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Intersectional Stigma and Access to Comprehensive Care: What Quality Improvement Interventions Are Available to You?

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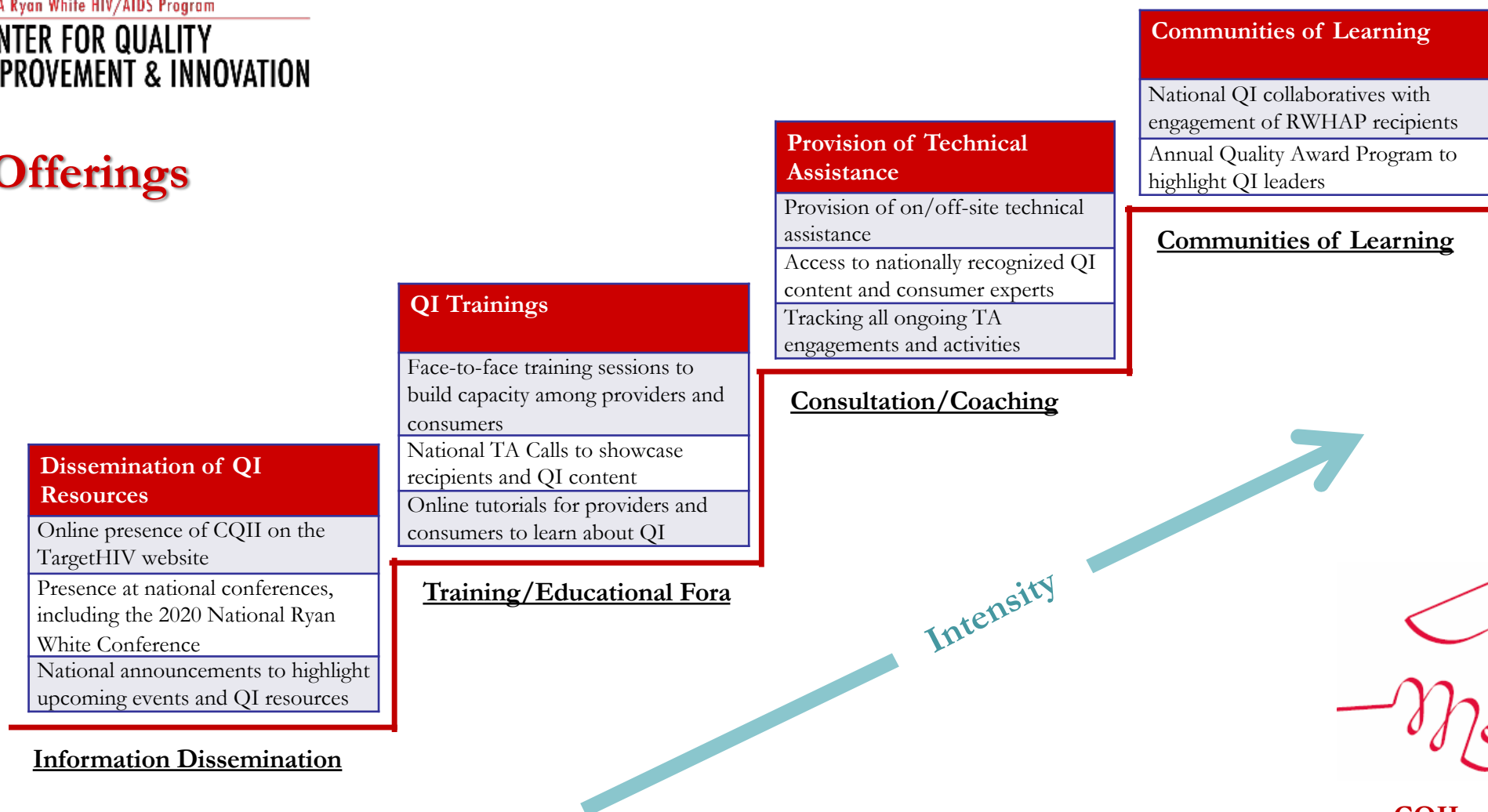
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“It is always in the back of your mind, if I get a job, should I tell my employer about my HIV status? There is a fear of how they will react to it. It may cost you your job, it may make you so uncomfortable it changes relationships. Yet you would want to be able to explain about why you are absent and going to the doctors.”

'Outsider Status: Stigma and Discrimination Experienced by Gay Men and African People with HIV'



Terminology of Stigma

Types of Stigma	
Experienced	Stigma that is enacted through interpersonal acts of discrimination
Perceived	Perception of the prevalence of stigmatizing attitudes in the community or among other groups (e.g., healthcare providers)
Anticipated	Fear of stigma, whether or not it is actually experienced
Internalized (self)	Acceptance of experienced or perceived stigma as valid, justified



Terminology of Stigma

Types of Stigma	
Secondary	Stigma by association, extended to family or other caregivers of stigmatized individual
Observed	Stigma occurring to others that is witnessed or heard about
Structural	Laws, policies, and institutional architecture that may be stigmatizing (or alternatively protective against stigma)
Intersectional	Convergence of multiple stigmatized identities within a person or group; intersecting of stigmas faced by individuals who are part of multiple marginalized groups



Stigma is a Fundamental Determinant of Health and Health Inequity

- ✓ Stigma undermines three key determinants of health
 - ✓ Access to resources
 - ✓ Access to social support
 - ✓ Psychological and behavioral responses
- ✓ Through exclusion, segregation, discrimination, stress and downward socio-economic placement

(Hatzenbuehler et al. 2013)



Stigma Background

- ✓ Higher internalized stigma results in lower adherence to HIV care visits [Rice]
- ✓ Black patients experience lower adherence than their white counterparts [Rice]

PREVENTION RESEARCH

Association Between Internalized HIV-Related Stigma and HIV Care Visit Adherence

Rice, Whitney S. DrPH^{*}; Crockett, Kaylee B. PhD^{*}; Mugavero, Michael J. MD, MHSc[†]; Raper, James L. PhD, CRNP, JD^{†,‡}; Atkins, Ghislaine C. MA^{*}; Turan, Bulent PhD^{*}

Author Information

JAIDS Journal of Acquired Immune Deficiency Syndromes: December 15, 2017 - Volume 76 - Issue 5 - p 482-487
doi: 10.1097/QAI.0000000000001543

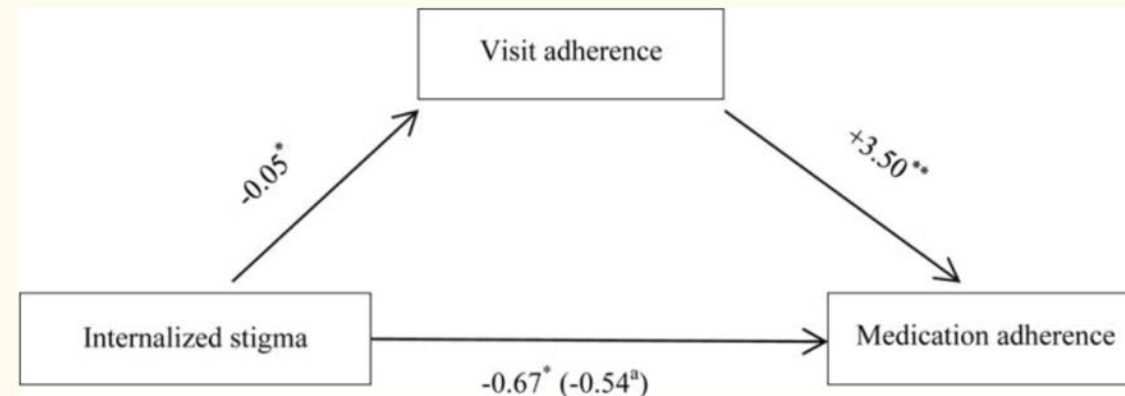


Figure 1

Visit Adherence Mediates the Effect of Internalized Stigma on Medication Adherence

Note. Associations are presented as path coefficients (unstandardized).

^a When visit adherence is in the model.

* $p < .05$; ** $p < .01$

Rice WS. Association between Internalized HIV-related Stigma and HIV Care Visit Adherence. J Acquir Immune Defic Syndr 1999. 2017;76(5):482-487.



Stigma Background

✓ More stigma experienced resulted in poorer outcomes for viral suppression, mental health, and interpersonal outcomes [Kay]

> [J Acquir Immune Defic Syndr](#). 2018 Mar 1;77(3):257-263. doi: 10.1097/QAI.0000000000001590.

Experienced HIV-Related Stigma in Health Care and Community Settings: Mediated Associations With Psychosocial and Health Outcomes

Emma S Kay¹, Whitney S Rice, Kaylee B Crockett, Ghislaine C Atkins, David Scott Batey², Bulent Turan

Affiliations + expand

PMID: 29140873 PMCID: [PMC5807196](#) DOI: [10.1097/QAI.0000000000001590](#)

[Free PMC article](#)

Kay ES. Experienced HIV-related stigma in healthcare and community settings: Mediated associations with psychosocial and health outcomes. *J Acquir Immune Defic Syndr* 1999. 2018;77(3):257-263.

