Rural Health Disparity Issues in Illinois: A Community Capacity Building Approach

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Presentation Overview
- Dimensions of Health Disparity
- Hispanic Health Disparities in Illinois
- A Rationale for Community Participatory Research
- Applying the CBPAR Method to Address Hispanic Health Disparities
  - Partnership Formation
  - Assessment
  - Community-based Implementation
  - Evaluation
  - Dissemination
- A Case Study Example/Discussion

What is Health Disparity?
- Differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions and health states that exist among specific population groups
- Disparity among population groups is also evident at the health care delivery system level, in differential rates of access and use of services

Types of Health Disparities
- Health Status AND/OR Health Outcomes
- Individual personal factors – biological/genetic, sociodemographic, socioeconomic, disabilities, residency, cultural norms and values, literacy levels, familial influences, environmental/occupational exposures
  - Patient preferences for care and treatment!
Types of Health Disparities

• Societal/System factors: Social resource distribution, social and political advantages such as knowledge and social connections, insurance status, transportation/geography, distribution of health resources (clinics, health professionals’ training and approaches or patterns in providing care)

Hispanics in Illinois

• 1,530,262 Hispanics in Illinois (12.3%):
  • 1,253,670 Spanish speakers
  • 74.8% Mexican
  • 11.7% Caribbean
  • 2.6% Central American
  • 2.5% South American
  • 8.4% Other
  • 121.5% is the growth rate of Hispanics in Illinois between 1990-2000

Health Disparities in Illinois: Behavioral Risk Factors

Hispanics less likely to have had cholesterol checked within last five years (50%) compared to White (75%) or African American (70%)

Hispanics less likely to participate in physical activities in past month (99%) compared to White (77%) or African American (70%)

Hispanics more likely to be current smokers (21%) compared to White (20%) or African American (16%)

Hispanics less likely to consume fruits and vegetables 5 or more times per day (18%) compared to White (24%) or African American (22%)

Hispanics less likely to self-report health status as ‘Good or Better’ (70%) compared to White (87%) or African American (75%)

Hispanics more likely to self-report health status as ‘Fair or Poor’ (29%) compared to White (12%) or African American (24%)

Health Disparities in Illinois: Diseases and Conditions

Hispanics less likely to have been told to have diabetes by physician (6.5%) compared to White (6.8%) or African American (16.2%)

Hispanics less likely to have been told to have asthma by physician (8%) compared to White (12%) or African American (17%)

Hispanics less likely to have been told to have arthritis by physician (12%) compared to White (27%) or African American (27%)

Hispanics less likely to have been told to have high blood pressure by physician (14%) compared to White (26%) or African American (36%)

Some Benefits of Participatory Research in Practice-Based Evidence

- Results are relevant to interests, circumstances, and needs of those who would apply them
- Results are more immediately actionable in local situations for people and/or practitioners
- Helps to reframe issues from health behavior of individuals to encompass system and structural issues.
- Generalizable findings more credible to people, practitioners and policy makers elsewhere because they were generated in partnership with people like themselves.


How to use the CBPAR Methods in Partnership Formation

- Exploration
- Approach
- Reflection
- Communication

1. Exploration: Assess communities for potential partnership opportunities

- Develop community profiles to determine which communities have significant growth in Hispanic immigrants
- Identify potential champion organization (e.g. University of Illinois Extension) to coordinate committee formation
- Organize initial meetings with Extension County Directors and other potential advocate organizations
2. Approach: Present case for CBPAR method and cost/benefit of participation in Hispanic Health Advisory Committees

- Develop presentation of the Hispanic health profiles
- Explain the philosophy of CBPAR
- Develop ownership in the project
- Clearly outline and negotiate with the community agreed upon roles and responsibilities

2. Approach: Technical Assistance

- Assist committee in determining relevance/feasibility of conducting health disparity research with focus on Hispanic residents
- Encourage committee to identify potential partnership organizations
- Help in recruitment/involvement of Hispanic community leaders/advocates

2. Approach: Capacity Building

- Dialogue with committee members about the stages of CBPAR
- Discuss Hispanic cultural competency issues
- Introduce the basic fundamentals of community research (e.g. IRB issues, community assessment approaches, research terminology)
- Develop plans for dissemination to maintain involvement of committee members and inform stakeholders/larger community about the project.

