Applying a Community Organizing Model of Leadership to Achieve Health Equity for Transgender Youth

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PROBLEM

Transgender and gender-expansive youth (hereafter transyouth)
- Face significant health disparities nationwide
- Disproportionate levels of bullying, homelessness, substance use, and suicide
- Few primary care providers trained in the care of transyouth[1]

Coachella Valley (desert valley east of Los Angeles)
- Almost 100,000 residents under age 18
  - Over 80% of youth are non-white
  - Nearly 80% live in households below 250% of federal poverty line
  - Number living in poverty nearly doubled in only six years[2]
- Anecdotally high transyouth population (but no specific data)
- Significant intersectionality expected among gender-minority identity, race/ethnicity, and socioeconomic status
- Pediatric subspecialty care of any kind exceedingly rare

"Justin," a 12-year-old Latino transgender male
- Unable to access affirming care in the desert
  - Family taking him to specialist pediatric care in Los Angeles
  - 6- to 8-hour round trip for routine 30-minute visits
- Already missing excessive number of school days
  - Dysphoric and unable to attend while menstruating
  - Presented to clinic with medication denial letter in hand
- Became first of many transyouth representing a health equity challenge within our Family Medicine Practice

APPROACH

Initial Plan
- Obtain support from transyouth, community organization leaders, and community members/leaders
- Design IRB-approved mixed-methods pilot study to identify transyouth at high risk for health inequity and assess intersectionality
- Fill gaps in household data collected regularly from adult members
- Answer: Where are our transyouth, and what are their health needs?

Leaders for Health Equity (LHE) Fellowship Program
- New program of George Washington University Health Workforce Institute
  - Goal to develop global leaders who understand foundations of health inequity
  - Equip with knowledge, skills, and courage to build more equitable organizations and communities
- Dramatically altered assessment approach
  - Encouraged application of community organizing model of leadership to scholarly activity aimed at achieving health equity
  - Fundamentally upended previously held perceptions about community-based research
  - Led to critical skillset for engaging in future advocacy work (as in Methods section)

Ultimately, this project should serve as a demonstration project for scholars in low-resource communities seeking to provide affirming support strategies for transyouth.

METHODS

TABLE 1. Selected organizing leadership practices applied during the course of this project's evolution.[3]

Organizing Leadership Practice	Project Implications
Coaching as a Leadership Practice	• Coaching enables others. • Newly identified potential team members quickly had to become effective team members.
Mobilizing Shared Values: Public Narrative and Story of Self, Us, & Now	• Stories that engage both the "head" and the "heart" can move others to action. • Justin's story easily compelled others to become involved and add to the "story of us."
Mobilizing Shared Commitment: Building Relationships	• Relationships built on shared values lead to mutual commitment to work together toward common purpose. • Gaining commitment from stakeholders led to an ever-growing network of relationships.
Mobilizing Shared Structure: Building Leadership Teams	• A team approach provides a structure that fosters distributed leadership. • It became clear very early on that this was not a project for a single person with limited community involvement. (See Figure 1.)
Turning Resources into Power: People, Power, & Change	• Mapping our actors allows us to generate collective power to co-produce health equity. • Getting to this step ensured a shift away from investigator-driven outcomes and toward community-driven outcomes. (See Figure 2.)
Turning Resources into Power: Tactics & Timeline	• Activities that make project strategy real should unfold as a structured narrative. • The kick-off event will be a youth celebration to engage and empower the transyouth community.
Mobilizing Shared Structure: Interdependent Leadership	• Distributed leadership is essential to connecting multiple teams across levels of coordination. • The "snowflake" model is allowing team leaders to enact particular parts of the strategy while continuing to work collectively. (See Figure 3.)

FIGURE 1. Hierarchical/siloed team structure. Few stakeholders are represented – none as leaders.

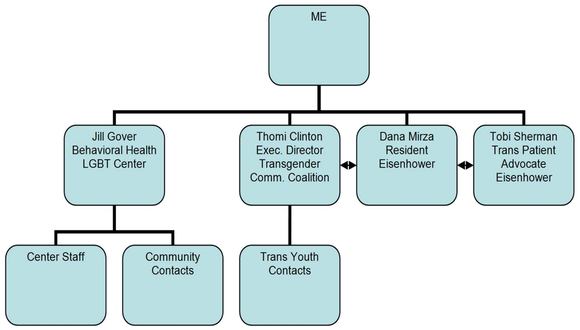
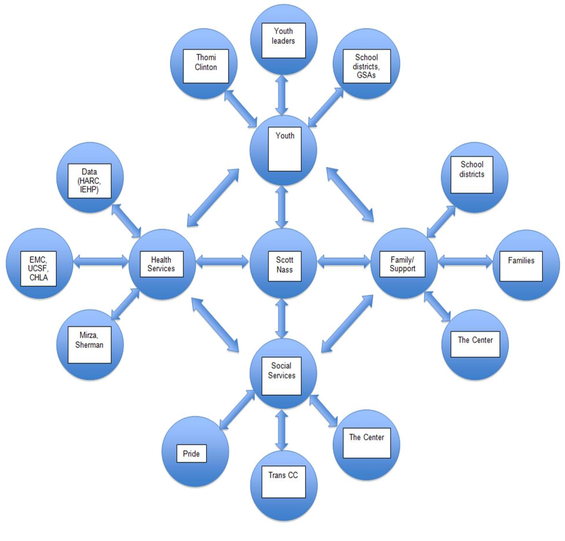


FIGURE 2. Organizing sentence. This foundational statement for this health equity project evolved over time in response to lessons learned and community feedback.

*"I am organizing **(WHO — leadership & constituency)** to do **(WHAT — measurable aim)** by **(HOW — tactics)** because **(WHY — motivating vision)** by **(WHEN—timeline).**"*

I am organizing transgender and gender-expansive youth, community organization leaders, and community leaders to develop a sustainable process of community self-assessment by formally evaluating assets and needs because services and opportunities for transyouth remain suboptimal, by Sep. 2018.

FIGURE 3. Distributed leadership model. Leaders now leverage collective values to grow the team structure and work together to achieve a common purpose.



DISCUSSION

Residency training sites quite often embedded within communities that face significant health inequity
- Significant opportunities for improved healthcare access, delivery, or quality
- Also significant barriers to effecting positive change within these communities

Tendency to independently formulate solutions to perceived problem before community engaged fully around issue[4]
- Need to resist urge to approach perceived inequities with a top-down model of leadership
- Serve local communities more effectively by empowering them through use of community organizing
  - Principles of great benefit to well-meaning educator and learners with "outsider" status
  - Can enable community members to transform available resources into the power they need to achieve their purpose

Meaningful purpose from within community as primary driver of sustainability[5]
- Community longevity greater than learner tenure
- Power of community as key factor when considering health equity projects
- Organizing for empowerment as the foundation upon which all projects are built

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