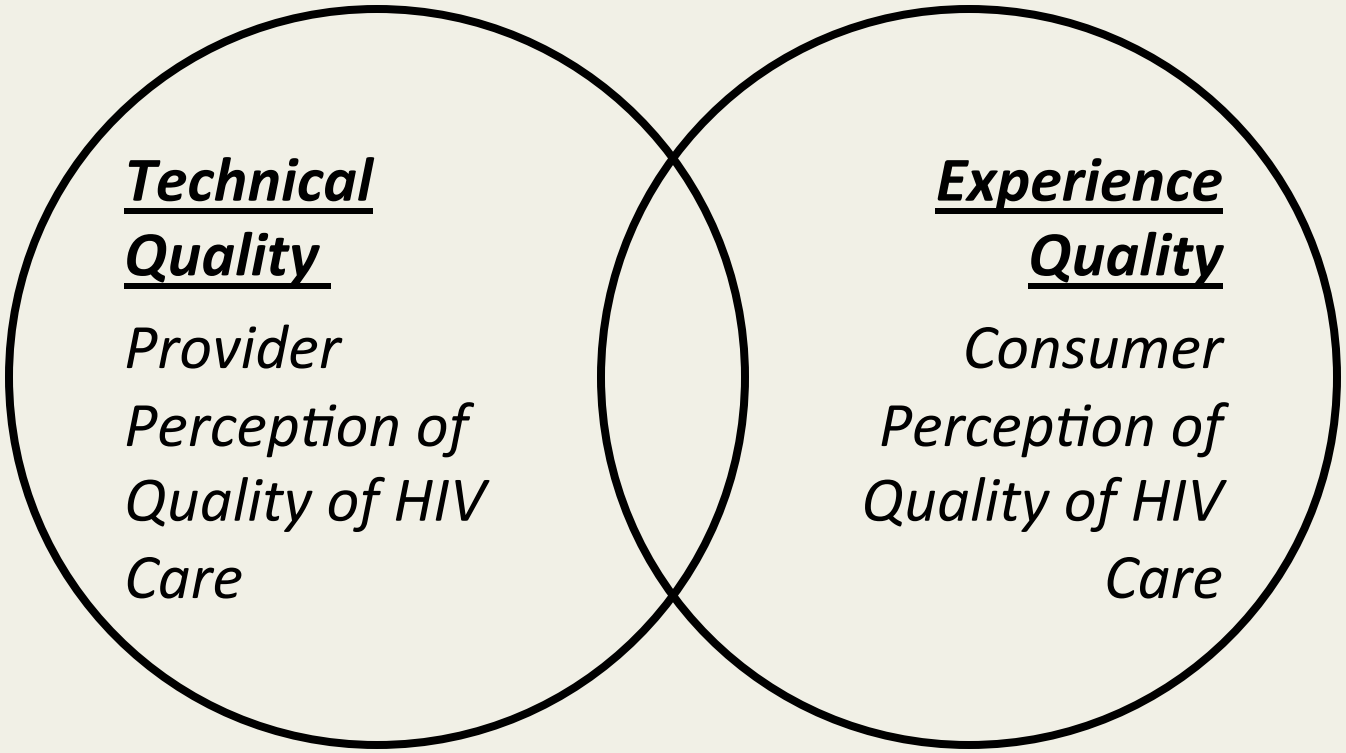
Virginia Ryan White HIV/AIDS Program Part B