3. Reflection: Strengthen organizational leadership development of committee

- Improve the participation of all the committee members in decision making
- Develop a sense of ownership with committee members sharing responsibilities
- Create an environment of cooperation and trust by honoring the principles of diversity friendly communities

4. Communication: Use local media to build and strengthen partnership

- Develop communication strategies that are appropriate and appealing to the target audiences
- Use press releases, informational breakfasts etc. to engage community stakeholders and formal leaders
- Recruit when possible local media representatives into the partnership

Overview: Communities Involved

- Beardstown
- Belvidere
- Carbondale / Cobden
- Champaign / Urbana
- Danville
- DeKalb / Sycamore
- Effingham
- Galesburg
- Monmouth
- Rochelle
- Rockford
Overview: Hispanic Population Growth (1990-2000) in Counties Involved

<table>
<thead>
<tr>
<th>County</th>
<th>1990 # Hispanic</th>
<th>2000 # Hispanic</th>
<th>Numeric Change</th>
<th>Percent Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cass</td>
<td>56</td>
<td>1,152</td>
<td>1,106</td>
<td>1975.0%</td>
</tr>
<tr>
<td>Union</td>
<td>182</td>
<td>481</td>
<td>299</td>
<td>164.3%</td>
</tr>
<tr>
<td>Boone</td>
<td>2,065</td>
<td>5,219</td>
<td>3,154</td>
<td>152.7%</td>
</tr>
<tr>
<td>DeKalb</td>
<td>2,329</td>
<td>5,830</td>
<td>3,501</td>
<td>150.3%</td>
</tr>
<tr>
<td>Winnebago</td>
<td>7,771</td>
<td>19,206</td>
<td>11,435</td>
<td>147.1%</td>
</tr>
<tr>
<td>Warren</td>
<td>207</td>
<td>507</td>
<td>299</td>
<td>144.9%</td>
</tr>
<tr>
<td>Ogle</td>
<td>1,379</td>
<td>3,066</td>
<td>1,687</td>
<td>122.3%</td>
</tr>
<tr>
<td>Effingham</td>
<td>121</td>
<td>252</td>
<td>131</td>
<td>108.3%</td>
</tr>
<tr>
<td>Vermilion</td>
<td>1,405</td>
<td>3,204</td>
<td>1,899</td>
<td>78.2%</td>
</tr>
<tr>
<td>Champaign</td>
<td>3,485</td>
<td>5,203</td>
<td>1,718</td>
<td>40.9%</td>
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<tr>
<td>Knox</td>
<td>1,416</td>
<td>1,896</td>
<td>480</td>
<td>33.9%</td>
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<tr>
<td>Jackson</td>
<td>1,082</td>
<td>1,443</td>
<td>361</td>
<td>33.4%</td>
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<tr>
<td>TOTAL</td>
<td>21,498</td>
<td>46,769</td>
<td>25,271</td>
<td>117.3%</td>
</tr>
</tbody>
</table>

Partnership Formation: EXPORT formed Hispanic Health Advisory Committees

- Formed and supported 10 pilot Hispanic Health Advisory Committees (HHAC) in 14 IL communities
- Stakeholders involved (based on preliminary HHAC evaluation; n=35):
  - Community Hospitals (5)
  - State/County Government Org (5)
  - School Districts (3)
  - Higher Education Org (12)
  - Community Foundations (2)
  - Hispanic CBOs (2)
  - FBOs (2)
  - Non-Hispanic CBOs (1)
  - City Officials (1)
  - Social Services Org (1)
  - State Legislators (1)
  - Private Healthcare Providers (1)
  - Private Clinics (1)

Case Study: DeKalb County

- County population in 2005: 89,223 (23% rural)
- Hispanic population: 5,830 (6.6%)
- Hispanic growth 1990-2000: 150.3%
- Main sources of Hispanic employment: Industry and landscaping
- Major mortality cause: CVD (244.6 rate, all ages, 1999-2001)
How to use the CBPAR Methods in Assessment

1. Exploration: Define data needs and appropriate research questions
   - Examine existing data (epidemiological, behavioral, archival, ethnographic, etc) and identify data needs
   - Develop exploratory research questions in collaboration with the partnerships
     - What?
     - How?

