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# Community Engagement Research and Dual Diagnosis Anonymous

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# Community Engagement Research and Dual Diagnosis Anonymous

## **Description**

Community engagement research is widely discussed but rarely implemented. This paper describes the implementation of a community engagement research project on Dual Diagnosis Anonymous, a rapidly spreading peer support program in Oregon for people with co-occurring mental illness and substance use disorders. After three years of discussions, overcoming barriers, and involving several institutions, this grass-roots research project has been implemented and is expanding. Active participants in Dual Diagnosis Anonymous inspired and instructed policy makers, professionals, and students. Community engagement research requires front-line participants, community members, and professional collaborators to overcome multiple barriers with persistence and steadfastness. Building trust, collaboration, and structures for community engagement research takes time and a community effort.

## **Disciplines**

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## ABSTRACT

Community engagement research is widely discussed but rarely implemented. This paper describes the implementation of a community engagement research project on Dual Diagnosis Anonymous, a rapidly spreading peer support program in Oregon for people with co-occurring mental illness and substance use disorders. After three years of discussions, overcoming barriers, and involving several institutions, this grass-roots research project has been implemented and is expanding. Active participants in Dual Diagnosis Anonymous inspired and instructed policy makers, professionals, and students. Community engagement research requires front-line participants, community members, and professional collaborators to overcome multiple barriers with persistence and steadfastness. Building trust, collaboration, and structures for community engagement research takes time and a community effort.

**Keywords** *community engagement research, community-based research, Dual Diagnosis Anonymous, consumer perspective*

The essence of community-based participatory research, also called community engagement research, is partnership among all stakeholders (Clinical and Translational Science Awards Consortium, 2011). Community partners, defined broadly, may include all citizens, leaders, health care workers, socio-economic or cultural groups, or people affected by a particular condition. Regardless of community group, community engagement emphasizes broad involvement in the research from the beginning – identifying the need, formulating the research, and collaborating with policy makers, funders, and researchers. Community engagement has attained particular salience nationally through the Center for Translational Science Awards Consortium (2011) and internationally through various World Health Organization initiatives, including the Movement for Global Mental Health (Patel et al., 2011). Despite these public declarations, community engagement research as a tool to reform healthcare is usually honored in the breach rather than by instantiation (Drake & Whitley, 2014).

One key area of policy failure is the co-occurrence of addictive and mental health disorders. The need for integration of addiction and mental health services has been clear since the 1980s (Ridgely, Goldman, & Willenbring, 1990), but despite numerous calls for reform (e.g., O'Brien et al., 2004), the fields have remained separate and largely incompatible for the many people who have co-occurring disorders (Kessler et al., 1987). Hence the need for community-based action – service development and research from the ground up rather than the top down – remains largely unmet. Community engagement efforts have heretofore been slowed by inadequate funding and a lack of partnerships between local stakeholders and policy makers, institutions, professionals, and researchers.

The leaders of Dual Diagnosis Anonymous (DDA), a self-help organization for people with co-occurring mental illness and substance use disorders, have attempted over several years to create community engagement research. This paper describes current progress.

## BACKGROUND

Oregon, like other states, experienced extreme difficulties implementing and sustaining evidence-based dual diagnosis groups led by professionals within mental health programs (Monica, Nikkel, & Drake, 2010). Because of the widely recognized need for services, DDA came to Oregon. The Oregon Addictions and Mental Health Division funded a small grant to implement DDA meetings in 2005. Since then, DDA has spread rapidly to provide regular meetings in 30 of the state's 36 counties. A private non-profit DDA office implements and monitors DDA in Oregon. A contract with the Addiction and Mental Health Division specifies that DDA provides: ongoing education, technical assistance, and support to all groups; brochures and outreach to local National Alliance on Mental Illness and other family groups; monthly fellowship meetings throughout Oregon; books, materials, and travel expenses for local chapters; and monthly and annual project status reports. A dozen funders now support DDA throughout the state.

DDA adds these five steps to the traditional 12 steps of Alcoholics Anonymous and Narcotics Anonymous: (1) acknowledging both illnesses, (2) accepting help for both conditions, (3) understanding the importance of a variety of interventions, (4) combining illness self-

management, peer support, and spirituality, and (5) following the program and helping others (DDA of Oregon, 2008).

## COMMUNITY ENGAGEMENT RESEARCH

Research on peer support programs for people with co-occurring disorders has been minimal (Drake, O'Neal, & Wallach, 2008), but DDA leaders and representatives in Oregon reached out to researchers at Dartmouth College and Pacific University to help document the spread and impact of the program. The request aligned with Dartmouth's long-standing interest in co-occurring disorders and community engagement research (NIH, 1999) and Pacific University's commitment to service development in Oregon.