PEOPLE LIVING WITH HIV/AIDS (PLWHA) INVOLVEMENT

Provider and Consumer Perceptions

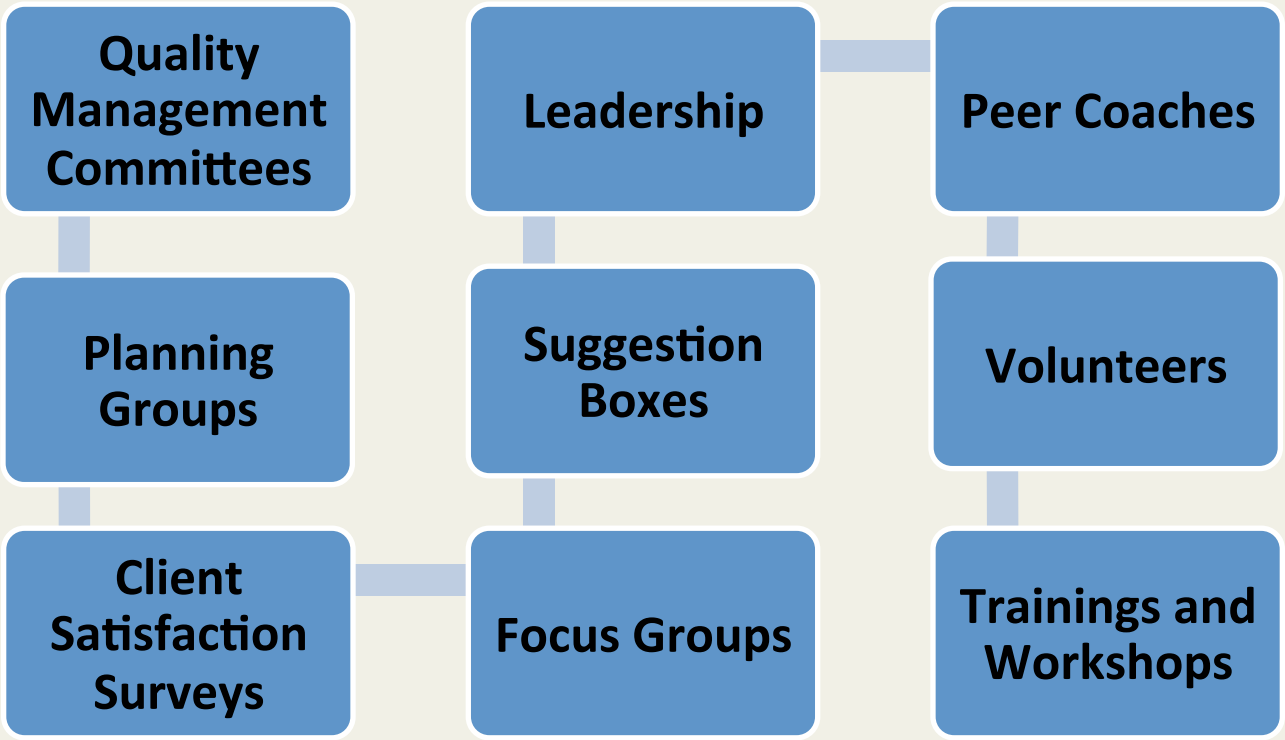


Leonard Berry, Texas A&M University, IHI conference 2001

BARRIERS

- Lack of some basic foundational skills for HIV
- Lack of knowledge related to data management
- High levels of denial, fear, and stigmatization
- Systematic lack of quality advocacy methods
- Unemployment
- Survey fatigue or same PLWHA in different planning groups

INFRASTRUCTURE:
Multiple Avenues for PLWHA Engagement



OUR ACHIEVEMENTS

- Consistency in PLWHA Involvement
- Increased PLWHA capacity to improve quality
- Different methods of engagement
- Recognition for leadership

Programmatic and Financial Changes Based on Input from PLWHA Engagement

- Training on Core Medical Services
- New services and modalities (Dental, Case Management, Hepatitis C treatment, smoking cessation, telemedicine)
- Allocation of Resources (increased $$ and removal of caps on services)
- Integration of HIV Prevention and Care Planning

BENEFITS OF ENGAGEMENT

Providers:

- Meet clients' needs based on successful advocacy from consumer-leaders
- Identify systems and procedural changes or adjustments
- Adapt program and training materials to accommodate PLWHA needs
- Recruit more PLWHA participation for sustainability of Quality Improvement activities
- Facilitate skills building and motivational interviewing methods