2. Approach: Define appropriate research tools and procedures
   - Define the target group(s) for the assessment
   - Identify appropriate quantitative, qualitative or (ideally) mixed methods of data collection
     - Survey
     - Focus groups
     - Community small group discussions
     - Interviews
     - Additional epidemiological data?
   - Data triangulation

2. Approach: Technical Assistance
   - Design of reliable and culturally-appropriate methods of data collection
   - Seek IRB approval
   - Support in data entry and analyses
   - Development of survey and/or focus group reports for the committees

2. Approach: Capacity building
   - Develop community capacity to:
     - Identify local health and healthcare disparities
     - Assess reliability and cultural-appropriateness of various assessment tools
     - Design instruments of data collection
     - Develop procedures for data collection that are sensitive to the characteristics of the target population
     - Understand, interpret, and prioritize assessment findings

3. Reflection:
   - Reflect on the appropriateness and effectiveness of assessment method selected
   - Request additional data analysis to further define assessment results
   - Review results of assessment reports to identify key community health disparity issues
4. Communication:

- Create community assessment reports for distribution
- Share data with community health providers and county health departments
- Distribute assessment results to local media via press releases, newsletters, and radio/television interviews

DeKalb Case Study: Assessment Objectives

- Assess DeKalb Hispanics’ major health concerns in order to identify health disparity issues and help focus prevention efforts
  - Provide data to the Hispanic Health Advisory Committee (HHAC) to facilitate decision-making and coordination regarding local implementation plans
  - Provide data to local practitioners, public health officials, and social service agencies to improve the access and quality of healthcare services offered to the Hispanic population of DeKalb
- Provide data to the Community to increase their awareness about local Hispanic health and health disparity issues

DeKalb Case Study: Research Questions

- What are DeKalb Hispanics’…
  - perceived health concerns?
  - perceived risk factors?
  - perceived barriers to access healthcare?
  - preferred health education strategies?
- How do these aspects vary according to various acculturation stages?

DeKalb Case Study: Assessment Procedures

- Surveys (n=239)
- Focus Groups (3; n=52)

DeKalb Case Study: Committee involvement

- Six of 18 HHAC members assisted in survey planning and distribution
- Seven HHAC members assisted in the focus groups and related community events

Survey Results: Self and family health problems
Survey Results: Self and family risk factors

Survey Results: Barriers to Access Healthcare

Survey Results: Insurance Status

Survey Results: Health Education Preferences

Survey Results: Self and Family Health Problems

Focus Groups Results

- Health problems shared by men and women
  - Diabetes
  - Back pain
  - Migraine headaches
  - Eye infections / visual problems

- Risk factors shared by men and women
  - High blood pressure
  - High cholesterol
Focus Groups Results (cont.)

- Preferred health education strategies
  - Workshops in Spanish in churches, schools or community centers
  - Printed material in Spanish
  - Media (Newspapers articles, radio and TV programs)
  - Healthy cooking classes

- Perceived barriers shared by men and women
  - Lack of health insurance
  - High costs of health and oral health services
  - Limited knowledge on where to find adequate and affordable healthcare
  - Language
  - Lack of medical interpreters
  - Limited transportation
  - Long waiting during appointment
  - Providers’ lack of cultural competency

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DeKalb Case Study: Assessment Summary

Converging evidence from survey and focus groups:

- Major health concerns included Oral health, CVD, Diabetes, and Mental health
- Major access and navigation barriers were related to Insurance, Costs, Limited information about available services, and Language
- Preferred health promotion strategies were Workshops in Spanish in community settings, and Spanish language media
- Significant variations according to Acculturation in some of these aspects

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Discussion (3 Minutes)

1. Identify a rural health disparity issue
2. List some organizations that you would want to be a part of a committee / partnership to address this health disparity
3. Define what assessment approach(es) would be more appropriate to gather this information?

