

A group of four diverse young adults (two men and two women) are smiling and posing together outdoors. They are dressed in casual, contemporary clothing. The background is a soft-focus outdoor setting with greenery.

From Data to Dialogue: Integrating Quality Improvement (QI) and Youth and Young Adult (YA) Perspectives to Drive Better HIV Outcomes

By Melissa Curry

December 2, 2025

Objectives

By the end of this session, participants will be able to:

01

Explain

Explain why youth & YA engagement in QI efforts is critical to improving HIV medical care.

02

Identify

Identify barriers to youth & YA engagement in QI and link those barriers to root causes.

03

Apply

Apply QI tools to test youth & YA engagement strategies including driver diagrams, Plan-Do-Study-Act (PDSA) cycles, and run charts.

04

Describe

Describe how to integrate youth & YA's into QI teams and processes.

**Why should youth
& YA engagement
in QI be a
priority?**



Importance of Youth & Young Adult Engagement

Nearly half of youth & YA (ages 13–24) with HIV are unaware of their diagnosis.

Youth accounted for **20% of new HIV diagnoses in 2022** (CDC, HIV.gov).

Engaging youth in QI improves key HIV performance measures used by the Health Resources and Services Administration (HRSA) to assess patient outcomes:

- Linkage to care
- Retention in care
- Viral suppression



Importance of Youth & Young Adult Engagement in QI

Encourages innovation → test new change ideas.

Builds trust → improves client experience.

Provides client experience → identifies systemic barriers.

Develops future leaders → ensures sustainability.



What are
common
challenges to
youth & young
adult
engagement in
QI?

Barriers to Youth & Young Adult Engagement

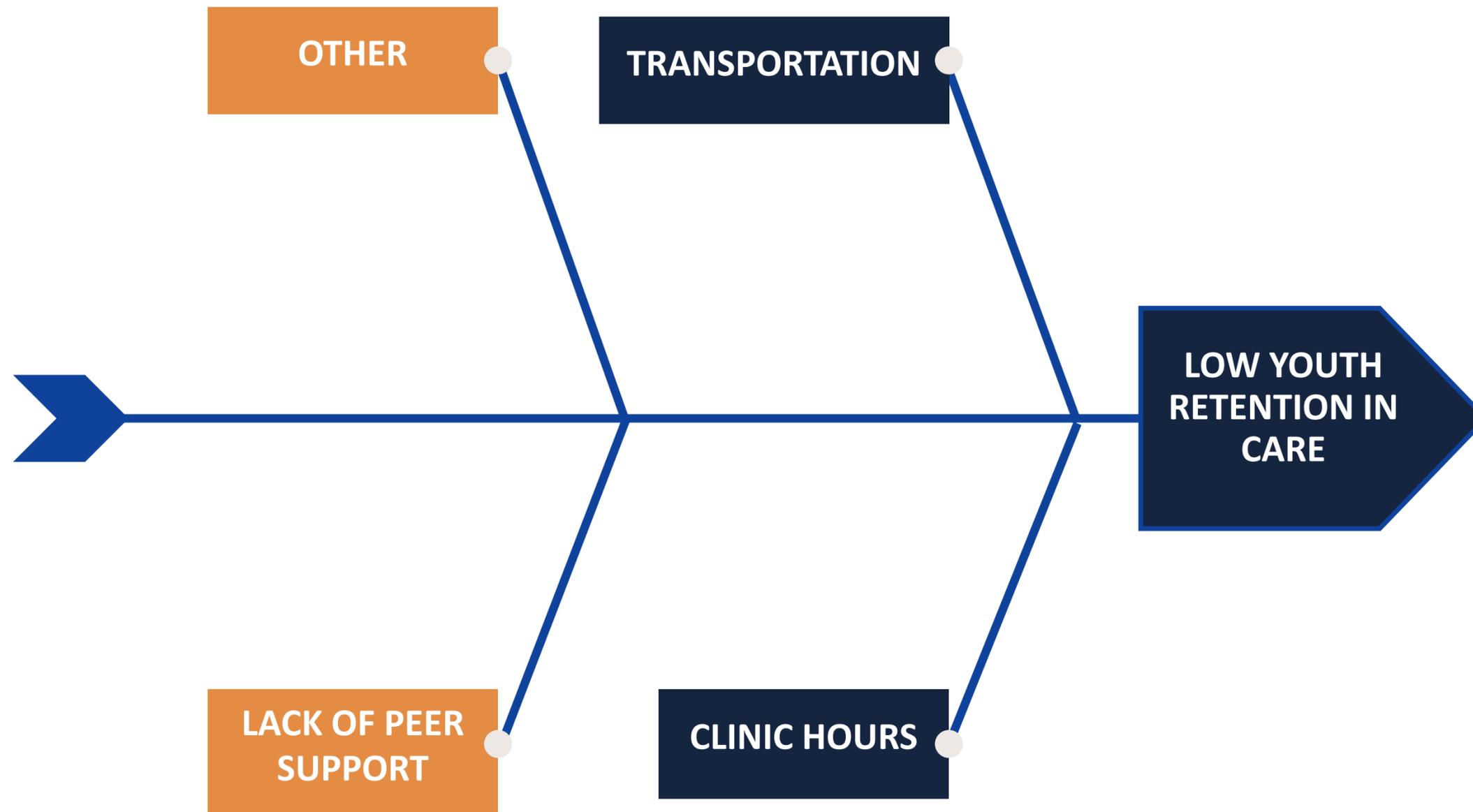
Common barriers include:

- Fear of disclosure
- Distrust in healthcare systems
- Limited clinic accessibility (hours, transportation)
- Lack of youth-friendly environments
- Ignoring youth voices
- Communication gap
- Cost of services
- Privacy

QI Tools & Resources for Youth & Young Adult Engagement



From Barriers to Root Cause Analysis



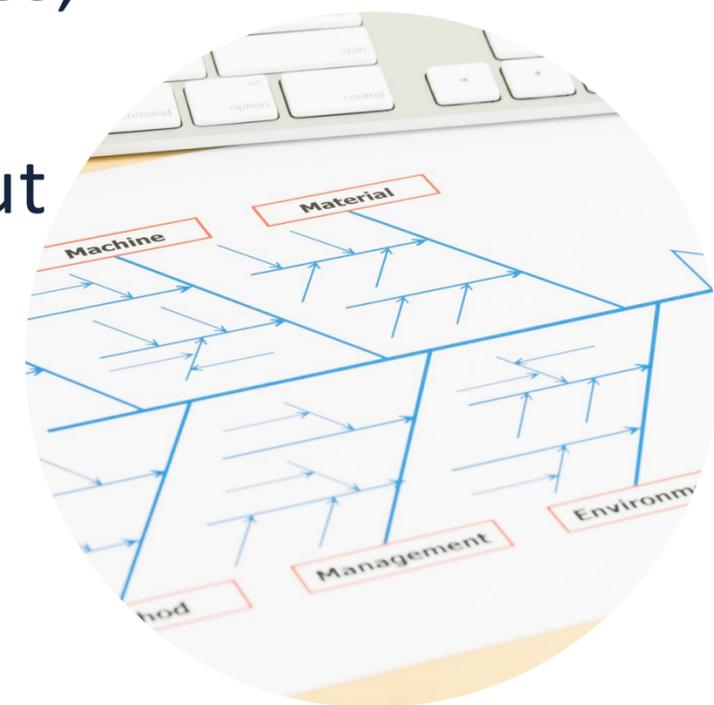
Fishbone (Ishikawa) Diagram

Purpose: Helps visualize all the possible causes of a barrier.

