

**CBPR's importance and critical role in research
as evidenced in "My Sister's Keeper":
A CBPR coalition to strengthen maternal mental
health and family resilience in a southern, urban,
low income community**

Community Based Public Health Caucus Symposium on Benefits and
Power of Partnerships Session
American Public Health Association Annual Conference
November 6, 2013

Sheila Tyson
Friends of West End
Birmingham City Council

Robin Lanzi, PhD, MPH
Department of Health Behavior
UAB School of Public Health

Suzy Davies, PhD
Department of Health Behavior
UAB School of Public Health

Maternal Depression

- Approximately 12% of all women experience depression in a given year
- For low-income women, the estimated prevalence doubles to at least 25%
- For pregnant and postpartum and parenting women, rates are in general range from 5-25%
- Low-income mothers of young children, pregnant and parenting teens report depressive symptoms in the 40-60% range

Unfortunately, very few get treated

- If treatment were provided, an estimated 80% would show benefits in terms of reduced symptom severity.
- Only 52% of those with major depressive disorder receive treatment.
- 38% of those receiving treatment receive what is judged to be “only minimally adequate” treatment.
- African American/Black and Latina depressed mothers more likely to experience multiple adversities and less likely to receive services than white depressed mothers (Ertel K et al, 2011).

How maternal depression affects their children

- Depressed mothers:
 - provide less stimulation, are less responsive to infants, show more parenting difficulties, are less likely to seek appropriate medical care for their child and less likely to use prevention practices
- Children exposed to maternal depression are at higher risk of:
 - delayed cognitive and language development, mental health problems, suboptimal physical growth and myriad interpersonal, neuroendocrine, and behavioral problems
- Maternal depression associated with poorer outcomes in the child from infancy through adulthood

The Need for My Sister's Keeper

- Maternal depression is common, expensive, and often undertreated, reducing significantly one's level of functioning and quality of life.
- A dearth of relevant programs coupled with heightened stigma in the African American community inhibits depressed mothers from seeking social support and/or treatment.

My Sister's Keeper

- Built on a partnership between members of the West End community and UAB researchers to engage in community-based participatory research (CBPR) to plan and implement a maternal mental health promotion intervention.
- CBPR methods guided MSK in creating a bridge to enable to two-way transfer of knowledge and behavioral skills between West End residents and academic scientists, a sustainable connection for continued efforts to eliminate health disparities.

My Sister's Keeper: Overview (to date)

- Identified priority resources and an easy-access location for the MSK Resource Corner: to be established at the West End Library, along with promotional tools to West End service providers to increase awareness and uptake of these and other available mental health resources.
- Identified and trained community leaders and staff to help recruit participants into the study, conduct focus groups and interviews, interpret the data, and plan next steps.
- Conducted over 175 individual surveys with mothers
- Conducted focus groups with mothers who screened positive for depression
 - Reviewed surveys, identified those with most severe depression and invited back for focus group sessions.

Our Successful Community-Partnered Strategy

- **Fundamental Premise:** Our proposed approach is multi-stage, starting with establishment of a formal long-term partnership with agreed upon and written goals, responsibilities, sharing of resources, and strategies for approaching issues and resolving problems that might arise.
- Partnership is designed to be mutually beneficial.
- Focus on fostering an active dialogue and generating practical ideas about how to strengthen the approaches for addressing health and well-being of women in the Birmingham area.
- Envision the partnership to be the beginning of a long-term relationship whereby both community and scientific perspectives are leveraged for the common good.

Best practices that emanated from our lessons learned through this community-partnered process

- Recruitment: Community partner led the design of the recruitment flyer and the selection of best venues for distribution; assisted in selecting venues for recruitment, and worked with staff at each location to arrange dates and times to hold meetings at their facilities.
- Enrollment: Community and academic partners collaboratively drafted the Informed Consent Form, making sure that it was written in clear language. Community partner present for the informed consent process prior to data collection, to ensure that participants understand the process and do not feel coerced to participate. Community partner assisted with answering any questions participants might have about informed consent or reimbursement.