- "I have been suffering from irregular bleedings and also have like a small ball inside my breast. One year ago, I went to the doctor and he said it wasn’t anything serious. He only said ‘if you don’t feel pain, you don’t have cancer, that’s it!’ He didn’t explain anything else to me. I decided to never go back again to that doctor […] I still have the same problem and I’m really worried because my Mom died from breast cancer two years ago”

Uninsured, undocumented DeKalb Hispanic resident
How to use the CBPAR Methods in Implementation

• Exploration
• Approach
• Reflection
• Communication

1. Exploration: Minigrant Proposal Development

• Develop a minigrant proposal based on the findings from the Assessment phase
  • Problem description (use of assessment results)
  • Partnership description
  • Proposed activities
  • Budget
  • Timeline
  • Technical assistance needs

2. Approach: Conduct Minigrant Program

• Hold series of briefings to announce minigrant award
• Develop strategic plan for minigrant implementation
• Obtain support from additional community partners to successfully carry out minigrant activities

2. Approach: Technical Assistance

• Provide technical assistance for community minigrant programs for example:
  • Feedback given to minigrant draft proposals
  • Find evidence-based programs and interventions
  • Assist in developing implementation plan
  • Assist the community in identifying indicators of success
  • Decision-making about prioritization of actions
  • Organization of training workshops
  • Information about additional funding opportunities
  • Dissemination through news releases, community stakeholder meetings, and conferences

2. Approach: Capacity building

Build community capacity to:
• Improve inter-institutional and interpersonal communication
• Bring all interested parties to the table
• Establish indicators of success
• Ensure commitment from partners
• Use an inclusive approach to decision-making
• Consult with bilingual and bicultural partners about feasibility of proposed strategies
3. Reflection: Minigrant Program

- Monthly assessment of progress during committee meetings
- Analysis of minigrant activity evaluations
- Engage in activity specific reflection
- Overall evaluation of minigrant program
- Rich environment for co-learning exists

4. Communication: Minigrant Program

- Information dissemination
  - Newsletters (English/ Spanish)
  - Community Reports (English/ Spanish)
  - Local newspaper articles (English/ Spanish)
  - Mass Media: Radio in Spanish (www.nuevoshorizontes.org)

DeKalb Case Study: Committee Involvement

- Six of 18 HHAC members assisted in the minigrant implementation
- Four assisted in organizing educational workshops or activities
- Three assisted in mini-grant writing
- Three in the minigrant planning
- Two in organizing educational workshop presentations

DeKalb Case Study: Minigrant Summary

Priority issue: Barriers to navigating the health care system
Title: "Enhanced Health Services for Hispanics"

| Project EXPER | $ 4,500 |
| Supplemental funding from TCCHC and DCCF | $15,000 |
| Total budget | $19,500 |

24 Organizations involved: DeKalb Schools, Sycamore Schools, Kishwaukee College, DeKalb County Health Department, Kishwaukee Community Hospital, DeKalb Clinic, Kishwaukee Medical Associates, Dr. Joseph Baumgart, St. Mary Church (DeKalb), Community Coordinated Child Care, Ben Gordon Center, Family Service Agency, American Heart Association, DeKalb County Community Foundation, DeKalb County Community Services, Conexta Comunidad, Rep. Robert Pritchard, Senator Brad Burzynski, University of Illinois Extension for DeKalb County, Tri-County Community Health Services, and Northern Illinois University – College of Health & Human Sciences and Center for Latino & Latin American Studies, DeKalb public transportation agency, University of Illinois College of Medicine at Rockford

DeKalb Case Study: Community Identified Priorities and Solutions

<table>
<thead>
<tr>
<th>Priorities identified in the Assessment Phase</th>
<th>Proposed Community Program</th>
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<tbody>
<tr>
<td>Language Barriers</td>
<td>Medical Interpretation Training</td>
</tr>
<tr>
<td>Lack of knowledge about &quot;where to go&quot; when health care services are needed</td>
<td>Bilingual Health Resources Guides – Newsletters</td>
</tr>
<tr>
<td>Lack of local health educational programs in Spanish</td>
<td>Health educational programs: Workshops in Spanish presented by Hispanic professionals covering health problems identified in the assessment process</td>
</tr>
</tbody>
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DeKalb Case Study: Description of Community Activities

- Bilingual Health Resources Guide
- Health Providers Guide
- Mobile Health Promotion Trailer
- Health Fair
- Medical Interpretation Training
- Community Workshops in Spanish
  - Dining with Diabetes
  - Stress prevention & management
DeKalb Case Study: Description of community activities

Discussion (3 Minutes)

- With limited resources, how would you design a community implementation or intervention?