Abstract

Introduction: There are multiple dimensions of HIV-related stigma that can compromise the mental and physical health of people living with HIV. We focused on the dimension of experienced stigma, defined as exposure to acts of discrimination, devaluation, and prejudice, and investigated its relationship with HIV health and psychosocial outcomes.

Methods: We examined associations between experienced stigma in the community and health care settings and psychosocial and health outcomes for people living with HIV (N = 203) receiving care at an urban HIV clinic in the Southeastern United States. We also investigated whether those effects are unique to experienced stigma or are mediated by other dimensions of HIV-related stigma.

Results: Experienced stigma was associated with suboptimal clinical outcomes such as viral nonsuppression, as well as poor affective, cognitive, and mental health outcomes (self-esteem, depressive symptoms, avoidance coping, and blame coping) and interpersonal outcomes such as social support and physician trust. Furthermore, serial mediation models suggested significant indirect effects of experienced stigma through internalized stigma and anticipated stigma from various theoretically expected sources of stigma (eg, community members, friends and family, and health care workers), with varying effects depending on the source.

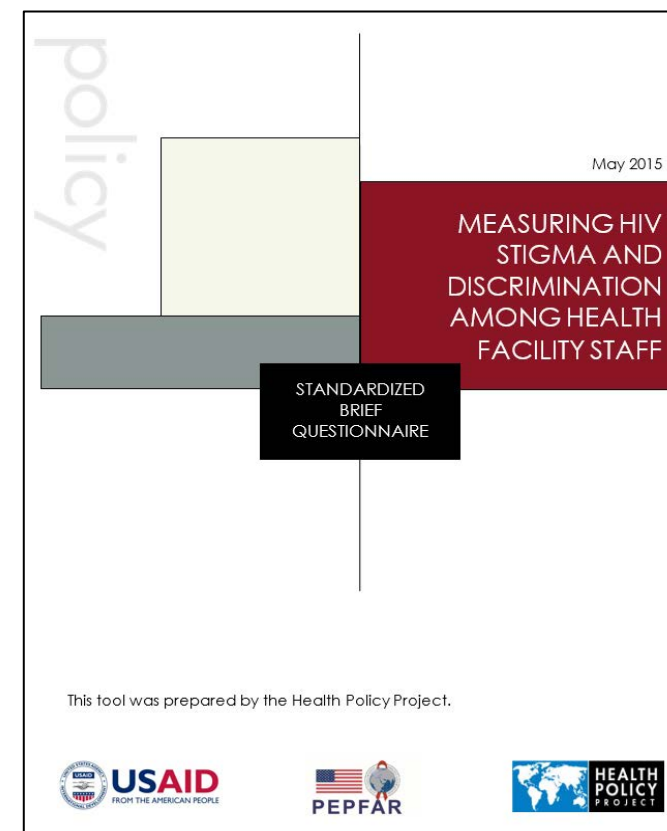
Conclusions: These findings suggest nuanced mechanisms for the effects of experienced HIV-related stigma, especially in health care settings, and may be used to inform stigma-reduction interventions. Interventions designed to address experienced stigma in health care settings might be more tailored to specific outcomes, such as depression and physician trust, than interventions designed to address experienced stigma in the community.



Measurement Tool for Stigma by Laura Nyblade

Measurement Tool for Stigma and Discrimination Among Health Facility Staff

- ✓ International stakeholders developed, field-tested, and refined a brief measurement tool
- ✓ This tool can help facilitate routine monitoring of HIV-related stigma, as well as the expansion and improvement of programming and policies at the health-facility level
- ✓ Two tools
 - ✓ Comprehensive Brief: 21–24 questions
 - ✓ Monitoring Tool: 7 questions
- ✓ Available in 6 languages
 - ✓ Arabic, Chinese, English, French, Spanish, Swahili



Health Policy Project. 2013. "Measuring HIV Stigma and Discrimination among Health Facility Staff: Comprehensive questionnaire." Washington, DC: Futures Group, Health Policy Project.



“ Whenever AIDS has won, stigma, shame, distrust, discrimination and apathy was on its side. Every time AIDS has been defeated, it has been because of trust, openness, dialogue between individuals and communities, family support, human solidarity, and the human perseverance to find new paths and solutions. ”

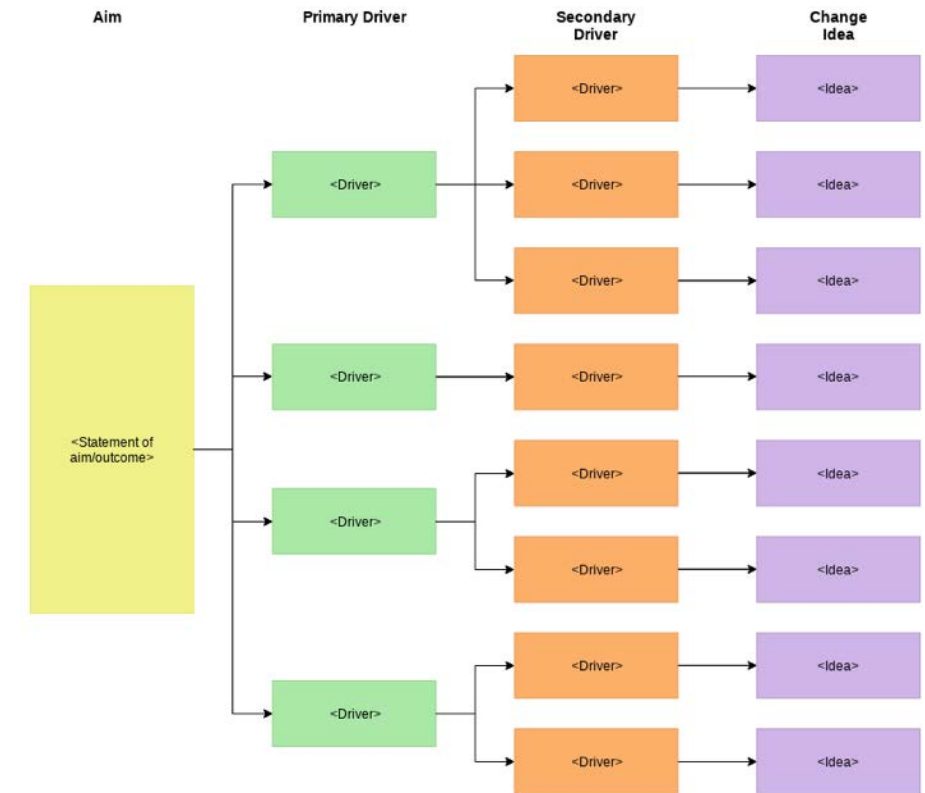
-Michel Sidibé, Executive Director of UNAIDS



Driver Diagrams

✓ Driver Diagrams

- ✓ Quality Improvement Tool
- ✓ A driver diagram shows the relationship between the overall aim of an improvement project, the primary drivers (sometimes called “key drivers”) that contribute directly to achieving the aim, the secondary drivers that are components of the primary drivers, and specific change ideas to test for each secondary driver
- ✓ A driver diagram is a visual display of a team’s theory of what “drives,” or contributes to, the achievement of a project aim



Source: IHI Website <http://www.ihi.org/resources/Pages/Tools/Driver-Diagram.aspx>