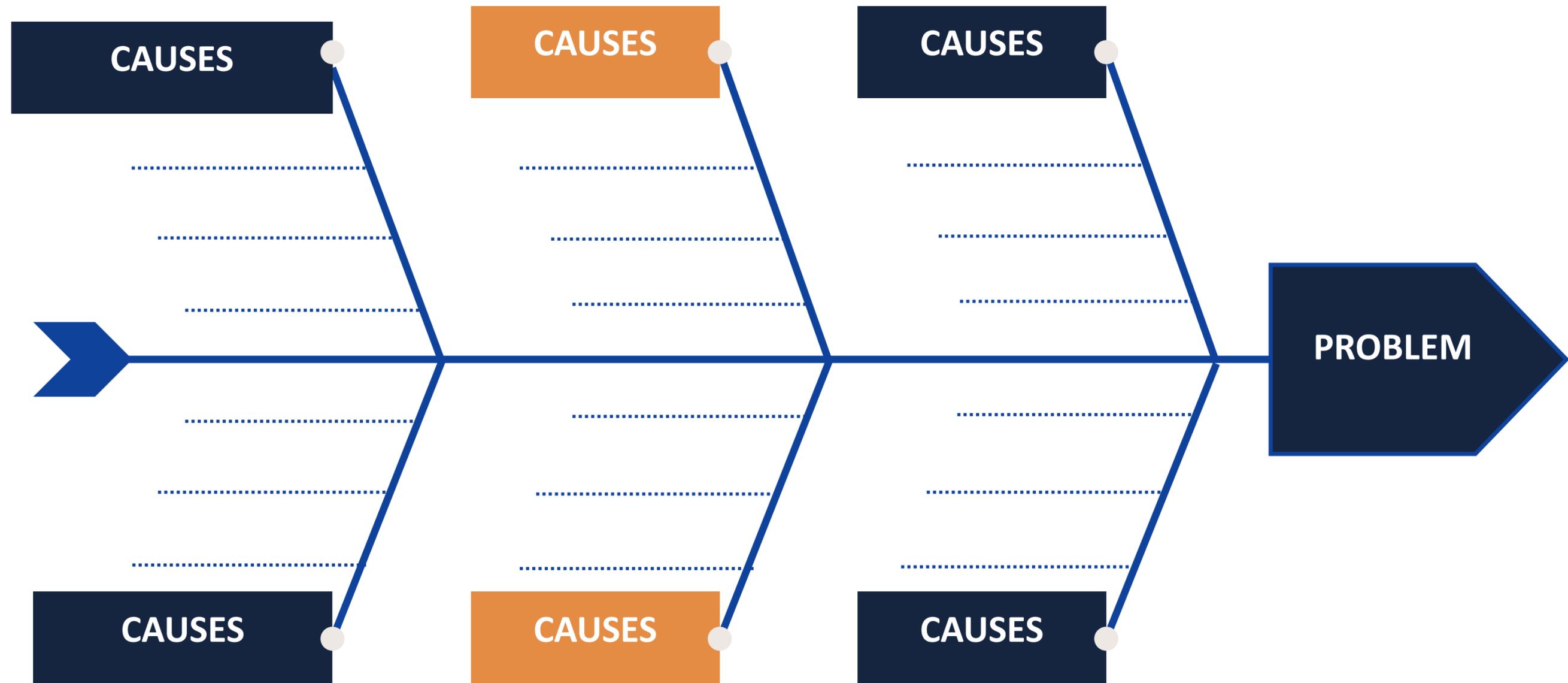
How to use:

- Place the “problem” at the head (e.g., *low youth retention in HIV medical care*).
- Create major categories of causes (e.g., people, processes, environment, policies, technology).
- Brainstorm specific barriers to youth & young adult input (e.g., transportation issues, limited clinic hours).

Youth Role: Youth can co-facilitate the brainstorm session(s) and validate whether causes are real.



Fishbone (Ishikawa) Diagram



5 Whys Technique

Purpose: Dig deeper into the root of a barrier rather than stopping at surface-level issues.

