Inclusion of vulnerable and marginalized youth in research: Who, why, what, when and how?

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Disadvantaged, vulnerable and/or marginalized adolescents are youth who are excluded from social, economic and/or educational opportunities enjoyed by other adolescents in their community due to numerous factors beyond their control.

Who are disadvantaged, vulnerable and/or marginalized adolescents in your community?
Art credits: Elvis Wolf, Micah Bazant, Melanie Cervantes, Kelly Bairds, Fox Fisher
Why?
Homeless Youth Experience Greater Mortality

Death rate for homeless group overall 9x the death rate for non-homeless age, gender, and race/ethnicity matched controls.
Disparities by Behavior

Youth → Health Outcome

Youth → Behavior → Health Outcome

Behavioral Interventions

STI Disparities By Race: STI Paradox


Boys are:
- More likely to be sexually active vs. not
- Onset sex earlier
- Have more sexual partners
- Are more likely to have had sex recently

Source: CDC and San Francisco Department of Public Health, STD Control Section.
Social Determinants of Health:

“Conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”

From: Healthy People 2020
Social Determinants of Health

Life Course

Economic Environment/
Poverty/Opportunities

Youth

Behavior

Health Outcome

Overall Health &
Wellbeing

Behavioral Interventions
Embodiment:

“We literally incorporate, biologically, the material and social world in which we live: no aspect of our biology can be understood in the absence of knowledge of history and individual and societal ways to living.”

Social Determinants of Health

- Life Course
- Economic Environment/Poverty/Opportunities
  - Youth
  - Behavior
  - Health Outcome
  - Overall Health & Wellbeing
  - Behavioral Interventions

EMBODIMENT
STI PARADOX? Gender disparity in STIs

OR of GC for African American young women relative to young men in economically marginalized neighborhood of San Francisco

(OR data—controlling for partner number)
### STI PARADOX? Gender disparity in STIs

<table>
<thead>
<tr>
<th>Partner Characteristic</th>
<th>Teen Girls</th>
<th>Teen Boys</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 5 y older</td>
<td>18%</td>
<td>4%</td>
<td>1.48 (1.08 - 2.03)</td>
</tr>
<tr>
<td>Perceived history of incarceration</td>
<td>61%</td>
<td>8%</td>
<td>1.86 (1.50 - 2.29)</td>
</tr>
<tr>
<td>Perceived history of gang membership</td>
<td>16%</td>
<td>9%</td>
<td>N.S.</td>
</tr>
<tr>
<td>Perceived other partners</td>
<td>21%</td>
<td>33%</td>
<td>N.S.</td>
</tr>
</tbody>
</table>

TABLE: Odds Ratio for Having a Partner With Specified Characteristic by Gender in a Random Digit Dial Household Sample of 14- to 19-Year-Old African American Youth From an Economically Marginalized Neighborhood in San Francisco.
TABLE: Odds Ratio for Having a Sexually Transmitted Infection (STI) by Partner Characteristic Controlling for Number of Sex Partners in a Random Digit Dial Household Sample of 14- to 19-Year-Old African American Youth From an Economically Marginalized Neighborhood in San Francisco

<table>
<thead>
<tr>
<th>Partner Characteristic</th>
<th>STI</th>
<th>No STI</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 5 y older</td>
<td>14%</td>
<td>86%</td>
<td>1.79 (0.45-7.21)</td>
</tr>
<tr>
<td>Perceived history of incarceration</td>
<td>17%</td>
<td>83%</td>
<td>6.56 (1.77-24.27)</td>
</tr>
<tr>
<td>Perceived history of gang membership</td>
<td>9%</td>
<td>91%</td>
<td>N.S.</td>
</tr>
<tr>
<td>Perceived other partners</td>
<td>14%</td>
<td>86%</td>
<td>N.S.</td>
</tr>
</tbody>
</table>
Social Determinants of Health and STIs

**With** effect of incarceration

**Without** effect of incarceration

**OR of GC for African American young women relative to young men in economically marginalized neighborhood of San Francisco**

- **Young women**
- **Young men**

**OR Value**

- 0
- 0.5
- 1
- 1.5

- 0.00
- 0.25
- 0.50
- 0.75
- 1.00
- 1.25
Homeless Youth Experience Greater Mortality

Death rate for homeless group overall 9x the death rate for non-homeless age, gender, and race/ethnicity matched controls.
Let’s review some concepts

1. **Marginalized Youth**
   - Are a diverse group of adolescents
   - Differ by region

2. **Disparities**
   - In health and wellbeing affect marginalized youth
   - Are insufficiently explained by individual behaviors

3. **Social Determinants of Health**
   - Affect the context and consequences of individual health behaviors

4. **Embodiment**
   - Is the direct effect of the SDoH on health and wellbeing

5. **To intervene on the SDoH:**
   - Behavioral interventions are insufficient
   - Need “upstream” or structural interventions.

