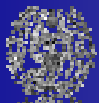


# Ethical Issues in Conducting Research with Low-income Mothers and Their Children: Implications for Practice and Policy

Robin Gaines Lanzi, PhD, MPH, Kathleen M. Baggett, PhD, Jennifer Burke Lefever, PhD, Kristi Carter Guest, PhD, Cathy Guttentag, PhD, Elizabeth Lerner, ATR-BC, LPC, Jeanne Mattei, MSW, LSW, Christine Willard-Noria, PhD, Centers for the Prevention of Child Neglect

Prepared for the American Public Health Association  
Washington, DC  
November 5, 2007

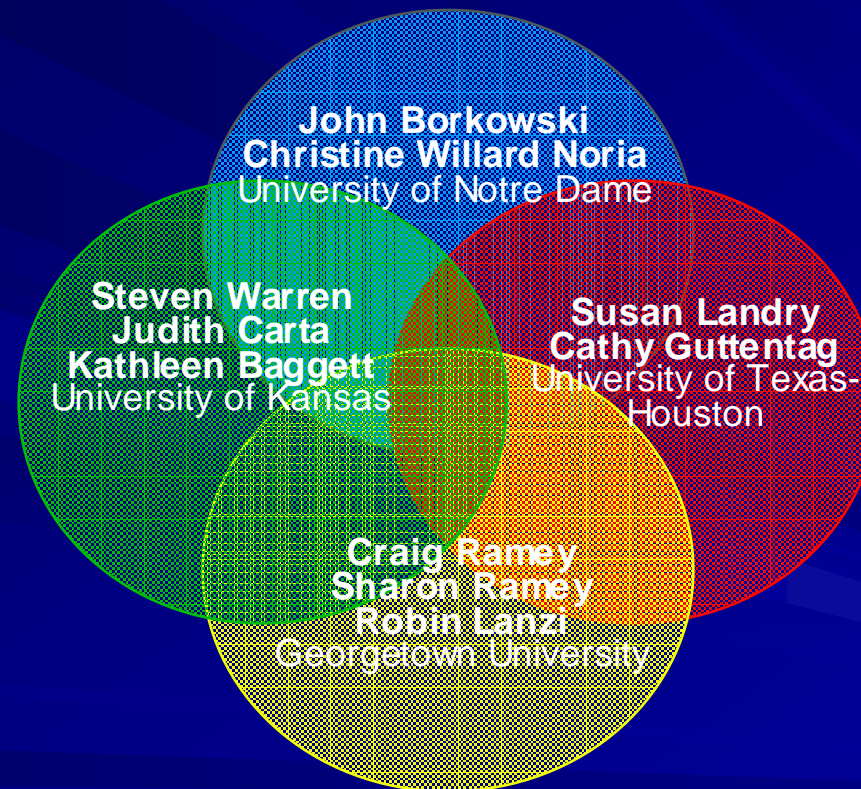


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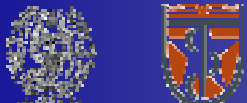


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# Preventing Child Neglect in High Risk Mothers



This research is funded by federal grants #R-01 HD04486801 NICHD and K01 HD42173, and a Reading is Fundamental grant



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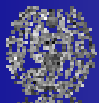


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# The Centers for the Prevention of Child Neglect

## Mission:

- Conduct rigorous scientific inquiry into the causes and consequences of child neglect
- Develop, implement, and evaluate effective prevention and intervention programs
- Disseminate critically needed scientifically based information about positive parenting practices and the prevention of child neglect to families, professionals, and policy makers



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# My Baby and Me Program RCT Design

■ High Intensity

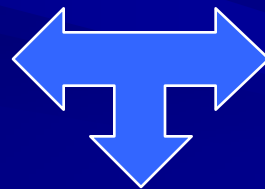


Receive intensive, hands-on  
parent training and  
support

■ Low Intensity

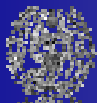


Receive no direct service  
provision and limited in-  
person contact



Same Maternal, Child, and Family Needs

All Receive Resource and Referral Information



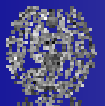
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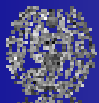
# Intervention Overview

- Approach to Intervention:
  - Begin early: pregnancy
  - Provide intensive intervention through 30 months of age
  - Use a relationship-based approach
  - Use a skills-based approach to support positive, healthy parent-child interaction
  - Use interventions for which there is the strongest empirical support:

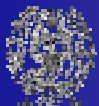
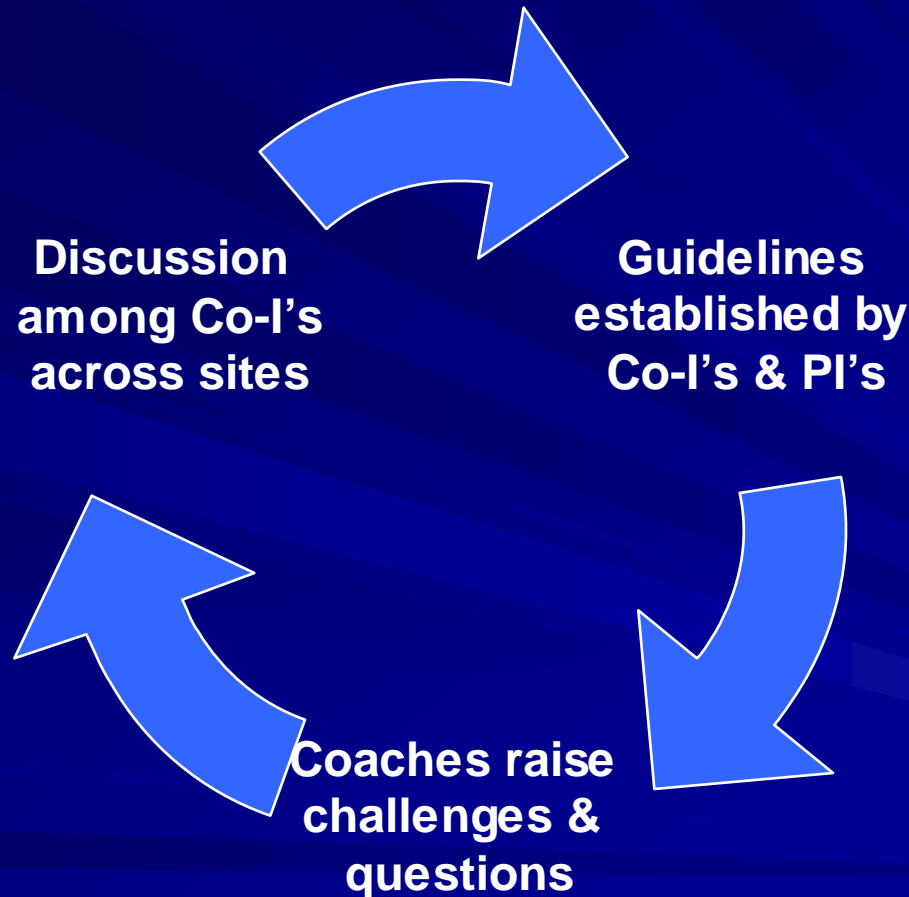


# Intervention Modules

- Problem-Solving & Decision-Making
- Early routines (building positive social interactions into earliest care routines)
- Health (Lutzker & Bigelow, 2002)
- Safety (Lutzker & Bigelow, 2002)
- Positive touch (very basic infant massage and soothing touch)
- Developmental milestones & play activities using positive touch and talking
- Play & Learning Strategies (PALS 1 & 2; Landry et al.)
- Reading with Babies/Toddlers (supporting pre-literacy activities)
- Autonomy and supporting early positive behavior
- Final 4 Sessions: 'Consolidation and Graduation'



# Cycle of Maintaining Cross-Site Consistency



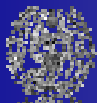
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# Response to Participants' Needs

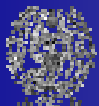
- Must adhere to the dictates of ethical rules to protect the rights of study participants
- Must have systematic process for addressing the on-going, yet frequently changing, clinical needs of the participants.
- Used ongoing “triage” to discern which issues Family Coaches could address directly, which required referrals to outside agencies or providers, and which we had no power to impact.