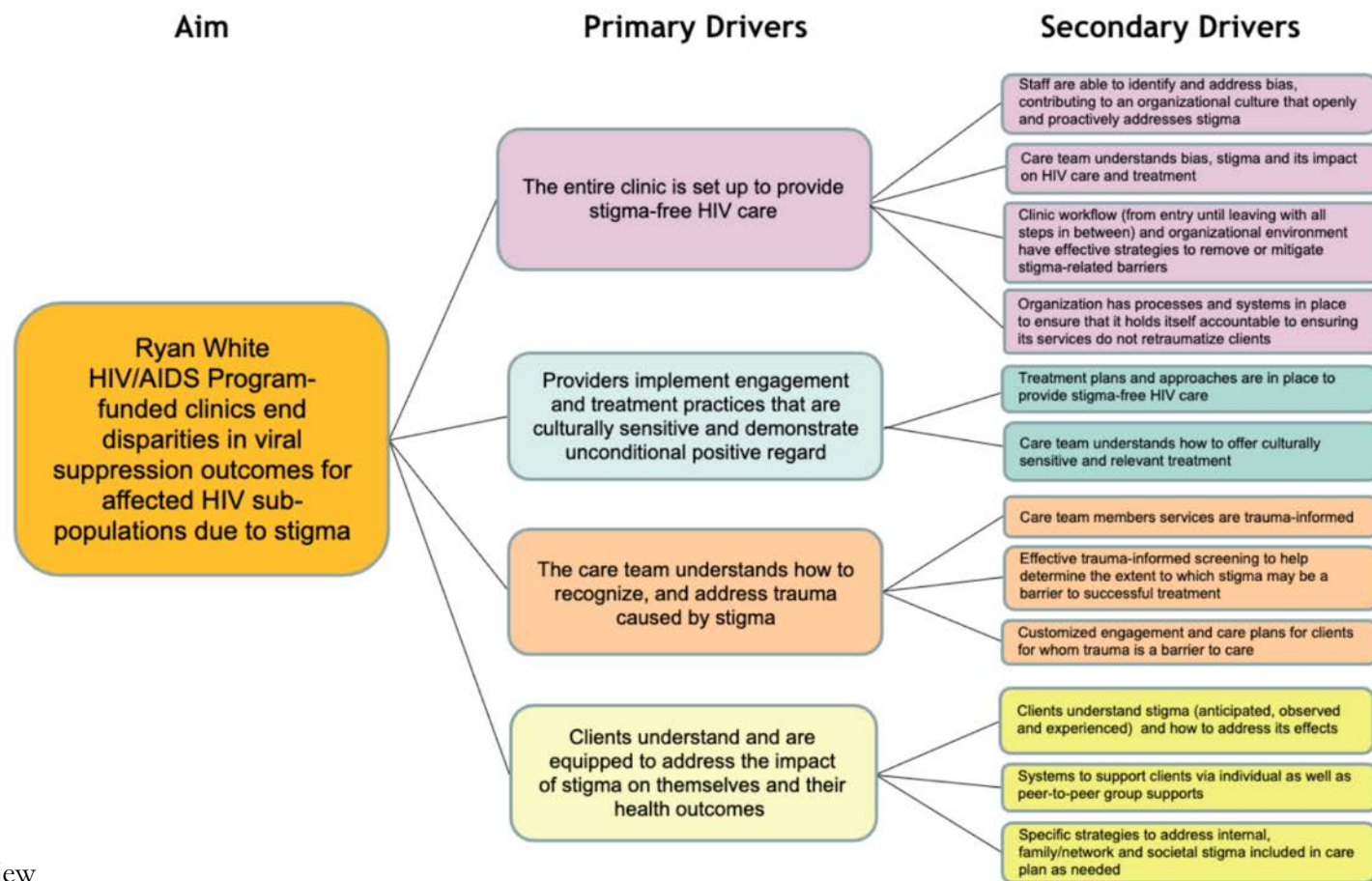


Driver Diagram and Change Packet

- ✓ The Stigma Driver Diagram and a related Change Packet were developed by CQII and the Institute of Healthcare Improvement (IHI)
 - ✓ A change package is an evidence-based set of changes that are critical to the improvement of an identified care process
- ✓ IHI's process is collaborative and consensus-based; it includes
 - ✓ desk research of published studies and other literature
 - ✓ virtual Stakeholder Review Meeting
 - ✓ input by seasoned operational leaders
 - ✓ insights from persons with lived experience of receiving or caring for friends or family receiving relevant care and services



Driver Diagram for Stigma



Source: CQII Stigma Dimension Overview



Driver Diagram for Stigma

Primary Drivers

The entire clinic is set up to provide stigma-free HIV care

Secondary Drivers

Staff are able to identify and address bias, contributing to an organizational culture that openly and proactively addresses stigma

Care team understands bias, stigma and its impact on HIV care and treatment

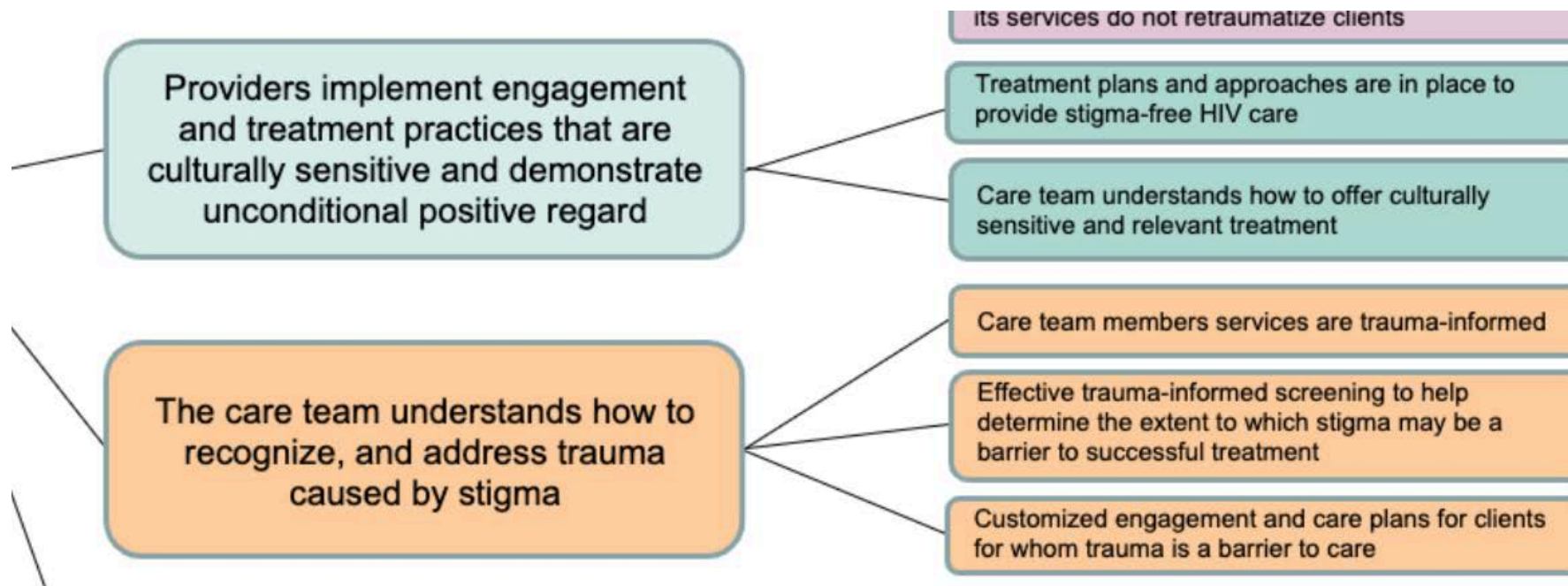
Clinic workflow (from entry until leaving with all steps in between) and organizational environment have effective strategies to remove or mitigate stigma-related barriers

Organization has processes and systems in place to ensure that it holds itself accountable to ensuring its services do not retraumatize clients