Best practices that emanated from our lessons learned through this community-partnered process

- Data collection: Community and academic partner collaboratively drafted assessment protocol; community partners discussed what concepts to measure and how best to measure them. Community partner a co-facilitator of the focus group meetings and interviews.
- Overall, identified and trained community leaders and staff to help recruit participants into the study, conduct focus groups and interviews, interpret the data, and plan next steps.

Key aspects of successful collaboration identified by community partners:

- Direct and ongoing involvement of those affected by maternal mental health
- Capitalize on each partners expertise (academic partners increased community members' data management and analysis skills, while community partners increased academicians' understanding of the extent to which community issues can affect the validity and reliability of results)
- Novel implementation strategy that is both self-sustaining and community-owned
- Equal voice among partners throughout planning, implementation and evaluation.

Key mental health strategies identified by the coalition include

- Shift the focus from mental illness to mental and emotional health
- Create a public awareness campaign of women's mental health needs
- Improve local policies to increase community access to existing mental health services.

Themes from coalition group discussions (slide 1 of 2)

- Recognition that depression is called many things
- Awareness that strengthening one's mental health is as important as strengthening one's physical health may reduce stigma toward mental health discussions and support seeking
- Caring for others is a common priority, though caring for self along with others can enhance quality of life for all family members
- Promoted as a gift to oneself, much like a manicure; mental health activities may become more socially acceptable and normative
- The need to normalize the topic of mental health – “It's your turn” conveys the notion that it's more than OK – it's important – to take care of yourself!

Themes from coalition group discussions (slide 2 of 2)

- The need for a high-visibility spokesperson to increase perceived salience and interest in attending MSK events and activities
- Recognition that clergy may be thought of as a high-visibility spokesperson but could also be identified as a group with the potential to reinforce old paradigms
- Recognition that data collection / mental health assessment may be deterrent for some participants (e.g., fear that if they share personal information about themselves it can be used against them)

**Significant local community
organizational policy changes
that are taking place as a direct
result of this community-based
participatory research**

Examples

- Local health department initiating maternal depression screens
- Libraries providing significant space for resource and referral information on maternal depression
- County-wide conference planned by the Children's Policy Council to address the mental health needs of mothers

Our Partnership.....Future Directions

- Promote My Sister's Keeper in activities in West End performed by the Friends of West End, including two annual community events, *Clean Our Community* and *Celebrate West End*.
- Survey the West End business community as the foundation for future efforts (using CBPR methods) to generate broad level support for sustainable mental health products/services in West End and beyond.
- Toolkits for present and future community partners (e.g., churches, clinics, schools, libraries, etc) to continue to address stigma and increase dissemination of MSK resources.
- A community based Par-Course (specially designed to integrate physical and mental health exercises at stations along a safe, aesthetically pleasing walking path) to be built with future funding.
- Submitting additional grants to support expansion and integration

Lasting thoughts....

- Throughout this process, the importance of and critical role of community partners in community based public health was clear.
- None of these changes would have happened without the trailblazing efforts of our community partner who served many roles:
 - Pioneer: the first ever to have such impact
 - Innovator: the creative new ways of making things happen
 - Initiator: ideas, plans, strategies were from the community
 - Architect: making things happen in the right place at the right time

Thank You!!!!!!!!!!!!

- For more information, please contact us at:

Sheila Tyson
Friends of West End
(205) 249-8559
sheilabtyson@bellsouth.net

Robin Gaines Lanzi, PhD, MPH
Associate Professor
Department of Health Behavior
UAB School of Public Health
(205) 934-6020
rlanzi@uab.edu

Susan Davies, PhD
Associate Professor
Department of Health Behavior
UAB School of Public Health
(205) 975-8049
sdavies@uab.edu

- Funding provided by the UAB Community Health Scholars Grant, UAB School of Public Health