**Barriers and Challenges**

- Inadequate data
- Challenge to recruiting and obtaining representative samples.
- Stigma
- Use of developmentally inappropriate definitions and approaches
- Limited variables (often individually focused and risk-focused)
Social Determinants of Health

Life Course

Economic Environment/
Poverty/Opportunities

Youth

Behavior

Behavioral Interventions

Health Outcome

Overall Health & Wellbeing

EMBODIMENT

**Barriers and Challenges**

- Inadequate data
- Challenge to recruiting and obtaining representative samples.
- Stigma
- Use of developmentally inappropriate definitions and approaches
- Limited variables (often individually focused and risk-focused)
- Concerns about research ethics

*When?*
Connect youth to supportive adults and peers, and to social safety net services
Reverse internalized stigma
Increased sense of self-worth

“I learned that we matter. That was the overall lesson. I mean, the people that showed up to the initial gala, there were a lot of people here and that just got me teared up on the way home.”

**Benefits for Youth**

- Connect youth to supportive adults and peers, and to social safety net services
- Reverse internalized stigma
- Promote skill development and promote sense of empowerment/agency
Increased self-confidence in creative expression and public speaking

“I learned how to give the feeling of – in your words, of how you felt about the picture, why you took it. It felt invigorating because it was something that I was able to speak on, that I felt needed to be spoken on. It was very different, ‘cause I normally don’t.”

**Benefits for Youth**

- Connect youth to supportive adults and peers, and to social safety net services
- Reverse internalized stigma
- Promote skill development and promote sense of empowerment/agency
- Increase civic and social competencies
- Improve the social capital for participating youth
Benefits for Community

- Increase ability to address community needs
- Develop and recruit of a new generation of leaders
Benefits for Research

- Access to hard-to-reach youth
- Maximize validity
- Increase uptake of the research/increased buy-in
- Improve feasibility, effectiveness and acceptability of resulting interventions
- Improve attention to research ethics

Best Practices

- CBPR/YPAR
- Inclusive team
- Sampling/recruiting a representative sample
- Range of variables (individual/contextual; risk/protective; modifiable structural factors)
- Mixed methods
- Appropriate data collection approaches
- Longitudinal data
- Ethical guidelines
- Dissemination

CBPR/YPAR

Ethical Guidelines

Sampling
Youth-led Participatory Action Research
Youth-led Participatory Action Research

Youth identify issues they want to improve, conduct research to understand the issues and possible solutions, and advocate for changes based on research evidence.

- Integrating iterative research and action phases
- Training adolescents in research, critical thinking and advocacy strategies
- Sharing power among adult facilitators and young researchers over key decisions and steps in the process.
Sampling / recruiting a representative sample
Convenience Sampling

Recruitment of those who are easy to reach, often those who are accessing services.

Convenience Sampling
Recruitment of who are easy to reach, often those who are accessing services.

**Strengths**
- Readily available
- Cost-effective
- May be able to build on relationships with providers

**Weaknesses**
- Non-probability sample
- Results biased towards adolescents who access services
- Limitations often overlooked
- The probability of selecting a member of the population of interest is unknown

Purposive Sampling

Recruitment of participants with specific characteristics within a population

Purposive Sampling

Recruitment of participants with specific characteristics within a population

**Strengths**
- Can be used to ensure the inclusion of all sub-sets of a population if the characteristics of the population are well known

**Weaknesses**
- The probability of selecting a member of the population of interest is unknown
- May introduce systematic bias

Targeted Venue-based Sampling

Sampling youth from venues or places where they live, work or socialize. Informed by formative research using qualitative and/or quantitative data to construct a list of sites where adolescents may be found and recruited.