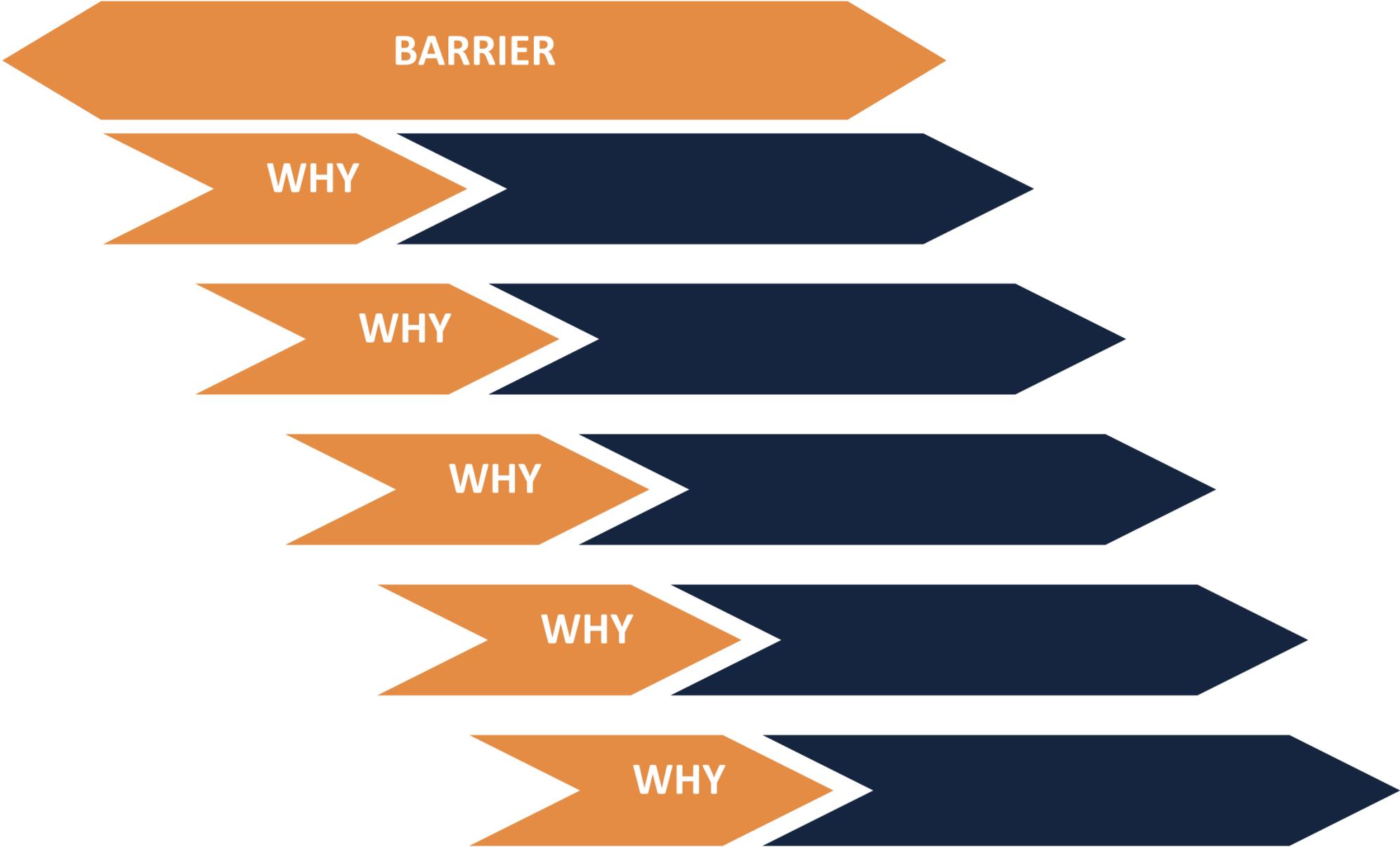
How to use:

- Start with a barrier (e.g., “Youth miss appointments”).
- Ask why up to five times:
 - **Why?** → “Because hours conflict with school/work.”
 - **Why?** → “Because clinics are only open 9–5.”
 - **Why?** → “Because staffing hasn’t been allocated for evenings/weekends.”
 - **Why?** → “Because funding wasn’t directed toward flexible schedules.”
 - **Why?** → “Because youth weren’t included in QI priority-setting.”

Youth/YA Role: Youth advisors can answer these “whys” directly, ensuring the real issues aren’t missed.



5 Whys Technique



Pareto Chart (80/20 Rule)

Purpose: A data visualization tool that highlights the most significant project or process issues.

