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Fordham University Center for Ethics Education
HIV Prevention Research Ethics Training Institute



Ethical Issues Involving Drug Users (and Other Marginalized Populations) in Prevention HIV Research



Introduction: Barbara Kail

- Associate Professor Graduate School Social Service
 - Base discussion on experience of two qualitative studies
 - Intervention IPV Latinas in substance abuse treatment. Treatment included HIV prevention
 - Qualitative evaluation family based model provide services to HIV orphans Moshi Tanzania
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Most Multiply Marginalized

- Latinas: marginalized as women, as Latinas, as drug users, as prostitutes.
Permanent sense of shame
- Wototo (children) orphans, association with HIV, association with Salaama Center, larger sense marginalized globally





Impact Multiply Marginalized

Belmont Principle	Effect Multiple Marginalization on Participant
Respect for Person	Isolation participant harder to participate
Do no harm	Synergistic effect <u>harms</u> <u>Potentially more risk</u>
Social Justice	Access to benefits less likely



Respect for Persons

- May serve to isolate researchers as well, especially outreach workers. Takes longer to recruit
 - Harder to truly get informed consent.
 - Increased stress psychologically and time management.
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Do. No. Harm.

- Increase risks for researchers as well. Harder to protect research participants
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Social Justice

- Increased ethical imperative but researchers have harder time funneling benefits back.





A More Supportive Environment – Develop Social Capital

- More holistic view of research endeavor
- Social capital is collective value of social networks who have inclinations to share based on norms and history of reciprocity.
 - Information
 - Goods
 - Support





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Bonding Social Capital

Mutual assistance within group. Translate “ I “ mentality into “we” mentality. Build research team.





Bridging Social Capital

Creates ties and opportunities outside research to community





Strategies for a More Supportive Environment

- Respect for Person: Build bonding social capital Reduce isolation.
 - Do no harm: Build bridging social capital Reduce potential for harm by anticipating.
 - Social justice: Leverage bonding and bridging capital to influence decision-makers who have power over resources. Engage in advocacy
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Bonding Capital Reduces Isolation

Training. Participative

- Expectations especially around time and productivity
- Discuss anticipate problems when can.



Regular staff meetings.

Participative

- Place to problem solve.
- Place to be appreciative.
- Create positive culture



Bridging Capital Reduces Risks

- Bridging capital helps awareness of multiple risks and synergistic effects
 - Create multiple connections at individual and community level with participants Culture of appreciation
 - Even more time cross culturally
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Leveraging for Social Justice



- Provide research team with shared vision. Feel study makes difference. Discuss expected outcome or deliverable from beginning. Probably good idea to have some flexibility in deliverable written into proposal



Belmont Principle	Effect Multiple Marginalization Participant	Effect Multiple Marginalization Researcher	Strategies
Respect for Person	Isolation · participant harder to participate	Increased stress · time and psyche	Build social capital among staff · reduce isolation
Do no harm	Synergistic effect · <u>harms</u> · Potentially more risk	Increased risks · harder to protect	Build bridging capital · anticipate as much as possible, involve community
Social Justice	Access to benefits · less likely	Increased ethical imperative · PI bring benefits to participants but harder	Leveraging · bonding · bridging capital · influence decision makers · who have power over resources · engage in advocacy