Source: CQII Stigma Dimension Overview



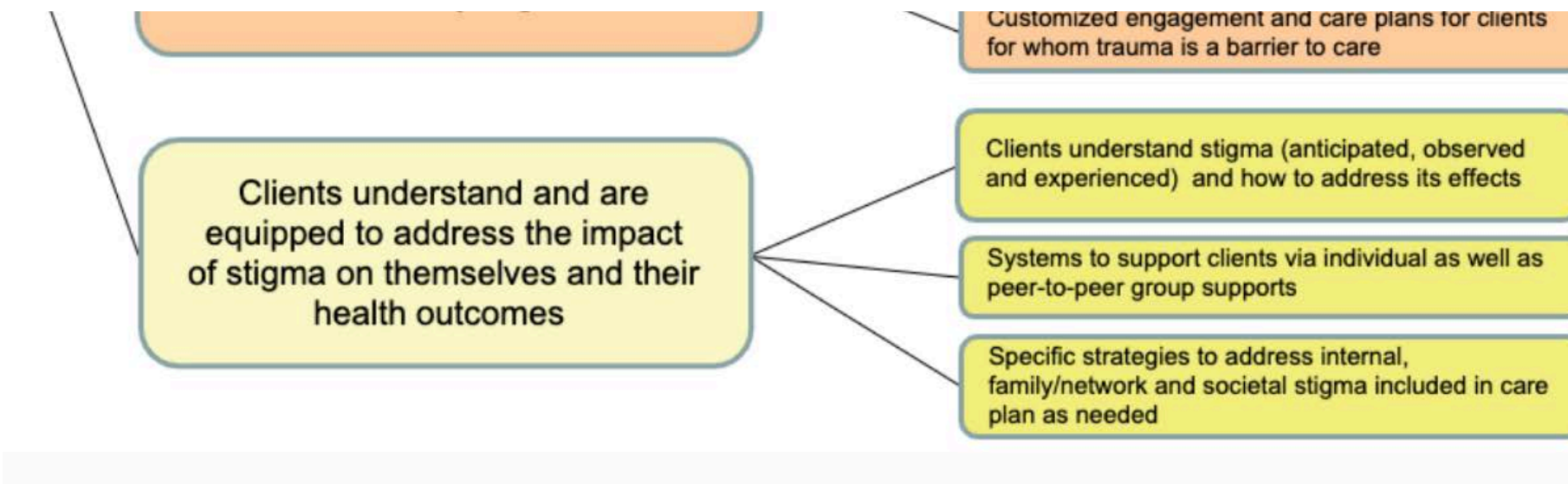
Driver Diagram for Stigma



Source: CQII Stigma Dimension Overview



Driver Diagram for Stigma



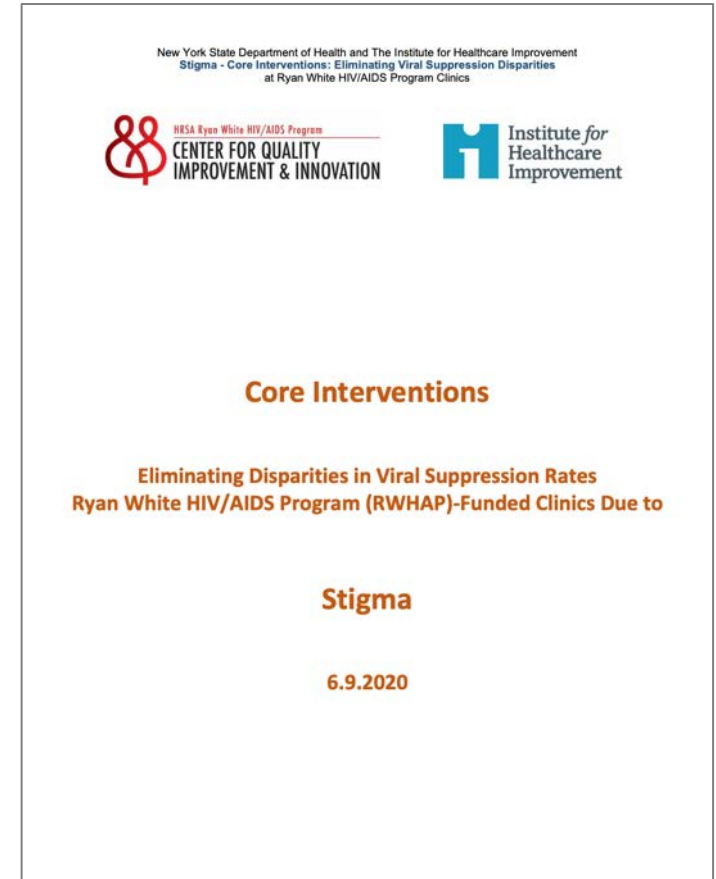
Source: CQII Stigma Dimension Overview

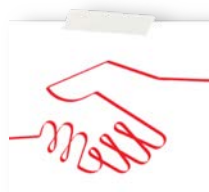


Process for Interventions

CQII and IHI prioritized interventions at Ryan White HIV/AIDS Program clinics

- ✓ Core Interventions Eliminating Disparities in Viral Suppression Rates at Ryan White HIV/AIDS Program-funded Clinics Due to Stigma
- ✓ 12 Core Interventions were developed
- ✓ An extensive list of evidence-informed interventions and emerging practices related to each focus area has been gathered by IHI by scanning existing work, reviewing the literature, and conducting interviews with key stakeholders





Use Evidence-Based Stigma Reduction Strategies

Dimensions: Stigma

This Intervention is Linked to the Following Secondary Driver:

- Treatment plans and approaches are in place to provide stigma-free HIV care

Level of Evidence: Well-Defined Interventions with an evidence-base

Use Evidence-Based Stigma Reduction Strategies

Tips and Tricks:

Laura Nyblade, Ph.D., the principle author of the referenced study and of several guides on stigma in healthcare, offers the following tips:

- The entire facility ecosystem needs to be aware of their stigma
- Signage and language used in signs around and inside the clinics need to be designed carefully
- Important to keep intersectionality in mind
- Consider Implementing a clinic wide assessment questionnaire for staff (see Measuring HIV Stigma and Discrimination Among Health Facility Staff: Standard Brief Questionnaire, in the Additional Resources Section below)

See Also the Intervention titled "[Measure HIV Stigma and Discrimination Among Clinic Staff](#)".

Additional Resources (Existing Guides, Case Studies, etc.):

- Health Policy Project - [Comprehensive Package for Reducing Stigma and Discrimination in Health Facilities](#)
- Health Policy Project - [Facilitator's Training Guide for a Stigma-Free Health Facility](#)
- ECHO Collaborative Presentation by Adam Thompson of Jefferson Health - [HIV-Related Stigma in Healthcare Settings](#)
- National Minority AIDS Council - [HIV/AIDS Stigma and Access to Care, Facilitators Guide](#)

Summary:

A review of forty-two studies revealed **6 core strategies** to reduce HIV, mental illness, or substance abuse stigma in healthcare facilities.¹

Core Components

The study identified the following evidence-based strategies to reduce stigma in healthcare facilities:

1. "Provision of information" teaching participants about stigma, its manifestations, and its effect on health.
2. "Skills-building activities" creating opportunities for providers to develop the skills to work with the stigmatized group.
3. "Participatory learning" requires participants (health facility staff or clients or both) to actively engage in the intervention.
4. "Contact with stigmatized group" involving members of the stigmatized group in the delivery of the interventions
5. An "empowerment" approach to improve client coping mechanisms to overcome stigma at the health facility level.
6. "Structural" or "policy change" approaches included changing policies, providing clinical materials, redress systems, and facility restructuring.

Among the key recommendations from the study are the following:

- Develop and test stigma reduction interventions tailored to the local context and culture
- Tackle multiple stigmas at once, while remaining attentive to the needs of individuals with specific health conditions or characteristics
- Focus on empowerment as an approach for clients or health workers to cope with or challenge stigma, and demand rights to stigma-free health services
- Recognize and address stigma experienced by health workers, including internalized and secondary stigma
- Target all levels of health facility staff, both clinical and non-clinical

- Leverage technology for interactive learning beyond video testimonials
- Work at a structural level to change the physical or policy aspects of the facility environment
- Concentrate on simultaneously targeting multiple ecological levels, such as targeting both individual attitudes and practices as well as the health facility policies and environment

Citations and Acknowledgements:

Nyblade, L., Stockton, M.A., Giger, K. et al. Stigma in health facilities: why it matters and how we can change it. *BMC Med* 17, 25 (2019). <https://doi.org/10.1186/s12916-019-1256-2>



Measure HIV Stigma and Discrimination Among Clinic Staff

Dimension: Stigma

This Intervention is Linked to the Following Secondary Drivers:

- Staff are able to identify and address bias, contributing to an organizational culture that openly and proactively addresses stigma
- Care team understands bias, stigma and its impact on HIV care and treatment

Level of Evidence: Well-Defined Interventions with an evidence-base

Measure HIV Stigma and Discrimination Among Clinic Staff

Summary:

A questionnaire developed and refined by Laura Nyblade, PhD and colleagues, can be customized for use by Ryan White HIV/AIDS Program-funded clinics to assess stigma and discrimination among clinic staff.

Core Components

A review of forty-two studies revealed several core strategies to reduce HIV, mental illness, or substance use stigma in healthcare facilities². The authors of this study recommend implementing a clinic wide assessment questionnaire for staff to help them understand their own bias, stigmatizing behaviors and discriminatory attitudes.

The questionnaire focuses on four areas that are especially relevant to stigma and discrimination in healthcare settings:

1. fear of HIV infection among health facility staff
2. stereotypes and prejudice related to people living with or thought to be living with HIV
3. observed and secondary stigma and discrimination
4. policy and work environment

Tips and Tricks:

- Measuring bias, stigmatizing behavior and discriminatory practices is a necessary step toward the goal of ensuring that a clinic is non-stigmatizing
- Based on the knowledge gained and where staff are in their own journeys of addressing bias and discrimination, ongoing training and other strategies can be employed to move the clinic toward a welcoming and accepting environment for all patients

Additional Resources (Existing Guides, Case Studies, etc.):

- Health Policy Project – [Measuring HIV Stigma and Discrimination Among Health Facility Staff: Standard Brief Questionnaire](#) (this questionnaire was developed for use outside of the United States but can be customized for the context of a Ryan White Clinic)

Citations and Acknowledgements:

Nyblade, L., Stockton, M.A., Giger, K. *et al.* Stigma in health facilities: why it matters and how we can change it. *BMC Med* 17, 25 (2019). <https://doi.org/10.1186/s12916-019-1256-2>



Case Conferencing to Support ART Adherence

Citations and Acknowledgements:

To come as this idea is tested and develops an evidence base.

Dimension: Stigma

This Intervention is Linked to the Following Secondary Drivers:

- Treatment plans and approaches are in place to provide stigma-free HIV care
- Customized engagement and care plans for clients for whom trauma is a barrier to care

Level of Evidence: Good idea worthy of testing

Case Conferencing to Support ART Adherence

Tips and Tricks:

- To be sustainable, case conferencing needs to fit within the workflow of the clinic and be valued by participating staff as a great use of their time.
- Effective case conferencing takes time, testing and refining before going to scale, using continuous improvement methods.