How to use:

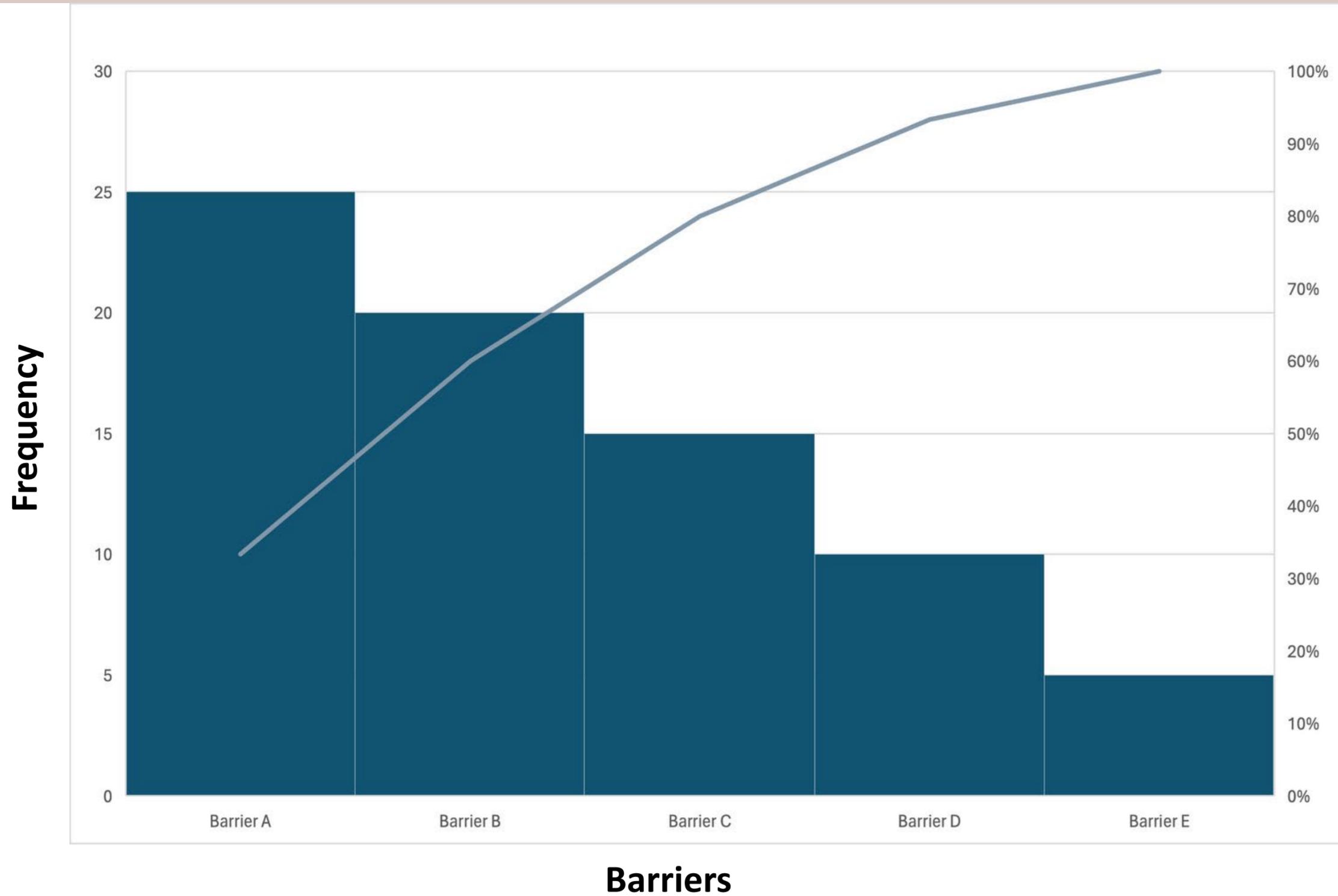
- Collect data on barriers (e.g., percentage of missed visits due to transportation, clinic hours, etc.).
- Plot them in descending order.
- Highlight the vital few barriers that account for most of the problem.