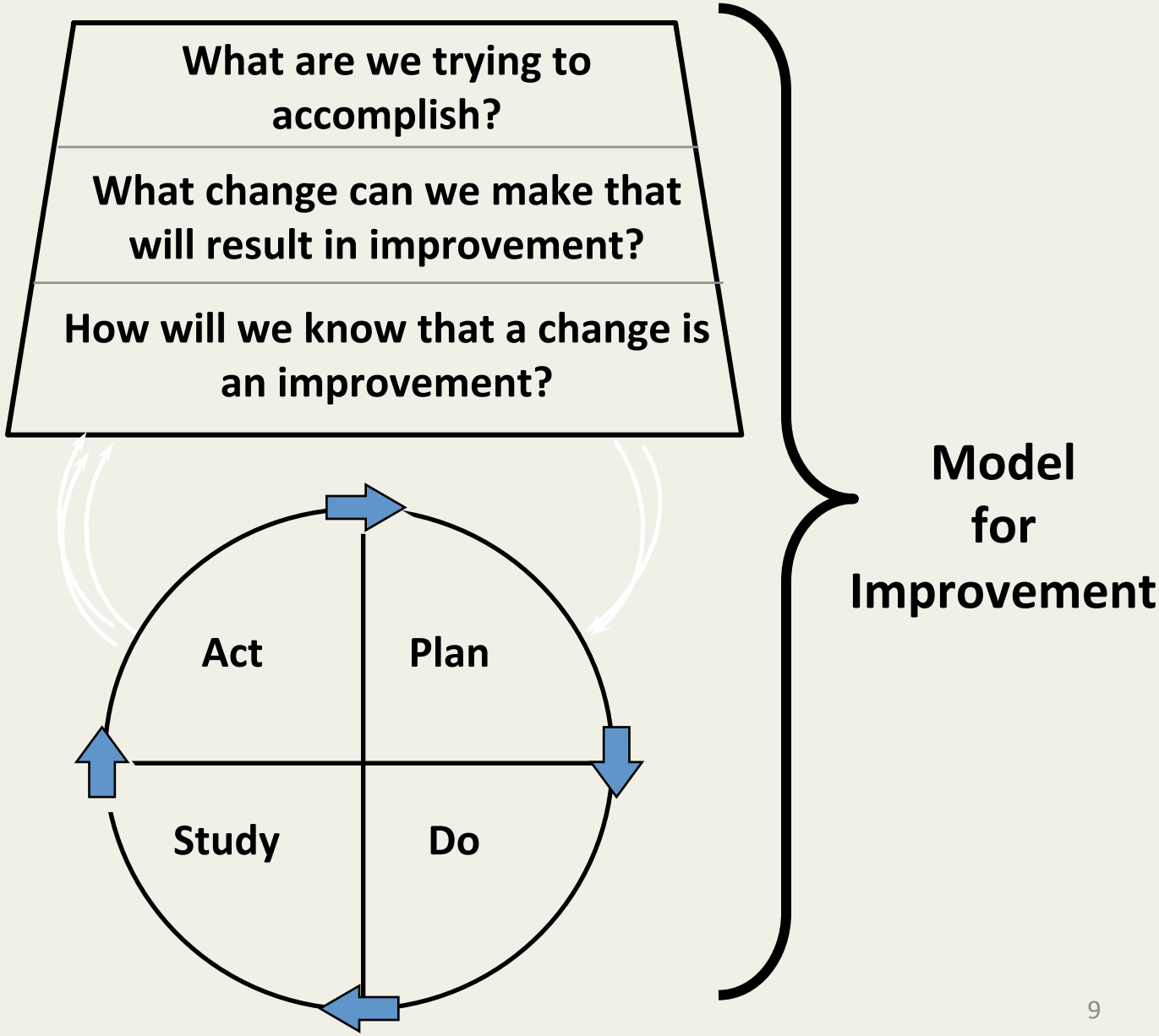
PLWHA:

- Increase capacity to improve quality of care
- Paid jobs opportunities for trained PLWHA – Peer Coaches
- Develop resources and tools that include PLWHA input
- AIDS Drug Assistance Program (ADAP) information vetted by stakeholders
- Participation in Planning and Advisory groups

LESSONS LEARNED

- Provide transportation, employment, and incentives as needed
- Develop and administer ongoing, brief consumer satisfaction survey
- Report all survey results to all stakeholders
- Ability and willingness to make operational changes
- Ensure assessments reflect the needs of consumers
- Ensure PLWHA are aware of involvement opportunities
- Ensure PLWHA see positive effects of their involvement

Model for Improvement



Questions

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