

Promoting Healthy Public Policy through Community-Based Participatory Research: Case study



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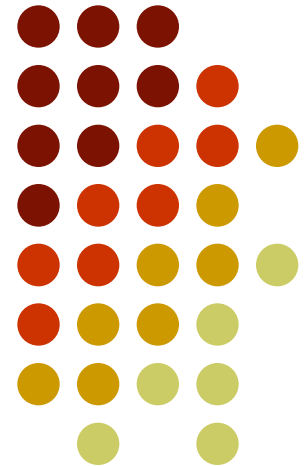
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Community-based participatory research (CBPR) in public health is a **partnership approach** to research that involves **community members, organizational representatives, and researchers** in different aspects of the research process and in which all partners **contribute expertise and share decision making and ownership.**



Principles of CBPR



1. CBPR recognizes community as a **unit of identity**.
2. CBPR builds on **strengths and resources** within the community.
3. CBPR facilitates **collaborative partnership** in all phases of the research.
4. CBPR promotes **co-learning and capacity building** among all partners.





5. CBPR integrates and achieves a **balance between research and action** for the mutual benefit of all partners.

6. CBPR emphasizes **ecological perspectives** that recognize and attend to the multiple determinants of health and disease.

7. CBPR involves systems development through a **cyclical and an iterative process**.

8. CBPR **disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process**.

9. CBPR involves a **long-term process and commitment**



Moving out of the nursing home and into the community





The number of disabled people under age 60 who were living in Illinois nursing homes grew 25 percent from 1997 to 2003, and 80 percent of the state's long-term care funding went to nursing homes and other institutional care.

Major impetus for CBPR project:

- difficulties for individuals in moving back to the community once institutionalized,
- social barriers experienced by disabled people who have moved out of nursing homes
- rebalance of funding



The Partnership:



- The project was born in 2000 from a long partnership between two professors in Disability Studies at the University of Illinois and their community partners at two local Centers for Independent Living (CILs), Access Living and Progress Center, founded and operated by and for disabled people.
- The topic grew out of conversation between the disability rights community and academic partners, who shared deep concerns about the number of disabled people in nursing homes in Illinois as well as the difficulties they experienced in leaving these settings and reintegrating into the community.





- ❑ Funded by a grant from the National Institute on Disability and Rehabilitation Research (NIDRR),

Project was designed to:

- ❑ Document the experiences and concerns of disabled people who attempted to move out of nursing homes,
- ❑ To develop, implement, and evaluate an individual and a community empowerment and policy change intervention known as the Social Action Group (SAG) Program.





Research Methods:

- ❑ Focus group with community and academic partners
- ❑ Initial focus groups with 30 disabled people transitioning out of nursing homes informed the development of the primary project intervention
- ❑ A five-week SAG Program, which then was field tested through a controlled intervention trial. Grounded in an empowerment model, the intervention included peer-led education about disability rights, help in accessing resources, and individual and community capacity building to promote systems change aimed at rebalancing long-term care funding in the state.
- ❑ A 300-item baseline survey was administered to 140 participants who had been randomly selected from the lists of individuals involved in the state's community integration waiver program and were divided into a SAG intervention group and a waitlisted control group.





- ❑ Repeated measures were used at three months and 12 months post-intervention to test the effects of participation.
- ❑ Qualitative interviews and life narratives were used to gather additional process data.
- ❑ Ten follow-up focus groups averaging 7 to 12 program participants each
- ❑ six town hall meetings ranging from 40 to 150 attendees, were conducted during and after the intervention.
- ❑ They enabled participants to “tell their stories,” discuss preliminary study findings, and develop action plans focused in part on helping to effect policy change.
- ❑ Members of the waitlisted control group also were invited to attend the post-SAG intervention town hall meetings.





Findings:

- ❑ A significant difference was observed between the SAG intervention group and the control group in terms of the proportion who had successfully transitioned out of nursing homes (37 percent of SAG members vs. 20 percent of controls).
- ❑ More than 200 disabled people had participated in the project through social action working groups, and many had developed skills as advocates for policy-level changes that could help address the bias toward institutionalization in long-term care funding and availability.
- ❑ Focus group data also helped uncover key community concerns that then became the basis for subsequent policy-focused efforts.





- a “Money Follows the Person” program, through which disabled consumers themselves would be enabled to select the support services they needed;
- Emergency backup personal attendant services for people at risk of re-institutionalization without such support;
- A community reintegration program for people over 60 who wanted to move out of nursing homes and often faced particularly difficult obstacles in doing so.





- These findings concerning disabled peoples' desired services and unmet needs in turn pointed to the need for new funding allocations and accompanying policy changes to support relevant programmatic interventions.





Getting to Action:

- ❑ Community and academic partners identified policy directions to pursue, drawing on the focus group data and policy relevant information from key sources within and outside the state.
- ❑ For each policy objective (e.g., getting the above-mentioned Money Follows the Person program and emergency backup personal attendant services), academic and community partners, along with SAG members, testified at public hearings, wrote letters to the editor, and took part in town hall meetings, rallies, and demonstrations to increase public and policymaker awareness of and support for their positions.





- The partners did careful advance work prior to public meetings to determine the best strategies, the data needed, and the most effective ways to communicate information.
- academic partner: “we always had a lot of evidence before we walked into a room for a meeting with the state [including] a ream of facts and life stories from participants ... to challenge them to move forward.”





Getting to Action:

- ❑ The effective use of media advocacy—especially by the CIL partners, including opinion and editorial pieces and articles in the Chicago Tribune helped publicize Illinois’ poor standing with respect to long-term care spending and highlighted the partners’ stance on key issues.
- ❑ SAG participants added a human dimension to the facts and statistics by telling their stories to journalists as well.
- ❑ Building strong coalitions beyond the existing partnership also was a key policy-related activity.
- ❑ Partnership members were founding members of The Illinois Olmstead Coalition, for example, which advocated for Illinois to develop an effective action plan for moving disabled people out of institutional settings while providing the supports needed (e.g., a living wage for attendants) to facilitate community living.





Getting to Action:

- ❑ **Policy Change Outcomes:**
- ❑ Increasing pressure on the state to comply with the Olmstead decision
- ❑ several policymakers and leaders in the disability community described the partnership as having contributed substantially to important policy and systems change efforts and outcomes.





Getting to Action:

- ❑ Money Follows the Person program provision, funded in 2007 through a **\$55.7 million** Phase I grant from the Centers for Medicare and Medicaid to the state .
- ❑ *Illinois' earlier reauthorization of a statewide council* to reassess Olmstead implementation and to prepare a **strategic plan for rebalancing long-term care funding toward community-based care**
- ❑ The programs helped nurture **a new generation of disability rights mentors and advocates** from among a highly marginalized population: disabled people in and transitioning out of nursing homes.





Barriers and Success Factors:

- ❑ The often formidable difficulties experienced in **working through the state bureaucracy, coupled with the power of the nursing home industry**, were major barriers to success.
- ❑ **Discrimination against disabled people at every level in society** also was noted.
- ❑ Despite these concerns, partners repeatedly pointed to success factors such as a **long history of collaboration and strong mutual trust, deep commitment to the cause, an effective and a diverse local disability rights network, and federal legislation mandating the enforcement of the civil rights of disabled people.**





- In the words of one policymaker, the SAG program and its town hall meetings helped create “a great influx of new voices carrying the message that it is time for a policy shift in Illinois ...
- Policymakers are hearing this message and are reaching out to the disability community for additional collaboration.”