Additional Resources (Existing Guides, Case Studies, etc.):

- [Targeted Team Discussions for Viral Load Suppression](#) - In this video, Margaret Haffey presents on a quality improvement project implemented by Boston Medical Center that used targeted team discussions to improve viral load suppression. The steps they took, including tools used to assess viral load suppression and changes to their team meetings, are covered in this presentation.
- [New York State Department of Health HIV Case Coordination and Case Conferencing Strategies](#)
- [Sample Case Conferencing Form](#) (NY State Department of Health)

Summary:

Case conferencing allows a multi-disciplinary team to review patients (either select patients or all patients), understand their challenges and assets, and develop customized strategies to stay in ongoing HIV care and improve viral suppression rates.

Core Components

Case Conferencing is frequently cited as an important component of an effective Ryan White HIV/AIDS Program-funded clinic and several evidence-based practices list case conferencing as a core component. In spite of this, case conferencing itself is often not well-defined. While the core components of a successful case conferencing strategy targeted to reach viral suppression, are not fully defined, the following components were identified in the CQII Initiative as useful:

- Regularly scheduled
- Triage and selection process to prioritize (not spontaneous or everyone)
- Standard format for presenting (often using a standard form)
- Didactic at the beginning
- Structured presentation
- Questions/consultation
- Development of a strategy/next steps
- Strategy and next steps are documented in the patient's record
- Patient record records the extent to which strategy and next steps are implemented and the apparent result(s) of these
- Subsequent case conferences for the same patient review strategies and next steps developed previously, document what did (and did not) work and a revised strategy and next steps.
- Staff both consult and present their own cases
- Diversity of positions and roles within the room (including case management, peers, pharmacy, etc.)
- Includes outside providers, when appropriate and feasible; the client's right to privacy and confidentiality in contacts with other providers is maintained
- Frequency depends on the organization and its culture
- 3-4 cases per Case Conferencing Session

- Case Conferencing session is not longer than an hour



Waiting Room Milieu Manager

Citations and Acknowledgements:

To come as this intervention develops an evidence base.

Dimension: Stigma

This Intervention is Linked to the Following Secondary Drivers:

- Client-centered and client-driven support systems in place to provide individual and peer-to-peer group support
- Customized engagement and care plans for clients for whom trauma is a barrier to care
- Clinic workflow (from entry until leaving with all steps in between) and organizational environment have effective strategies to remove or mitigate stigma-related barriers

Level of Evidence: Good idea worthy of testing

Waiting Room Milieu Manager

Tips and Tricks:

- There are other potential names for this position, including Waiting Room Concierge and Waiting Room Manager
- Making effective use of a Milieu Manager takes time, testing and refining before going to scale, using continuous improvement methods.
- Ongoing, brief surveys of patients can help you determine if you are on the right track and can provide specific ideas for improvement
- The Boston Health Care for the Homeless Program has successfully used Milieu Managers to make the waiting room (and sometimes some fairly substantial waits to see a provider) more welcoming and comfortable.

Additional Resources (Existing Guides, Case Studies, etc.):

- [Center for Care Innovations: Create a Waiting Room Concierge](#)
- [The Waiting Room "Wait": From Annoyance to Opportunity](#)
- Boston Health Care for the Homeless - [Sample Job Description for the Milieu Manager](#)

Summary:

Using a Milieu Manager to manage the waiting area, welcome people, help manage the atmosphere of the waiting room, act as liaison between patient and clinic staff, and help people feel comfortable.

Core Components

While there are numerous clinics that use a Milieu Manager or similar position in their waiting rooms, this is not yet a well-defined intervention with well-defined components. In theory, an effective Waiting Room Milieu Manager strategy would include:

- Trained peers are used as Milieu Managers when feasible
- A job description clearly outlining the specific role, duties and tasks of the Milieu Manager
- Milieu Manager role's position as part of the overall clinic team is clearly articulated and understood by all staff
- Specific duties and tasks might include:
 - Welcoming each patient as they enter the clinic, ensuring they understand how to sign-in and answering any immediate questions
 - Helping all first-time patients understand what the first visit will entail and preparing them to see their primary care provider and other members of the care team
 - Assisting patients with answering questions on any requested paperwork/forms
 - Helping administer questionnaires/surveys to better understand patient experiences and improve services (before and/or after visit with primary care provider)
 - Providing educational material, including decision aids in the patient's preferred language
 - Monitoring the environment of the waiting room to help ensure that all patients feel safe and welcome
 - Encouraging patients to write down any questions or items they want to cover with the provider in advance of the visit
 - Acting as a peer health coach
 - Relating the needs of patients to clinic staff
- A simple and effective way to track the extent to which the Milieu Manager is:
 - Providing patient triage services for other members of the clinic team
 - Providing status updates to patients (especially if there has been a long wait)
 - Otherwise helping to ensure that the patient feels comfortable and prepared for their visit
- Making clients feel welcomed (patient survey)
- Preparing clients for their visits (patient survey)
- Making the visit with the provider(s) more productive (provider survey)



Making the Clinic's Physical Environment Less Stigmatizing

Citations and Acknowledgements:

To come as this intervention develops an evidence base.

Dimension: Stigma

This Intervention is Linked to the Following Secondary Drivers:

- Client-centered and client-driven support systems in place to provide individual and peer-to-peer group support
- Customized engagement and care plans for clients for whom trauma is a barrier to care
- Clinic workflow (from entry until leaving with all steps in between) and organizational environment have effective strategies to remove or mitigate stigma-related barriers
- Care team understands how to offer culturally sensitive and relevant treatment
- Care team understands bias, stigma and its impact on HIV care and treatment
- Organization has processes and systems in place to ensure that it holds itself accountable to ensuring its services do not retraumatize clients

Level of Evidence: Good idea worthy of testing

Making the Clinic's Physical Environment Less Stigmatizing

Summary:

The design, signage and feel of a clinic can either be welcoming or stigmatizing. Thoughtful design and planning can make the environment more welcoming to patients.

Core Components

The components of a welcoming and less stigmatizing clinic environment, ideally the entire facility environment, would likely include the following:

- Understanding the needs and preferences of the patients seen in the clinic (not one-size-fits all)
 - Using design thinking/human centered design principles to understand the wants, needs and aspirations of patients, including relevant subpopulations
 - Developing a theory with patients and staff using a Driver Diagram or similar visualization tools to understand the drivers of a welcoming (non-stigmatizing) clinic environment
 - Continually using brief self-report surveys to monitor patient's thoughts about the clinic's physical environment, as well as that of the entire facility that the clinic is part of, and ideas for improvement
 - Include a Likert Scale question such as "[name of clinic] offers a welcoming physical environment that makes me feel comfortable (Scale of 1 – 5 with one being "Strongly Disagree" and 5 being "Strongly Agree")
 - Include a question to identify areas for improvement

- Developing a team that includes patients and both clinical and non-clinical (including auxiliary) staff to make the clinic environment more welcoming
 - Use data from patients and the Driver Diagram to develop a survey of the clinic's physical environment
 - Have members of this team conduct an analysis of the clinic and the facility using the survey
 - Based on the survey, have the team develop concrete ideas for improving the clinic's physical environment
 - Test and refine the ideas with patients, bringing those that work to scale
 - Conduct a (review quarterly or annually) using the survey (updated as needed) to ensure that the clinic physical environment remains welcoming

Common Components for A Welcoming Clinic Physical Environment

- Do away with signage such as "Infectious Disease Clinic", "HIV Medication Line" etc.
- If you specialize in specific subpopulations, make them feel comfortable (e.g., for injection drug users consider using signage such as "User-Friendly" let's them know this is a safe space)
- Individuals on posters and other visuals in the clinic match the patients seen in the clinic
- Ensure that signage is gender friendly
- Have gender neutral bathrooms
- Layout of the clinic promotes privacy
- Signage, look and feel of the broader organization and the building in which the clinic is located, are also welcoming

Tips and Tricks:

- Ensuring the clinic offers a welcoming physical environment takes time, testing, refining and ability to continually monitor and improve
- Ongoing, brief surveys of patients can help you determine if you are on the right track and can provide specific ideas for improvement

Additional Resources (Existing Guides, Case Studies, etc.):

- [Whole Building Design for Healthcare Facilities](#)



Patient Self Care Plans

Dimension: Stigma

This Intervention is Linked to the Following Secondary Drivers:

- Treatment plans and approaches are in place to provide stigma-free HIV care
- Customized engagement and care plans for clients for whom trauma is a barrier to care

Level of Evidence: Good idea worthy of testing

Patient Self Care Plans

Tips and Tricks:

- Making effective use of Patient Self Care Plans takes time, testing, refining and ability to continually monitor and improve
- Ongoing, brief surveys of patients can help you determine if you are on the right track and can provide specific ideas for improvement
- Patient Self Care Plans can help build deeper, more authentic relationships between patient and provider.
- Ursuline Sisters HIV/AIDS ministry uses a Self Care plan that allows a patient to develop a detailed plan for what they will do (or not do) during specific situations and to practice regular Self Care.