Example: If 70% of youth missed appointments are due to transportation and clinic hours, focus Plan-Do-Study-Act (PDSA) cycles on them first.

Youth Role: Youth can help prioritize which barriers feel most urgent to address.



Pareto Chart (80/20 Rule)



From Barriers to Root Cause Analysis

Example: “Low youth retention in care.”

Causes:



Transportation



Clinic Hours



Lack of Peer Support

Youth can **co-lead root cause analysis sessions to validate findings.**

Using a Driver Diagram to Guide Youth Engagement in QI

What is a Driver Diagram?

A **visual QI tool** that links the **overall aim** to the **key drivers** (factors that influence success) and the **specific change ideas** which need to be tested.

Helps teams, including youth, **see the big picture** of how efforts connect to measurable outcomes.

Encourages **shared ownership** of improvement work across staff, providers, and youth advisors.

Aim

To meaningfully link and re-engage people with HIV who are out of care to HIV medical care to measurably improve their HIV care outcomes and experiences with the healthcare system through the application of QI methodologies.

Care Collaborative

Primary Drivers

Clients experience their care and interact with the care team in a client-centered setting.

Patient support systems are in place to address barriers to care and help clients to stay in care and treatment.

The clinic workflow facilitates the engagement of out of care clients into ongoing HIV medical care and rapid start of antiretroviral therapy.

Internal and external partnerships support the linkage and retention of out of care or undiagnosed.

Data systems are optimized and routinely used to facilitate the identification of clients who are not linked to or retained in HIV medical care.

Secondary Drivers

- Train staff to provide culturally sensitive, and respectful HIV medical care
- Utilize motivational interviewing and teach-back when engaging out of care clients
- Promote the uptake of evidence-based self-management strategies to empower clients to manage their own health care and participate in their own care
- Routinely measure the healthcare experiences of out of care clients using validated measures
- Utilize findings from patient-reported experience measures to improve clinic flow and care experiences
- Co-produce a working definition of client-centered care that is informed by community and staff input
- Update clinic policies and procedures that reflect the needs of clients with community input

- Train all staff, including onboarding of new staff, to competently support clients and their needs
- Individually and routinely assess client barriers for staying in care and treatment, including care handoffs
- Develop individualized care plans to mitigate the impact of social determinants of care and unmet client needs
- Provide individualized case management support services by trusted team members
- Conduct interdisciplinary rounds with the entire care team to address individual client needs
- Offer group peer support and group visits to out of care clients
- Empower clients to engage other out of care individuals in their communities
- Engage and support clients to participate as equal members on your out of care QI project

- Set up and train staff on process maps on how to optimally engage and treat newly linked and re-engaged clients
- Have same-day appointments available for out-of-care clients, ensure all client touch points (front desk, lab, pharmacy, etc.) understand their role in influencing the overall client experience and flow
- Integrate processes for same-day ART initiation into workflows to reduce handoffs and promote care coordination
- Create protocols and procedures for expeditiously enrolling clients, including verification of eligibility and clinical documentation
- Assess and enhance the organizational readiness within the HIV team and the larger organization
- Identify and support staff champions to lead implementation and help sustain momentum despite turnover
- Expand HIV testing internally and externally to identify new HIV diagnoses

- Set up sustainable partnerships with external HIV testing & referral sites to reach undiagnosed populations
- Develop protocols to optimally engage out of care clients and ease their navigation to the clinic
- Expand HIV testing internally to identify new HIV diagnoses
- Optimize internal systems to engage out of care clients who touch the agency (ED, OB/GYN)
- Establish internal and external support systems to tackle social determinants of care and unmet needs

- Define who is presumed out of care and what data systems are used to identify them
- Use data to identify never been linked to care or are not currently retained clients in ongoing HIV care
- Enhance agency medical record systems to facilitate the identification of out-of-care clients
- Routinely generate and review data reports, including data drill-downs
- Share digestible visual data formats to improve data use at all levels and across departments and roles
- Assess and enhance organizational data readiness within the HIV care team and the larger organization

Youth Engagement Driver Diagram Example

- **Aim:** Increase youth retention in HIV medical care from 60% → 80% within 12 months.
- **Primary Drivers:** Access, trust, youth engagement.
- **Secondary Drivers:** Clinic hours, peer navigators, technical tools.
- **Change Ideas:** Youth Advisory Councils, texting campaigns, Saturday clinics.

