADAPT	TRANSFORM



Organizational Characteristics

Barasa et al resilience factors, 2018

Key Questions

- What challenges did Bottom Up face?
- How did the Bottom Up organizations respond?
- How did responses influence the collaboration, and the maturing of Bottom Up over time?

Methods

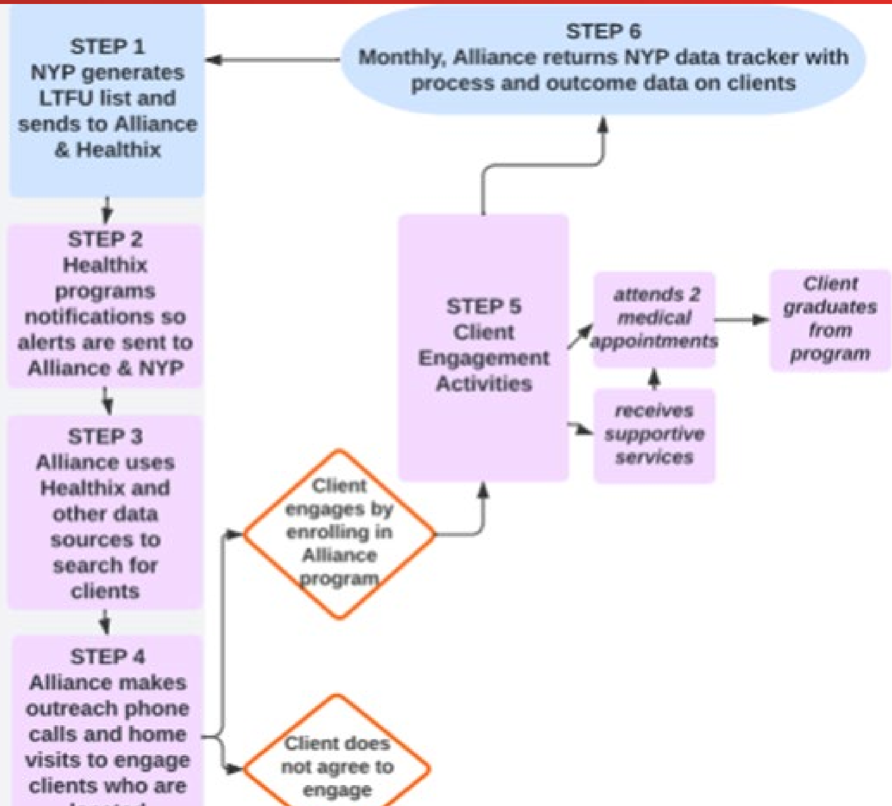
Data Collected

- Semi-structured interviews in May 2020 w/ implementation staff (N=6)
- Documents review:
  - program planning minutes between February 2019 and June 2021 (N=32)
  - 3 protocol documents

Analysis:

- Thematic and process analysis using CFIR and organizational resilience
- Use of rapid techniques: periodic reflections and templates to organize data by program steps and key constructs

Findings: Implementation Challenges



- 20 implementation challenges identified overall, 2-5 challenges per step
  - Chronic = Information technology and management & Patient engagement challenges
  - Crisis = COVID-19 NYC shutdown; rapid funding losses
- Chronic & Crisis combine in the same steps
- Chronic & crisis challenges affect >1 step

Methods

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Analysis:

- Thematic and process analysis using CFIR and organizational resilience
- Use of rapid techniques: periodic reflections and templates to organize data by program steps and key constructs

Findings: Organization Responses

Organization develops new outreach protocols to support vulnerable peer staff members during COVID-19 Wave 1

ADAPT

Organization develops more robust data management system

Staffing losses slow down client-seeking activities

ABSORB

TRANSFORM

*** Observed single as well as a mix of responses to a challenge at different time points**

Organizational Characteristics to Support Resilience Responses

[One partner organization] initially had very low consent rates, and ***we provided some best practices****…about how we had achieved high consent rates for participation.*

-Healthcenter Leadership

Organizational Characteristics

- Social networks & collaboration
- Human capital
- Organizational culture
- Leadership practices
- Governance processes
- Collateral pathways & Redundancy
- Information management
- Preparedness & planning
- Material resources

Organizational Characteristics to Support Resilience Responses

***And we can borrow peers**, thank God, and if we need to, to send them to do stuff and make sure our clients are good. So the peer support is great and well needed, as well as our supervisors are great support, because **our supervisors roll up their sleeves and get in the streets if need be,** and help us to locate clients. So, we have a lot of support at the [CBO]. **Nobody is a big 'I' and a little 'you'**, which I really, truly appreciate.*

-CBO Peer Linkage to Care Specialist

Organizational Characteristics to Support Resilience Responses

*This was a very unique project in my opinion because **all of the major stakeholders participated** in calls to see how they could help, how they could improve, and what they thought best practices was. Because I've been on a lot of other projects, bu**t I've never been on a project that brought everybody who served play a part together so consistently.** Not quarterly, not annually, but literally **every week or every other week for months.***

-CBO Director of Linkage to Care Program

Facilitators by CFIR Constructs

Intervention Characteristics

Adaptability

The intervention allowed alternative pathways to accomplish tasks when roadblocks were presented.

Began tracking data in Excel when existing EHR system was too rigid.

Inner Setting

Leadership engagement

Leadership at all organizations were consistently present to troubleshoot issues large or small.

Weekly/bi-weekly calls with developer and end users to troubleshoot tech problems led to creative solutions.

Outer Setting

Cosmopolitanism

Tapping into the knowledge base of external social networks for advice on best practices.

Getting legal advice on consent invalidations, or info on best model for outreach during COVID-19 from other CBOs.

Discussion/Summary

- Challenges
  - Bottom Up experienced a range of implementation challenges, which affected program steps in unique and recurring ways.
  - 'Crisis' and 'chronic' helpful to distinguish, and both can combine and take a toll on implementation.
- Responses
  - Challenges led to specific responses, that in coordination sustained the program over time.
  - Adaptation most common by using creative strategies to accomplish tasks and due to leadership dedication.
  - **Program implementation can also lead organizations to transform, with potential effects beyond the program.**

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