Additional Resources (Existing Guides, Case Studies, etc.):

- [Common Elements in Self-Management of HIV](#)
- [Institute for Healthcare Improvement: HIV Self-Management and Adherence](#)
- Ursuline Sisters HIV/AIDS Ministry uses an assessment adapted from the following: Saakvitne, K. W., & Pearlman, L. A. (1996). Transforming the pain: A workbook on vicarious traumatization. New York: W.W. Norton & Company.

Citations and Acknowledgements:

To come as this idea is tested and develops an evidence base.

Summary:

A Patient Self Care Plan is a patient-centered planning technique that recognizes a patient's own strengths, assets and networks as part of their overall care plan.

Core Components

A Strategy for Using a Patient Self Care Plan might contain the following elements:

- Training for relevant staff on the purpose and use of the Patient Self Care Plan and how to support patients in developing their own
- Developing a brief patient self-assessment form and a brief patient Self Care plan form with clinic patients and utilizing the resources provided below.
 - A brief, user friendly patient self-assessment might include:
 - A survey of patient's own assets
 - An understanding of their family and social networks
 - An understanding of what (in their words) is important to them and could include prompts such as "favorite quotes", etc.
 - Areas in which they would like to include (include in their Self Care Plan)
 - A brief, user-friendly patient care form might include:
 - Patient goals (in their own words)
 - What they can do to help achieve their goals
 - Who they can call on (support system) to help them achieve their goals
 - How they will know if their plan is working or starting to work
- A simple and effective way to track the extent to which developing a Patient Self Care Plan:
 - Is viewed as useful by patients
 - Makes patients feel more involved in their own care
 - Results in better patient outcomes
- The patients' goals and strategies in their Self Care Plan can be used to motivate patients, to re-energize them when they are feeling down, and to help ensure that the care provided meets the patient's needs
- The plan can be reviewed and updated with the patient at regular intervals (e.g. every six months)



Optimal Linkage and Referral (Active Referral Intervention)

Dimension: Stigma

This Intervention is Lined to the Following Secondary Driver:

- Clinic workflow (from entry until leaving with all steps in between) and organizational environment have effective strategies to remove or mitigate stigma-related barriers

Level of Evidence: Well-Defined Interventions with an evidence-base

Optimal Linkage and Referral (Active Referral Intervention)

Summary:

Active Referral involves successful linkage of people with HIV to primary care as well as other services and supports. This may include newly diagnosed individuals, persons previously diagnosed who have never been linked to care, or persons who have fallen out of care and are being re-linked.

Core Components

Active Referral⁹ addresses several key areas that have been found to improve linkage and re-engagement in care, including:

- removal of structural barriers
- increased social support services
- use of peers, client navigation, and care coordination
- a culturally responsive approach
- appointment scheduling and follow up
- timely and active referrals post-diagnosis
- integrated one-stop-shop care delivery

One study⁹ looked at 16 barriers to successful linkages and proposed evidence-informed methods for mitigating their effects. One strategy associated with increased linkage to care is active referral. Many studies have shown that referral by a tester who makes the treatment appointment or accompanies the patient to an appointment increases the likelihood of linkage, compared with passive referral (e.g., only providing written material).

The table below outlines the barriers and potential strategies for mitigating them.

TABLE 1.

Common Barriers to Linking or Retaining HIV-Infected Patients in HIV Medical Care

Barriers (Reference Number)	Examples of Potential Means of Mitigating Barriers
Psychosocial	
Low self-efficacy ¹⁹	Strength-based case management
Health literacy ¹⁹	HIV counseling and education, appropriate and varied educational materials
Concerns for confidentiality ²⁰	Explain and post confidentiality protections, provide private spaces for triage and examination
Concerns for stigma ²¹	Nonjudgmental and inclusive approach and clinic environment
Language barriers ^{19,22}	Access to translation services through staff on site or by phone
Cultural barriers ^{16,22}	Cultural competency training, hiring cultural concordant staff
Substance use ²³	Screening for, and access or referrals to, substance-abuse programs
Mental illness ¹⁶	Screening for, and access or referrals to, mental health services
Isolation ²⁰	Peer patient navigation, support group, case management
Socioeconomic	
Homeless ¹⁷	Access to HIV/AIDS housing resources
Poverty ^{16,17}	Access to jobs training, social security disability benefits, or poverty reduction programs.
Lack of transportation ¹⁸	Providing HIV care appointments at locations convenient to the patient; directly providing transportation assistance
Lack of insurance ^{16,18}	Providing health insurance enrollment service at the clinic or referrals to such
Health care system Complexity of health care systems ^{17,18}	Colocating HIV care and STD clinics; strong referral or linkage systems
Complexity of insurance systems ^{18,19}	Providing health insurance enrollment service at the clinic or referrals to such; ongoing support and education for using benefits

Tips and Tricks:

- Active referral programs often include peer navigators.
- While formal linkage and referral agreements between providers may be useful, they cannot replace active referrals.
- Implementing a successful active referral system at an HIV clinic takes time, testing and refining before going to scale, using continuous improvement methods.

Additional Resources (Existing Guides, Case Studies, etc.):

- HRSA HIV/AIDS Bureau (HAB) - [Active Referral Intervention: Case Study, Overview, and Replication Tips](#)
- [Linkage and Referral to HIV and Other Medical and Social Services](#): A Focused Literature Review for Sexually Transmitted Disease Prevention and Control Programs
- Target HIV's [Using Community Health Workers to Improve Linkage and Retention in Care](#)

Citations and Acknowledgements:

1. Active Referral Intervention. (2017, June). Retrieved May 17, 2020, from <https://targethiv.org/sites/default/files/file-upload/resources/hiv-linkage-to-care-Active-Referral-Case-Study-and-Intervention.pdf>
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Trauma Informed Approaches: Improving Care for People with HIV

Dimension: Stigma

This Intervention is Linked to the Following Secondary Drivers:

- Care team members services are trauma-informed
- Customized engagement and care plans for clients for whom trauma is a barrier to care
- Effective trauma-informed screening to help determine the extent to which stigma may be a barrier to successful treatment

Level of Evidence: Well-Defined Interventions with an evidence-base

Trauma-Informed Approaches: Improving Care for People Living with HIV

Tips and Tricks:

- While foundational knowledge can often be obtained through effective training, ensuring that a clinic uses trauma-informed approaches in every aspect of its work, requires changes to culture, processes and systems.
- Implementing effective trauma-informed approaches takes time, testing and refining before going to scale, using continuous improvement methods.

Additional Resources (Existing Guides, Case Studies, etc.):

- NASTAD's [Trauma-Informed Approaches Toolkit](#)
- SAMHSA's [Trauma-Informed Approach: Improving Care for People Living with HIV Curriculum Trainer's Manual](#)
- SAMHSA's [Concept of Trauma and Guidance to a Trauma Informed Approach](#)
- [Attitudes Related to Trauma Informed Care \(ARTIC\) Scale](#)

Summary:

According to NASTAD's Trauma-Informed Approaches Toolkit (see link below), being trauma-informed is an approach to administering services in HIV care that acknowledges that traumas may have occurred or may be active in clients' lives, and that those traumas can manifest physically, mentally, and/or behaviorally.

Core Components

SAMHSA offers 6 key principles of a trauma-informed approach:

1. Safety
2. Trustworthiness and Transparency
3. Peer Support
4. Collaboration and Mutuality
5. Empowerment, Voice and Choice
6. Cultural, Historical, and Gender Issues

NASTAD's Trauma-Informed Approaches Toolkit, discusses and provides guidance on the following components of integrated trauma informed approaches to care:

- Recognition & Awareness
- Foundational Knowledge
- Agency Readiness
- Process & Infrastructure
- Gather Information & Identify Opportunities
- Prioritize & Create a Work Plan
- Implement & Monitor
- Celebrate & Maintain

Citations and Acknowledgements:

1. Sales, J. M., Swartzendruber, A., & Phillips, A. L. (2016). Trauma-Informed HIV Prevention and Treatment. *Current HIV/AIDS reports*, 13(6), 374–382. <https://doi.org/10.1007/s11904-016-0337-5>
2. Nightingale, V. R., Sher, T. G., Mattson, M., Thigles, S., & Hansen, N. B. (2011). The effects of traumatic stressors and HIV-related trauma symptoms on health and health related quality of life. *AIDS and behavior*, 15(8), 1870–1878. <https://doi.org/10.1007/s10461-011-9980-4>
3. Baker, C. N., Brown, S. M., Wilcox, P. D., Overstreet, S., & Arora, P. (2016). Development and psychometric evaluation of the Attitudes Related to Trauma-Informed Care (ARTIC) Scale. *School*

Mental Health: A Multidisciplinary Research and Practice Journal, 8(1), 61–76. <https://doi.org/10.1007/s12265-015-9585-2>



U=U Education Initiatives

Dimension: Stigma

This Intervention is Linked to the Following Secondary Drivers:

- Clinic workflow (from entry until leaving with all steps in between) and organizational environment have effective strategies to remove or mitigate stigma-related barriers
- Treatment plans and approaches are in place to provide stigma-free HIV care
- Specific strategies to address internal, family/network and societal stigma included in care plan as needed

Level of Evidence: Well-Defined Interventions with an evidence-base

U=U Education Initiatives

Tips and Tricks:

- While generalized messaging about U=U is helpful, some people with HIV will need customized messaging to understand and process what U=U means for them and their lives.
- U=U messaging needs to go beyond posters in the clinic, to messaging that is shared consistently and accurately by providers with every patient and that is embedded into the workflow of the clinic.
- Initial conversations on U=U should include a discussion of what the message means to the patient and how they live their lives to both increase motivation for ART adherence and decrease stigma.