Strategies as QI Change Ideas

Examples of interventions to test:

Create a welcoming atmosphere.

Flexible clinic hours.

Technology-based engagement: apps, text reminders.

Youth-friendly marketing.

Variety of services: mental health, social support.

QI framing: Each strategy becomes a **change idea** to test via **PDSA cycles**.



Putting Change to Work: Plan-Do-Study-Act (PDSA)

Plan:

Set goals and design.

Do:

Pilot test with small group.

Study:

Review outcomes.

Act:

Refine and expand.

PDSA supports responsive, sustainable improvements in peer-led care.

A well-established QI approach that enables structured testing of changes in real-world community health settings.

Case Example (QI in Action)

- **Problem:** Youth missed follow-up visits.
- **Root Cause:** Inconvenient clinic hours.
- **Change Idea:** Saturday clinic hours.
- **QI Tool:** PDSA cycle and run chart to track attendance.
- **Result:** Increased youth retention from 58% → 72% in six months.



**Great...
now what?**



Strategies to Engage Youth & YA's



Outreach, Outreach, Outreach.



Social media is a game changer.

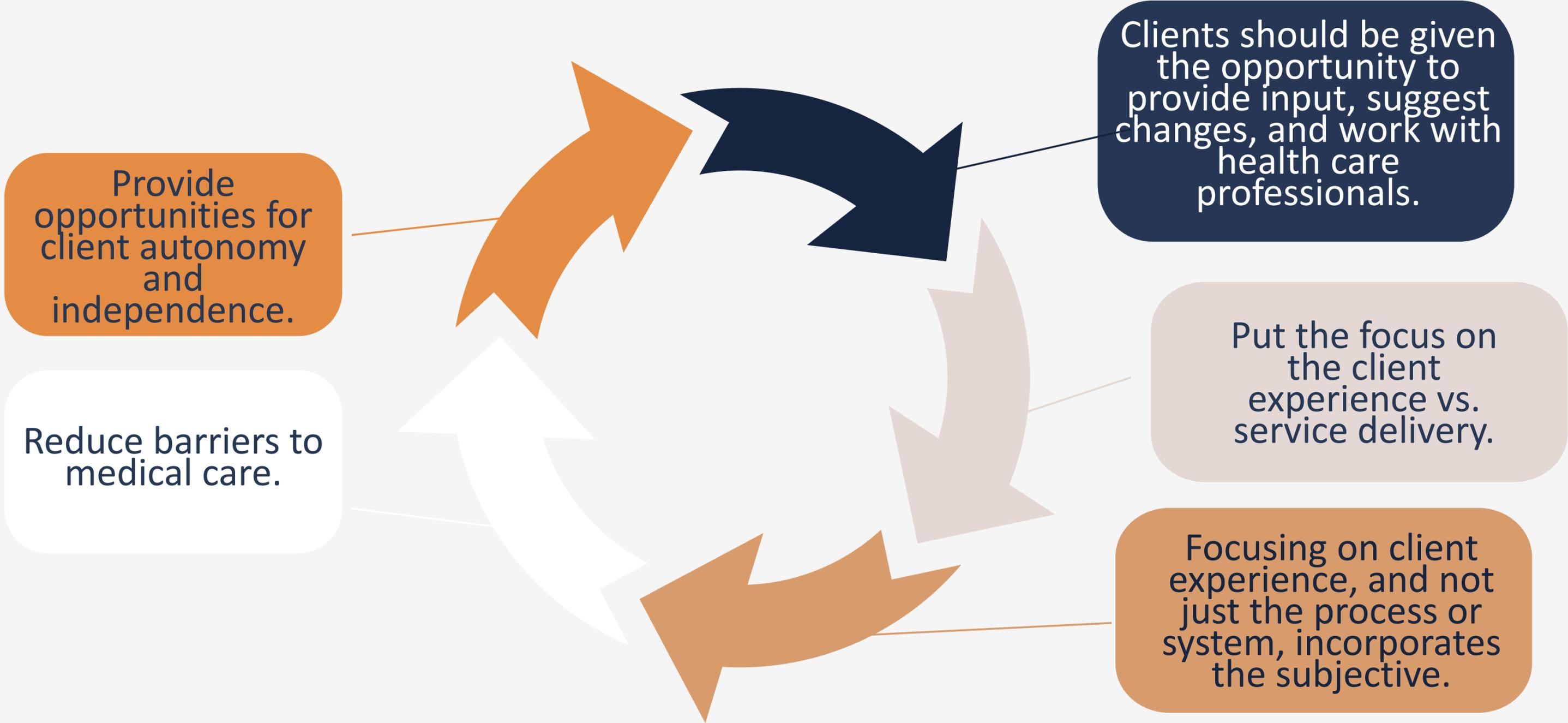


Offer resources to help support the sustainment of client engagement.



Develop a protocol for your process - people love consistency & stability.

The Wheel of Client Experience



Domains of Youth & YA Involvement



Empathic Listening



Gathering Perspectives



Engaging in Activities



Co-Producing & Leading



Real - World Example Youth Advisory Councils