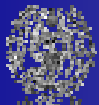
# Training

- Goals of the study and expectations of staff
- Philosophical tenets of the program
- Confidentiality and scientific integrity
- Roles and boundaries
- Safety and security
- Interviewing techniques
- Effective questioning
- Generic supportive comments
- Being culturally responsive
- Dress and appearance
- Alarm Values and Special Issues
  - Depression and Suicide
  - Drugs and Alcohol
  - Child Maltreatment
  - Domestic Violence
  - Developmental Delay and Special Needs
- Role playing
- Demo tapes



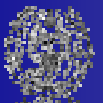
# Supervision

- Weekly staff meetings
- Biweekly individual clinical supervision meetings
- Field supervision
- Cross-site discussion



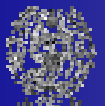
# Ethical and Clinical Dilemmas Overview

- Immediate crisis needs of families
- Not taking advantage of info/referrals
- Depression and suicidal
- Child maltreatment
- Role/Boundary issues
- Custody cases/shelter
- Domestic violence
- Illegal activities
- Sexual behavior
- Family conflicts
- Inappropriate expectations of child
- Questions about/issues with other children
- Cognitive impairments
- Consenting pregnant teens
- Safety and security
- Providing reference for participant
- Need for researcher's support
- Use of laptops and other electronic devices in the field



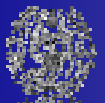
## Case Scenario: Roles and Boundaries

- Issue: Coach asked to attend celebratory functions for families (birthdays, graduations, christenings, etc.), made to feel guilty when need to say no
- Resolution:
  - During the enrollment process, discuss roles and expectations of relationship
  - Respond in a supportive and understanding manner
  - Explain office policy with every invitation
  - Alternative acknowledgements such as sending card, giving birthday gifts, built into program
  - Some moms understand, others find it difficult especially after coach has worked with mom for a significant amount of time



## Case Scenario: Living in Shelter

- Issue: Mom and child are living in shelter during participation in program
- Resolution:
  - Discuss the situation with mom, determine if mom is agreeable to conducting the sessions in the shelter
  - Obtain from mom a consent to share information with shelter administrator
  - Discuss program and schedule with shelter administrator
  - Conduct sessions in a confidential setting
  - Be flexible!



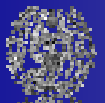
# Case Scenario: Ongoing Crises or Competing Priorities

## ■ Issue:

- Moms stating they have “too many crises to deal with the project” (housing, finances, partner conflict, medical appts.)
- Frequent cancellations due to work/school/other priorities affecting session consistency

## ■ Resolution:

- Flexibility & persistence in scheduling
- Reminders that parenting interactions are still important (sometimes especially so) in times of stress & crisis
- Assistance with concrete problem-solving & prioritizing of needs, provision of referrals to address immediate needs.



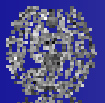
# Case Scenario: Participants' Lack of Follow-Through

## ■ Issue:

- Not using information we provide them; not following through on referrals (including for counseling, ECI, housing options, etc.)
- Moms may accept and involve self in the intervention but quickly revert to “the way they have always done it” outside of sessions
- Safety concerns in home; mom is either unable or refuses to make changes for child's safety

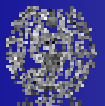
## ■ Resolution:

- Continue to bring up issue at each session, reinforce seriousness of concern, call between sessions to follow up.
- Explain potential consequences of doing nothing (“I'm worried that...”).
- Remind mom of how current issue relates to her short- & long-term goals/hopes for her child.
- Help problem-solve obstacles to follow-through (e.g., intimidated to call professional, lack of transportation)
- Let mom know if a child-related concern may need to be reported to Protective Services.
- Assist coaches with frustration associated with limits of our influence.



# Case Scenario: Family Relationship Issues

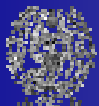
- Issue: Teen mom has conflict with family members (e.g., parents, grandparents, in-laws); attempts to draw coach into taking sides.
- Resolution:
  - Patient listening and empathy via phone and in-person visits; encourage mom to meet her needs and those of her children
  - Use the Problem Solving approach, opens the door for discussion and lends support to mom and her situation, gives mom the opportunity to look at her own strengths in dealing with the issues before her
  - At times, this has required us to allot a significant portion of the session on problem solving concerning the issue
  - When new issues arise, helpful to link the issue with previous intervention sessions that have addressed this situation, reminding mom what the research indicates.





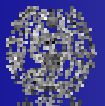
# Summary

- As a research study, essential to ensure the protection of human subjects and the voluntary nature of participation, while adhering to the study protocol requirements to deliver the program in a scientifically sound manner
- Process involves:
  - Responsive, timely attention
  - Problem solving strategies with mom
  - Ongoing “triage” – assess which issues Family Coaches could address directly, which required referrals to outside agencies or providers, and which we had no power to impact
  - Resource and referral information in most instances



# Implications

- Research
- Practice
- Policy



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