Additional Resources (Existing Guides, Case Studies, etc.):

- The Prevention Access Campaign provides a full range of resources on [U=U Communications Strategies for Providers](#)
- ECHO Collaborative Video Presentation: [Communicating U = U](#)
- British HIV Association (BHIVA) Presentation: [Do You Speak U = U?](#)

Summary:

The science⁷ has confirmed that as a person living with HIV continues to use ART as prescribed gets to undetectable they can no longer sexually transmit the virus to other people or, more simply put, Undetectable = Untransmittable or U=U. Communicating this to patients can help motivate ART adherence, reduce stigma and improve their wellbeing.

Core Components

Various U=U educational initiatives or communication campaigns are sharing the U=U message, including customized and targeted strategies for specific subpopulations of people with HIV.

The [Prevention Access Campaign](#) summarizes the message as follows:

The U=U message is an unprecedented opportunity to transform the lives of millions of people with and affected by HIV and to radically transform the field:

- Well-being of people with HIV: Transforms the social, sexual, and reproductive lives of people with HIV by freeing them from the shame and fear of sexual transmission to their partners.
- HIV stigma: Dismantles the HIV stigma that has been destroying lives and impeding progress in the field since the beginning of the epidemic.
- Treatment goals: Reduces the anxiety associated with testing and encourages people with HIV to stay on treatment to stay healthy and prevent transmissions to their partners.
- Universal access: Offers a critical public health argument in advocacy for universal access to treatment, care, and diagnostics to save lives and prevent new transmissions, bringing us closer to ending the epidemic.

Citations and Acknowledgements:

1. Eisinger, R. W., Dieffenbach, C. W., & Fauci, A. S. (2019). HIV Viral Load and Transmissibility of HIV Infection: Undetectable Equals Untransmittable. *JAMA*, 321(5), 451-452. <https://doi.org/10.1001/jama.2018.21167>
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Use of Peer Navigators

Dimension: Stigma

Secondary Drivers:

- Clinic workflow (from entry until leaving with all steps in between) and organizational environment have effective strategies to remove or mitigate stigma-related barriers
- Client-centered and client-driven support systems in place to provide individual and peer-to-peer group support

Level of Evidence: A reasonably well-defined Intervention (numerous models) with an evidence-base

Use of Peer Navigators

Tips and Tricks:

- It appears that peer navigator programs are most successful when their roles are fully integrated into the clinic's care team
- Most Models stress the importance of ongoing training, supervision and ongoing support of peers.
- Implementing an effective Peer Navigator program takes time, testing and refining before going to scale, using continuous improvement methods.

Additional Resources (Existing Guides, Case Studies, etc.):

- U.S. Health Resources and Services Administration (HRSA) - [Integrating Peers into Multidisciplinary Teams: A Toolkit for Peer Advocates](#)
- HRSA's Target HIV - [Building Blocks to Peer Program Success: Toolkit for Developing HIV Peer Programs](#)
- AIDS United's [Best Practices for Integrating Peer Navigators into HIV Models of Care](#)
- ECHO Collaborative Video Presentation – [Peer Programs: A Community Health Worker Program](#)

Summary:

Peer navigator services are often useful for new patients, patients who have inconsistent engagement and patients who have disengaged. Several organizations participating in the ECHO Collaborative as well as several controlled studies have showed the efficacy of peer navigators, particularly around engagement and re-engagement.

Core Components

While there is significant evidence indicating the effectiveness of peer navigators in certain roles, the exact roles of peer navigators and the specific models used, vary. Many potential roles including:

- Community outreach to bring newly diagnosed and out-of-care clients to services
- Weekly/regular calls to check-in with patients and reminder calls for upcoming appointments
- Accompanying clients to appointments related to their overall care
- Coordinating and assisting with successful linkage and referral to other services and supports including assistance with transportation
- Treatment adherence education and support
- Having peer navigators conduct targeted outreach to patients who have disengaged from care.
- Having peer navigators serve as Waiting Room Milieu Managers (see separate write-up of this intervention)

Several potential models – see Additional Resources below.

Tips and Tricks:

- It appears that peer navigator programs are most successful when their roles are fully integrated into the clinic's care team
- Most Models stress the importance of ongoing training, supervision and ongoing support of peers.

Citations and Acknowledgements:

1. Melanie A. Thompson, Michael J. Mugger, K. Rivet Amico, Victoria A. Cargill, Larry W. Chang, Robert Gross, Catherine Orrell, Frederick L. Alice, David R. Bangsberg, John G. Bartlett, Curt G. Beckwith, Nadia Dowshen, Christopher M. Gordon, Tim Horn, Princy Kumar, James D. Scott, Michael J. Simoni, Robert H. Remien, Jane M. Simoni, and Jean B. Nachega. Guidelines for Improving Entry into and Retention in Care and Antiretroviral Adherence for Persons With HIV: Evidence-Based Recommendations From an International Association of Physicians in AIDS Care Panel. *Annals of Internal Medicine* 2012;156:111-117-833. <https://doi.org/10.1093/aim.2007.2687>
2. Bradford, J. B., Coleman, S., & Cunningham, W. (2007). HIV System Navigation: an emerging model to improve HIV care access. *AIDS patient care and STDs*, 21 Suppl 1, S49-S58.
3. AIDS United. Best Practices for Integrating Peer Navigators into HIV Models of Care. Washington, DC. 2015.



Staff Training on Motivational Interviewing Skills, Strategies and Tools

Dimension: Stigma

This Intervention is Linked to the Following Secondary Drivers:

- Treatment plans and approaches are in place to provide stigma-free HIV care
- Clinic workflow (from entry until leaving with all steps in between) and organizational environment have effective strategies to remove or mitigate stigma-related barriers
- Care team understands how to offer culturally sensitive and relevant treatment

Level of Evidence: Well-Defined Interventions with an evidence-base

Staff Training on Motivational Interviewing Skills, Strategies and Tools

In one study⁴ involving a clinic serving adolescents, 9 hours of foundational motivational interviewing training for clinicians and 3 hours of foundational Motivational Interviewing training for other staff, improved patient outcomes.

Another study's⁵ findings suggest that a two-day introductory course is effective in improving Motivational Interviewing knowledge, perception of the effectiveness of Motivational Interviewing, perception of behavior change, and likelihood of Motivational Interviewing use. The findings contributed sustainability recommendations to use Motivational Interviewing to promote ART adherence within a clinic setting.

It is critical to ensure that the clinic receives the right training(s), with the right dosage and the right trainer(s) for their specific context and planned use of Motivational Interviewing. Before holding a training on Motivational Interviewing, consider the following:

- What are we trying to accomplish (what are we hoping to improve by offering training for Motivational Interviewing? What are our desired results?)
- Who needs to be trained and for what specific purposes?
- How will we follow-up on this training and help staff embed what they have learned into their daily work?
- What changes at the clinic/organization are needed for Motivational Interviewing to take hold?
 - Changes to organization/clinic culture?
 - Changes to workflow?
 - Changes to documents (intake forms, screening tools, etc.)?
- Who will be the clinic "champion" to help ensure that patients benefit from this training?
- How will we know (measure) if Motivational Interviewing training has achieved its desired result(s)?

Embedding Motivational Interviewing strategies, methods and tools in a Ryan White clinic

Many people think of Motivational Interviewing as a tool of clinicians. In addition, clinics can embed the core principles of Motivational Interviewing into all aspects of its work, including but not limited to:

- Intake, including intake form and how questions are asked
- The work of Peer Navigators, especially around engaging new patients and re-engaging patients who have disengaged
- Primary Care Provider conversations about ART and ART Adherence
- Patient reports, questionnaires and surveys

Training can help clinic staff understand Motivational Interviewing and help them see the benefits of this approach. But for Motivational Interviewing strategies, methods and tools to fully take hold, the clinic/organization needs cultivate a culture where this approach can thrive, provide ongoing training and support on the use of Motivational Interviewing and redesign its workflow and documents to fully align with this approach to care.