Targeted Venue-based Sampling

**Strengths**

- Target population is visible
- High-quality formative research can maximize validity
- Can ensure inclusion of sub-groups through selection of venues where members of sub-groups spend time
- Can be effective for sampling highly mobile populations
- Can adjust sampling in response to information in the field
- Can be paired with outreach interventions

Targeted Venue-based Sampling

Weaknesses

- Non-probability sample
- Sampling may be biased and difficult to replicate
- Sample may not be representative of target population
- Leaves out those who do not attend venues
- Over-represents frequent venue-goers
- The probability of selecting a member of the population of interest in unknown
- Labor intensive
- May require difficult hours of operation
- Safety issue depending on venues

<table>
<thead>
<tr>
<th>Venue Location</th>
<th>Venue Score</th>
<th>Description/ Specific Location/ Time to Recruit</th>
<th>Types of Youth Who Are There, M/F Distribution, Volume of Traffic</th>
<th>Other Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between 17th and 18th and Mission</td>
<td>3</td>
<td>18th and Mission, NW corner</td>
<td>Taggers, 15-17 years old, mostly male (VL/?VML taggers)</td>
<td>Clicking/BSI to pick best sites in this area</td>
</tr>
<tr>
<td>Sycamore and Mission</td>
<td>2</td>
<td>?</td>
<td>May be one entrance to &quot;alleys&quot; where FK taggers and Surenos hang out, i.e., San Carlos and Lexington. Primarily a M venue. Hours: anytime after 12 into the night.</td>
<td>Researchers should go in pairs here</td>
</tr>
<tr>
<td>Between 18th and 19th on Mission</td>
<td>3</td>
<td>Taqueria Cancun</td>
<td>Important block to recruit Surenos (19th st. set) who are here from mid-day into the night. They are male, 16-25 years old, some female associates may be at the site too.</td>
<td>?</td>
</tr>
<tr>
<td>20th and Mission</td>
<td>2</td>
<td>Ritmo Music Store at SE corner</td>
<td>Regular youth. M/F site? Many youth approached were monolingual Spanish speakers. Probably best to sample after school; other hours/weekends?</td>
<td>Need clicking and BSI's during the school year too, because of proximity to high school</td>
</tr>
<tr>
<td>20th and Mission</td>
<td>3</td>
<td>Outside Donut Shop on SW corner</td>
<td>MS Surenos hang out; they are generally older (over 21). The MS set is Salvadoran.</td>
<td>Clicking/BSI</td>
</tr>
</tbody>
</table>
**Time Location**

Variant of targeted venue-based sampling

Approximates a random sample by employing a comprehensive list of venues with days of the week and times

Investigators then conduct random selection of venue, day, and time (VDT) periods, followed by systematic counting and recruiting of eligible adolescents.

Strengths

▪ All advantages listed for venue sampling
▪ The probability of selecting a member of the population of interest can be calculated—approximates a probability sample
▪ Statistical methods are available to produce unbiased estimates
Weaknesses

- Leaves out those who do not attend venues
- Over-represents venue-goers
- Hard to statistically adjust
- Labor intensive
- May require difficult hours of operation
- Safety of staff and of population may be an issue
Snowball Sampling

Sampling people through their social connections or networks. Adolescents recruited by research staff are requested to recruit their eligible social contacts to the study.

Snowball Sampling

Strengths

▪ Targets hidden population
▪ May be best available option for some populations
▪ May be faster and less expensive than locating and recruiting people with research staff
▪ Peers know each other better than researchers
▪ Peer recruiters can also recruit people for interventions

Snowball Sampling

Weaknesses

- Non-probability sample
- Biased towards the socially well connected; leaves out the socially isolated
- The probability of selecting a member of the population of interest is unknown
- There is no statistical method to produce unbiased estimates

Respondent-Driven Sampling (RDS)

A modified form of snowball sampling: adolescents recruited by research staff (‘seeds’) are incentivized to recruit their eligible social contacts to the study.

Social contacts are incentivized to recruit eligible individuals from their social network, who are in turn incentivized, and so on...

Data are used to estimate the characteristics of the population as a whole.

Respondent-Driven Sampling (RDS)

Strengths

▪ All advantages of snowball sampling
▪ Probability of selecting a member of population of interest can be calculated; it approximates a probability sample
▪ Statistical methods available to produce unbiased estimates
▪ High-quality formative research can maximize validity
Respondent-Driven Sampling (RDS)

Weaknesses

▪ Inaccurate estimates in communities with sub-networks
▪ Bias towards to socially well connected; leaves out the socially isolated
▪ Statics for analysis difficult and debated
▪ Findings sometimes inconsistent with qualitative research
▪ Theoretical assumptions hard to meet and to verify
▪ Sometimes peers fail to recruit others
▪ Secondary incentives may be coercive or commoditized

Dissemination

Challenges & Opportunities
Ethical principles

Benificence
Respect
Justice
Thank you!

Any questions?
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- i4Y.berkeley.edu
- yparhub.berkeley.edu/