## CHALLENGES

The Oregon DDA consortium members first decided to explore the effects of the program through qualitative interviews. Survey research depends on qualitative research to identify and define appropriate outcomes. We sought approval from various institutions, which turned out to be a more than two-year process with multiple barriers. The Department of Corrections, the Oregon State Hospital, and the Pacific University Institutional Review Board all had specific requirements for language and procedures in the study protocol. Due to the different needs of the populations, these requirements conflicted. For example, the Pacific University Institutional Review Board required phone numbers of contact personnel to be included in informed consent

documentation, but the Department of Corrections required addresses and no phone numbers because corrections inmates typically do not have phone privileges and rely on the postal service for communication. The Department of Corrections and the Oregon State Hospital had separate background checks on all research personnel who would enter the facilities, requiring multiple background checks on each focus group leader. The Oregon State Hospital required a separate session for informed consent in order to provide an individualized process for each subject, while the Department of Corrections required that informed consent and focus groups be led in one session in order to minimize disruption and use of resources (i.e., correctional officers) within facilities.

Barriers to community engagement research are legion. We encountered a significant barrier because the Oregon State Hospital had disbanded its Institutional Review Board and had no alternative method for approving research. Conducting focus groups at this site was critical because many DDA members are hospitalized at some point, and many DDA groups occur on the grounds. After two years of discussions, personal lobbying, and developing professional partnerships, common sense prevailed. A review panel of members of the former Institutional Review Board convened and approved the study under the jurisdiction of the Pacific University Institutional Review Board.

## IMPLEMENTATION

The partnership of DDA, the Oregon Addictions and Mental Health Division, the Oregon State Hospital, the Oregon Department of Corrections, Pacific University, and the Dartmouth

Psychiatric Research Center eventually completed the qualitative study (see companion article in this issue). DDA and various institutions provided access, Pacific University provided occupational therapy students to lead focus groups and collaborated with the partners to design the interviews, and the Dartmouth Psychiatric Research Center analyzed the data.

Once focus groups began, consumers who attended DDA were very eager to participate and share their experiences. All of the partners expanded their understanding of DDA. In addition, the students who led focus groups gained first-hand insights into the realities of living with dual diagnosis -- experiences that transcended what they learned in the classroom. At the conclusion of the study, student focus group leaders expressed the following:

“My experience in working on this project has been one of profound understanding of what it may be like to live with a mental illness. The participants of the study have helped me to consider the necessity of peer support on the path to recovery. This experience will help to incorporate greater compassion in my future occupational therapy practice.”

"Facilitating DDA groups has given me more insights into the realities of the recovery process; it remains uniquely significant to each individual and DDA creates a safe space for participants to express their personal journey of recovery."

"Leading the focus groups increased my confidence in conversing with the mental health/substance abuse population.“

## DISCUSSION

Community engagement research takes many forms and includes diverse partners. The level of community involvement extends on a continuum: outreach, consultation, involvement, collaboration, and shared leadership (Clinical and Translational Science Awards Consortium, 2011). The shared leadership end of the continuum, exemplified by community-based participatory research, encompasses not only strong bidirectional leadership but also decision-making at the community level, strong partnership structures and trust, and an emphasis on outcomes at the broader community level.

This end of the continuum represents our goal in Oregon. The extent of partnerships already built is remarkable for self-help organizations and has obviously stretched the capacity of participating organizations. As we move toward studying personal and community outcomes, we will need further participation from community partners.

## Conclusions

Community engagement research to understand the consumer perspective on DDA across the many settings where individuals with dual diagnosis live their lives proved daunting, but we believe the research will improve our understanding of phenomenology, peer-run services, and meaningful outcomes. Because many people with dual disorders spend some time in correctional facilities and/or psychiatric hospitals as well as living in the community, we need to examine experiences and peer-run services that bridge these environments. Our next steps include using the qualitative interview findings and our experiences to design and implement a large survey research project on DDA outcomes. We also hope to study the dissemination and implementation of DDA in other states.

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## DISCLOSURES

Sean Roush declares no conflicts of interest and no compensation for professional services related to this manuscript.

Corbett Monica received compensation as the executive director of DDA during this study.

Danny Pavlovich declares no conflicts of interest and no compensation for professional services related to this manuscript.

Robert E. Drake declares no conflicts of interest and no compensation for professional services related to this manuscript.

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