Summary:

Motivational interviewing is a client-centered, directive therapeutic style to enhance readiness for change by helping clients explore and resolve ambivalence. An evolution of Rogers's person-centered counseling approach, Motivational Interviewing elicits the client's own motivations for change.

Core Components

Motivational Interviewing is a collaborative, goal-oriented style of communication with particular attention to the language of change. It is designed to strengthen personal motivation for and commitment to a specific goal by eliciting and exploring the person's own reasons for change within an atmosphere of acceptance and compassion.³

The approach upholds four principles:

1. Expressing empathy and avoiding arguing
2. Developing discrepancy
3. Rolling with resistance
4. Supporting self-efficacy (client's belief s/he can successfully make a change)

Training on Motivational Interviewing

While using the full range of Motivational Interviewing strategies, methods and tools requires intensive training and practice, all clinic staff interacting with patients can benefit from a relatively brief training to learn and implement a smaller, core set of Motivational Interviewing strategies.

Tips and Tricks:

- While it may be helpful to have one or more experts on Motivational Interviewing, the clinic should consider providing foundational training on Motivational Interviewing to all staff who come in contact with patients. The amount (dosage) of training can vary based upon the position from 1-2 hours on up.
- It may be useful to design training and follow-up related to specific improvement work at the clinic. For example, if the clinic wants to improve how it has open and honest conversations about substance use, it might offer a general foundational training in Motivational Interviewing, followed by a working session on how clinic staff can embed what they have learned into their conversations with patients and their screening for substance use.

Additional Resources (Existing Guides, Case Studies, etc.):

- HRSA HIV/AIDS Bureau (HAB) [Innovative Models of Care: Motivational Interviewing](#)
- NMAC's [Motivational Interviewing and HIV: A Guide for Navigators](#)
- SAMHSA/HRSA Center for Integrated Health Solutions' [Motivational Interviewing](#) (2016)
- SAMHSA/HRSA Center for Integrated Health Solutions' [Motivational Interviewing for Better Health Outcomes](#) (2011)
- [Motivational Interviewing Knowledge and Attitudes Test \(MIKAT\)](#)⁶

Citations and Acknowledgements:

1. Miller, W. R., & Rollnick, S. (2013). *Applications of motivational interviewing*. Motivational Interviewing: Helping people change (3rd edition). Guilford Press.
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4. Leffingwell, T. R. (2006). Motivational Interviewing Knowledge and Attitudes Test (MIKAT) for evaluation of training outcomes. <https://nanopdf.com/download/motivational-interviewing-quiz-oklahoma-state-university.pdf>



Training on Continuous Improvement

Dimension: Stigma

This Intervention is Linked to the Following Secondary Drivers:

- Clinic workflow (from entry until leaving with all steps in between) and organizational environment have effective strategies to remove or mitigate stigma-related barriers
- Organization has processes and systems in place to ensure that it holds itself accountable to ensuring its services do not retraumatize clients

Level of Evidence: Well-Defined Interventions with an evidence-base

Training on Continuous Improvement

Summary:

Organizational leaders frequently make bold statements about their commitment to quality and its components (e.g., safety, efficiency, effectiveness, value and listening to their customer). However, the real test of whether an organization is making quality improvement its north star is how well it has prepared its leaders and staff to apply quality concepts, methods and tools to daily work. Building capacity and capability for continuous improvement, therefore, is a fundamental building block of this journey.

In addition, not all aspects of a clinic's work will have a specific evidence-based or evidence-informed practice to implement. By training clinic staff on how to improve any process, program, or system, they will have a way to systematically improve outcomes related to viral suppression, even in the absence of an evidence-based intervention.

Core Components

Building capacity and capability for continuous improvement requires the following set of interrelated and mutually supported components:

- Building a cascading system of learning that involves everyone, and we do mean everyone, in the organization.
- Developing a group of internal quality experts who can teach the concepts, methods and tools of QI.
- Developing Quality Improvement Coaches who can support improvement teams
- Developing a core curriculum of programs focused on QI and its various dimensions.
- QI learning sessions should be of varying length and be designed around multi-trait and multi-method principles of adult learning.
- Create an evaluation process to continuously gather participant experiences with the learning sessions.

Tips and Tricks:

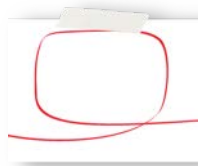
- Don't plan to send all staff to a day or week of "training" and expect to see significant results in outcomes. Learning is a journey not a one-off training course.
- If your organization has multiple sites or clinics, take the QI workshops out to the sites rather than expecting the sites to all come to the corporate offices.
- Work to build internal expertise with QI rather than always bringing in consultants to deliver QI training sessions.
- Remember that the staff is responsible for the actual delivery of services, but management is responsible for quality. Quality is not a department!

Additional Resources (Existing Guides, Case Studies, etc.):

- Lloyd, R. "Quality is Not a Department" IHI blog posting, November 2018. <http://www.ihi.org/resources/Pages/ImprovementStories/ImprovementTipQualityIsNotaDepartment.aspx>
- Lloyd, R. "Standardize Before you Improve" IHI blog posting, July 3, 2018. <http://www.ihi.org/communities/blogs/standardize-before-you-improve>
- Lloyd, R. "What Health Care Can Learn from Making Motorcycles" IHI blog Friday, February 8, 2019 <http://www.ihi.org/communities/blogs/what-health-care-can-learn-from-making-motorcycles>
- Lloyd, R. "Building Capacity and Capability" *Healthcare Executive*, May/June 2018.
- IHI [Whiteboard Videos](http://www.ihi.org/education/IHIOpenSchool/resources/Pages/BobLloydWhiteboard.aspx) on the Science of Improvement <http://www.ihi.org/education/IHIOpenSchool/resources/Pages/BobLloydWhiteboard.aspx>
- IHI [On Demand Videos](http://www.ihi.org/education/WebTraining/OnDemand/ImprovementModelIntro/Pages/default.aspx) on the Science of Improvement
 - Deming's System of Profound Knowledge and the Model for Improvement <http://www.ihi.org/education/WebTraining/OnDemand/ImprovementModelIntro/Pages/default.aspx>
 - Data Collection and Understanding Variation http://www.ihi.org/education/WebTraining/OnDemand/DataCollection_Variation/Pages/default.aspx
 - Using Run and Control Charts http://www.ihi.org/education/WebTraining/OnDemand/Run_ControlCharts/Pages/default.aspx

Citations and Acknowledgements:

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6. Benwick D The "Science of Improvement" *Journal of American Medical Association*, 12 March 2008 299 (10).
7. Deming WE. *The New Economics*, 2nd edition, Cambridge: The MIT Press, 1994.



CQII Website – CQII.org

- ✓ Detailed description of and access to CQII services, including Quality Academy
- ✓ CQII resources are available, including didactic presentations, past recordings
- ✓ Guides and tools to learn more about quality improvement
- ✓ Resources of end+disparities ECHO Collaborative
- ✓ Access to TA Request Form
- ✓ Access point to CQII trainings

[CQII.org](https://www.cqii.org)

Tools for HRSA's Ryan White HIV/AIDS Program

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Home » Help » Technical Assistance Directory » Center for Quality Improvement and Innovation

Center for Quality Improvement and Innovation

HRSA's Ryan White HIV/AIDS Program Center for Quality Improvement and Innovation (CQII) provides technical assistance on quality improvement to Ryan White HIV/AIDS Program recipients. CQII (formerly the National Quality Center-NQC) has the expert quality improvement consultants with whom many of you have worked. CQII provides face-to-face trainings, TA webinars, and many of the other services you have come to appreciate.

CQII has a plethora of resources to assist you in meeting your quality improvement requirements. Our publications are available on line for download as well as the full range of Quality Academy and Consumer Academy tutorials. [View our online resources.](#)

CQII's program is modeled after the three components of a good quality management program. Which is defined by Policy Clarification Notice 15-02: Infrastructure, performance measurement, and quality improvement. [HAB's Clinical Quality Management Bureau](#) is handling the infrastructure and performance measurement. CQII helps Ryan White HIV/AIDS Programs structure and implement quality improvement projects. The Center is here to help you use your data and implement quality improvement projects. Simply fill out the [online technical assistance form](#) and HAB will contact you with next steps.

Resources

Resources formerly found on the on the NQC website have been transferred to the [Clinical Quality Management webpage](#) of this site.

Center for Quality Improvement and Innovation Home

- [end+disparities ECHO Collaborative](#)
- [Publications](#)
- [Quality Academy](#)
- [Quality Consumer Academy](#)
- [Quality Improvement Webinars](#)
- [Ryan White Conference](#)
- [Training for Consumers on Quality Plus](#)
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