Importance of Evaluation

The whole evaluation process has to lead to self-determination. This means that any evaluation process has to be empowering to the stakeholders/community and give them something that benefits them...something that gives them more knowledge about what is happening in the project, the program and/or the community.

How To: Evaluate CBPAR? Our Perspectives...

- Social programs have become more broad, complex and interactive
- Seek to bring about changes in community capacity, social support, decision-making, control over resources and individual behavior
- Time to supplement traditional strategies with new approaches reflecting complexity of community-based initiatives

Our Perspectives (cont.)

- Some evaluators believe communities lack skills to design, engage in and interpret evaluations
- However, ‘experts’ may lack insight/ flexibility needed to capture ‘essence’ of community projects or to answer questions raised by communities, CBOs and other stakeholders
Our Perspectives (cont.)

- Community-based evaluation perspective involves more participatory and inclusive process that incorporates the values, knowledge, expertise and interests of the community and uses evaluation as a tool for community capacity building.
- Community involved as full/equal partner allows for development of more ‘relevant’ program success measures and produces data that are useful in community settings.

How to use the CBPAR Methods in Evaluation

1. Exploration: Use Guiding Questions

- EXTERNAL: What impacts do local communities have on local efforts to address the issue of health disparity in rural communities? How and Why?
- INTERNAL: What impacts does a university located, grant funded Community Outreach initiative have on national, state and local efforts to address the issue of health disparity in rural communities? How and Why?

2. Approach: Consider Mixing Evaluation Frameworks and Models

- Community Comparison Case Study(ies): (Yin, 1994):
  - Evaluate each of the 14 communities
- Organizational: (Donabedian, 1966):
  - Structure Process Outcomes
- Impact: REAIM (Glasgow, 1999):
  - Reach, Effectiveness, Adoption, Implementation, Maintenance

2. Approach: Technical Assistance in Evaluation

- Provide training in basic purpose/uses of evaluation for various projects
- Assist in the development of instruments to measure the impact of the work of the project
- Provide analysis of data and share results
2. Approach: Capacity Building in Evaluation

- Promote community re-assessment through reflection during evaluation activities
- Encourage community independence and self determination during evaluation discussions
- Support communities towards sustainability through identification of other funding sources (both community and university sources)

3. Reflection: Identify Evaluation Areas

1. Hispanic Health Advisory Committee Evaluation
2. Community Activities and Implementation Efforts
   a. Individual activities
   b. Individual mini-grant implementation
3. Global Community Impact
   a. Mini-grant Cluster Evaluation
   b. Community Oral History Evaluation
   c. Community Comparative Case Study

3. Reflection: HHAC Evaluation

1. Hispanic Health Advisory Committee (HHAC)
   **FOCUS:** Self Assessment via survey administered to HHAC committee members of their effectiveness.
   **Example Indicators:**
   - Awareness of health issues or concerns in their communities
   - Perceptions regarding the ability to utilize culturally appropriate activities/approaches to reach Hispanic populations
   - Perception of the community’s satisfaction with the programs and activities supported by Export Outreach
   - Knowledge about health disparities and the healthcare needs of the people of their communities.
   - Ability to address local needs through Export Community Outreach assessments

3. Reflection: Global Community Impacts

3. Global Community Change
   **Focus:** Extent to which interventions or programs increase health knowledge and healthy lifestyle changes in target populations, such as individuals, households, organizations, communities, etc
   **Example Indicators:**
   - Change in Community Members Knowledge, Awareness, Behavior
   - Change in Community Capacity
   - Change in Community Competency
   - Change in Social Capital
   - Change in Health Status of the Community
   - Change in Policy

