

Participatory Research in Obesity Prevention: The Disability Community Partners with the Academy

Mary Segal, PhD

Temple University

Philadelphia, PA

Participatory Research at McGill

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R03 HD059566:

Health Promotion: Persons with Disabilities Partner with
the Academy

An application to be funded by NIH under the Roadmap
“Partners in Research” program

Collaborators: **United Cerebral Palsy – PA** and **Institute
on Disabilities**, Temple University

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Purpose of the “Partners in Research” program:

Address practical questions surrounding the development of true partnerships between the research community and the public, through research to develop/evaluate new approaches to building partnerships...to support research projects, designed and implemented by scientist-community partnerships, that **test a broad variety of methods and relevant interventions.**

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**Approach for the “Partners in Research”
program:**

NIH is not specifying a particular research approach or methodology to be used by investigators responding to this RFA. However, in general, it should be noted that this initiative incorporates and applies the principles of Community-based Participatory Research (CBPR).

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**Evaluation of the “Partners in Research”
program:**

Research proposed should include an evaluation of the effectiveness of the strategy, technique or intervention under investigation and the conditions (e.g., settings and approaches) that will enhance and/or impede the effectiveness of such activities. This evaluation may address both process and outcome, as appropriate.

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A true partnership:

The funding mechanism stipulates that in the event the proposal is funded, the funding will be disaggregated and **each institution will receive its own grant**, headed by its own Principal Investigator. Thus, Dr. Segal, Research Director at the Institute on Disabilities, will be the PI from Temple, and Mr. Cooper, Executive Director, from United Cerebral Palsy of Central Pennsylvania.

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Specific Aim 1:

Promote a grass-roots understanding by I/DD community group members of the benefits of health care research, using a wellness/prevention framework to work through issues about research design, methodology, and shared ownership of protocol development, data processes and analysis of results.

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Specific Aim 2:

Increase the academic partner's sensitivity towards issues related to I/DD and how they may affect vulnerability of research participants and can lead to inequitable distribution of power in traditional research paradigms, which in turn result in distrust of the academic research process.

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Specific Aim 3:

Develop with co-leadership from both community and academic partners a funding proposal for a research intervention to improve wellness/prevention for persons with I/DD served by UCP Central PA.

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These aims and outcomes will result in a model for CBPR developed with the community of persons with I/DD. We will pilot ways to disseminate the model, including a handbook for academic and community settings, reports in the literature, and community outreach venues. Our evaluation should allow comparison of its effectiveness with that of others developed through this and other funding opportunities.

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CBPR is participatory; cooperative; involving a co-learning process, systems development and local capacity building; empowering, allowing participants to increase control of their lives; and achieves a balance between research/action. **It reflects [the]belief that people can...assess their strengths/needs and have a right to act on these.**

Minkler M. Ethical challenges for the "outside" researcher in community-based participatory research. *Health Education and Behavior*. 2004;31(6):684-697.

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Issues to be investigated:

- How is respect for the autonomy of the affected participant reconciled with the need, because of limited understanding due to intellectual disability, to enlist help from the care provider?
- To what extent is it important, or even necessary, to involve the care provider in the intervention?

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Issues to be pursued (2):

- Are there differences between support that can be expected from a family member compared to an agency-paid staff person for a participant living in a group home?
- Should the intervention be delivered in a home setting or in the community, e.g. a gym or other fitness setting, or a mix depending on the situation of the person?

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Issues to be pursued (3):

- Are workshops delivered in an intensive, shorter but less expensive format as effective as more spaced, ongoing routinized training?
- What are the ethics of providing support as mentors to participants and then needing to withdraw this support, with its emotional and social implications, at the end of funding?

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Issues to be pursued (4):

- What kind of informed consent is appropriate for participants with I/DD?
- Is it ethical to withhold an intervention, even if the current evidence base for its effectiveness is weak, from a randomly selected control group of participants, given that these are among the most under-served in the health care sector?

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Issues to be pursued (5):

- How can the needs for standardized samples be reconciled with the very different individual comorbidities that affect participants?
- How can information that results from the intervention be appropriately disseminated to this community?

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Issues to be pursued (6):

- Should results be published if they suggest that the intervention is somewhat successful for this group of persons, but to a lesser extent than other groups, e.g. those without I/DD?