Youth Advisory Councils (YAC) are structured groups of young people, often between the ages of 14 and 24, who work in partnership with healthcare organizations to improve systems, services, and outcomes.

Core Functions of YACs:

- **Feedback Providers:** Share real-life experiences with healthcare access and quality.
- **Co-Creators:** Help design youth-friendly materials, programs, and clinic spaces.
- **Advocates:** Represent youth needs in institutional policies and procedures.
- **Bridging the Gap:** Act as liaisons between healthcare providers and the youth community.

Why It Works:

- **Allows youth to have a real voice in decisions that affect them.**
- **Builds trust and increases engagement with health services.**
- **Ensures services are tailored to the needs of clients.**

Real Impact of Youth & YA Engagement

Accessibility:

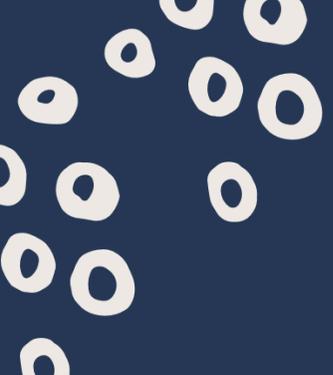
Services redesigned to be more youth-friendly result in higher usage among youth.

Better Policy:

Youth-informed programs are more effective in youth engagement.

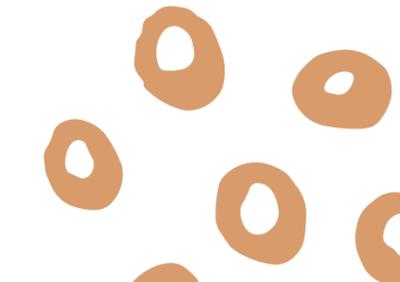
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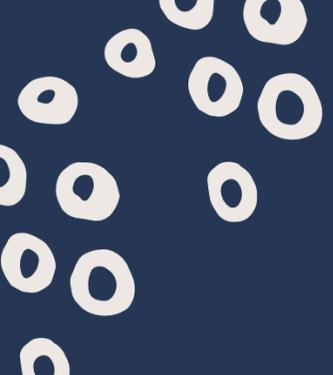
Youth can help identify and develop strategies to address barriers.



Call to Action

If young people are not showing up,
what needs to be changed and how?

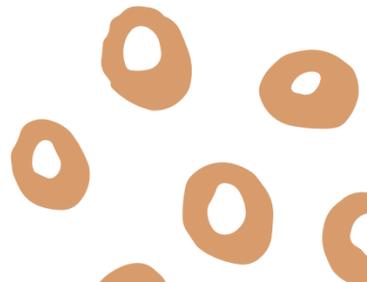




The time is now!

“The youth of today are the leaders of
tomorrow.”

~Nelson Mandela~



Any
questions?



Thank You!

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