4. Communication: Evaluation Products & Outcomes (Community Specific)

**EXTERNAL (Examples from DeKalb Case Study)**
- Medical Interpreters Training (daily, final & 6 month follow-up)
- Diabetes Program Evaluation (from another study)
- Workshop on Depression and Anxiety
- Provider Resources Guide
- Community workshop
- Community Oral History
- Community Comparative Case and Cluster Study
- Hispanic Health Advisory Committee – DeKalb Case Study

**INTERNAL**
- Key Informant Interviews
  - Faculty and Staff
  - Administrators
  - Periodic SCOR
DeKalb Case Study: Committee Involvement

- Fourteen of 18 HHAC members filled out the HHAC evaluation questionnaire
- Nine of 14 organizations represented in the HHAC participated in the HHAC evaluation
- The HHAC Coordinator assisted in questionnaire distribution and evaluation data collection

DeKalb Case Study: HHAC Evaluation Assessment Phase Results (n=14)

- Structure Component
  - Partnership Formation, Stakeholders include: Community foundations, private sector, hospitals/clinics, FBO’s, CBO’s, health sector, education sector, Hispanic advocacy, HCSAFETY net providers, local government, social service
  - Participation of HHACs in development and implementation of assessment procedure

DeKalb Case Study: HHAC Survey Implementation Phase Results (n=14)

- Process Component
  - Establishment of procedures for consensus building and decision-making
  - Evaluation of development of plans to create and implement interventions based on assessment phase data for mini-grants
Level of satisfaction or dissatisfaction with each of the following:

DeKalb Case Study: HHAC Survey Evaluation Phase Results (n=14)

- Outcome Component
- Benefits and barriers to participation (individual and for the community)
- Sharing of Lessons Learned
- Current and future plans/Sustainability

HHAC has had an impact on the following:

How to use the CBPAR Methods in Dissemination

- Exploration
- Approach
- Reflection
- Communication
1. Explore: Translational Research

Translation Research characterizes the sequence of events (i.e., process) in which a proven scientific discovery (i.e., evidence-based public health intervention) is successfully institutionalized (i.e., seamlessly integrated into established practice and policy). Translation research is comprised of dissemination research, implementation research, and diffusion research.

- **Dissemination Research** is the systematic study of how the targeted distribution of information and intervention materials to a specific public health audience can be successfully executed so that increased spread of knowledge about the evidence-based public health intervention achieves greater use and impact of the intervention.

- **Implementation Research** is the systematic study of how specific sets of activities and designed strategies are used to successfully integrate an evidence-based public health intervention within specific settings (e.g., primary care clinic, community center, school).

- **Diffusion Research** is the systematic study of the factors necessary for successful adoption by stakeholders and the targeted population of an evidence-based intervention, which results in widespread use (e.g., state or national level) and specifically includes the uptake of new practices or the penetration of broad-scale recommendations through dissemination and implementation efforts, marketing, laws and regulations, systems research and policies.


- How targeted distribution of information and intervention materials to a specific public health audience can be successfully executed so that increased spread of knowledge about the information (intervention) achieves greater use and impact (CDC, 2007)

- Community, Practitioners, and Academic audiences

3. Reflection: DeKalb Dissemination Efforts

- Health resources guide
- Press release
- Stakeholders breakfast
- Community calendar
- Culturally-appropriate dissemination:
  - Word of mouth
  - Announcements after the Latino Mass
  - Using flyers in restaurants, stores, and church events

4. Communication: DeKalb Case Study - Dissemination

Some Final Reflections to Communicate: Evidence and Practice Practice and Evidence

- If we want more evidence-based practice, we need more practice-based evidence.
- Recognize the importance of practitioners and other end-users in shaping the research questions.
- Practitioners and their organizations represent the structural links (and barriers) to addressing the important health issues. Engage them.

Discussion (3 Minutes)

- What components of your intervention do you want to focus on in your evaluation efforts?
- Should you include a dissemination plan? Why?

Overall Discussion and Reflection (15 min)

- Plenary discussion (Q & A; similar experiences; potential applications):
  - Rural Hispanic health disparity issues
  - Partnership formation plans
  - Assessment strategies
  - Implementation strategies
  - Evaluation strategies
  - Dissemination strategies
  - Other?

Acknowledgments

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- UI Extension Office in DeKalb
- DeKalb HHAC

Thanks…