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Approach:

Academic investigators are “subjects,” as are Community staff and members.

Small groups meeting over a sustained period at the Community center.

Two phases: forming the community and then developing the proposal.

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Approach (2):

The second year will “kick off” with an informal community discussion and reception sponsored by UCP.

During the following 10 months, all participants will develop the protocol, with both an Academic and Community PI. Again, a memorandum of understanding will be developed for procedures and evaluation strategies for the 2nd year.

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Approach (3):

Early in Year 2, the PIs will liaison with Temple research offices, including IRB, Off of Clin Trials, and Off of Strat Init, to discuss how these offices may become more attuned to the needs and concerns of people with I/D about research.

Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical dilemmas in community-based participatory research: recommendations for Institutional Review Boards. *Journal of Urban Health*. 2007;84(4):478-493.

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Evaluation:

- Is attentive listening, openness, inclusiveness, opportunity for all to participate, compromise and mutual respect in evidence?
- Is there evidence of deciding how decisions will be made, and with regard to which issues?
- Do the leaders foster democratic processes and decision-making?

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Evaluation (2):

It is essential to allow evaluation elements to be jointly determined. The PIs will be open to feedback about frameworks they have identified as well as concepts proposed by team members.

Israel B, Checkoway B, Schulz A, Zimmerman M. Health education and community empowerment: conceptualizing and measuring perceptions of individual, organizational, and community control. *Health Education Quarterly*. 1994;21(2):149-170.

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Evaluation (3):

Community team members will be interviewed by the project coordinators using a standardized protocol at the end of Years One and Two about their understanding of the important aspects of research methodology and processes for the community of persons with I/DD.

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Evaluation (4):

“A desired outcome of research collaborations is the empowerment of community members with additional skills to become more effective advocates for their communities. In practice, however, researchers and community groups seem to struggle for power and control of research projects.”

Bracht N, ed. *Health promotion at the community level*.
Newbury Park, CA: Sage.; 1990.

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Evaluation (5):

Another major theme we anticipate is balancing scientific methodology and feasibility according to community wishes.

Atienza A, King A. Community-based health intervention trials: an overview of methodological issues. *Epidemiologic Reviews*. 2002;24(1):72-79.

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Evaluation (6):

Key aspects of the data analysis are that it

- uses a rigorous qualitative methodology;
- strives for objectivity;
- makes extensive use of feedback from all team members as analytic results are reported back to them for validation and information sharing; and
- systematically evaluates the outcomes listed under the proposal's Specific Aims.

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Evaluation (7):

1A: Community members will acquire an understanding of the systematic nature of scientific inquiry: Audio-taped interviews at the end of Years One and Two with community team members about research methodology will be transcribed by the project coordinator at Temple. The analysis of the interviews will use classic iterative techniques of qualitative analysis.

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Evaluation (8):

1B: This core group will serve as an initial group of “research mentors” to the wider community: Using the principles and processes described for 1A, the audiotaped session in which team members self-evaluate the effectiveness of the community forum early in Year Two will be analyzed.

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Evaluation (9):

2A: The team of academic investigators will use a case study approach in applying the general attributes of CBPR to the specific case of persons with I/DD: Verbal audiotaped responses of team members each month reflecting on process, described above under Evaluation Materials and Instruments, will be transcribed by the project coordinator at Temple.

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Evaluation (10):

2B: The research structures at Temple will acquire increased knowledge/sensitivity towards needs of the community: Coding will be based on a review of the minutes of meetings conducted by the PIs with the Temple University offices during Year Two, and include analysis of current state of Temple offices and proposed changes based on information developed during the project.

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Evaluation (11):

The funding proposal will include safeguards for the community as well as individuals; standards of research design and experimental control; and roles for both community and academic partners: Coding based on review and written/audiotaped feedback about the protocol by all of the team.

Israel B, Schulz A, Parker E, Becker A. Review of community-based research: assessing partnership approaches to improve public health. *Ann Rev of Publ Health*. 1998; 19:173-202.

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Next steps at project conclusion:

- Development of a handbook.
- Dissemination of results through academic and community outlets.
- Promotion through the national UCP and also AUCD.
- Continued reaching out to UCP-Central PA.
- Funding of jointly developed proposal. 😊