

ARCC Round 4 Seed Grant Project Summaries

Partnership Building Grants

Barriers to Prostate Cancer and HIV Screening in African American Men in Chicago

Marcus Murray, Project Brotherhood, and Adam Murphy, Department of Urology, Feinberg School of Medicine

African American (AA) men suffer worse health outcomes in diseases that are screened for in the United States including HIV and prostate cancer (PCa). Since PSA screening became standard practice in the US, the disparities between PCa outcomes in AA and Caucasian men have widened. AA men now have 1.4 times higher risk of being diagnosed and 2-3 times higher risk of dying of PCa, compared to Caucasian men. Similarly, HIV incidence in AA men exhibits a striking racial disparity compared to Caucasian men. Lower rates of screening among AAs due to real and perceived barriers contribute to these health disparities. Project Brotherhood (PB) actively engages in health education and disease prevention with groups of AA men through barbershop outreach and capacity building to facilitate healthy habits in a non-threatening, culturally sanctioned environment. Through building a collaborative community engaged research partnership between Dr. Murphy and his colleagues at Northwestern University with Mr. Murray and his associates at Project Brotherhood, the aim of this project is to combine efforts to elucidate major barriers that prevent AA men from participating in PCa & HIV screening. An overarching aim is to also expose and educate one another (and associated teams) on the implicit and explicit cultural rules, norms, values, and expectations of the others' working environments, communication patterns and short and long term visions for success. It is our hope that this type of organic partnership building will facilitate the needed trust, understanding and motivation for future co-led initiatives that will bridge community and university efforts to benefit the health of AA men.

Refugee Communities: Disability, Health, & Inclusion Partnership Project

Rene Luna, Access Living of Metropolitan Chicago, and Mansha Mirza, Institute for Healthcare Studies, Feinberg School of Medicine

The demographic landscape of the United States is becoming increasingly diverse, a result of growing immigrant and refugee populations. This overall trend has parallels for sub groups such as people with disabilities. As ethnic diversity among individuals with disabilities increases, service delivery systems must be prepared to respond to the cultural implications of an increasingly diverse client base. However, disability-related services have been slow in responding to this challenge. Research indicates underrepresentation of ethnically diverse persons with disabilities in disability and rehabilitation research, creating knowledge gaps in the field and leading to poor outcomes. To redress these research and service gaps, leaders in the field of disability and rehabilitation recommend establishing collaborative partnerships with ethnic minority communities as a first step toward the development and evaluation of culturally relevant interventions.

Our project is in response to the need identified above and proposes the development of a community-academic partnership between Northwestern University (Institute for Healthcare Studies), Access Living and refugee service agencies and refugee communities in Chicago. Chicago has a large presence of refugee communities and refugee service agencies. A recent ethnographic study conducted by one of the Co-PIs showed how disabled refugees

were at high risk of falling through cracks between refugee and disability service systems, underscoring the need for our project. The partnership will draw on community-based participatory research (CBPR) approaches such as key informant interviews and group facilitation exercises to develop a Community Advisory Board (CAB). The role of the CAB will be to identify cultural and systemic issues affecting the health of refugees with disabilities in Chicago and their access to disability-related services. The activities of the CAB will culminate into a systemic research plan and grant application to empirically assess community-identified issues affecting disabled refugees, with the long-term goal of developing culturally-specific and empirically-supported interventions targeted at this group.

KARE- Korean American Alzheimer's Research and Education

Hyeyoung Lee, Korean American Community Services, and Darby Morhardt, Cognitive Neurology & Alzheimer's Disease Center, Feinberg School of Medicine.

In response to the growing number of Korean American seniors in the Chicago area and the lack of research and information on culturally appropriate interventions for Alzheimer's disease, Korean American Community Services (KACS) and the Cognitive Neurology and Alzheimer's Disease Center (CNADC) of Northwestern University's Feinberg School of Medicine are seeking partnership building support from the Alliance for Research in Chicagoland Communities.

CNADC and KACS each bring unique strengths to the proposed partnership, including several combined years of clinical social work experience, including working with older adults and their families; prior experience in community-based participatory research (CBPR); a comprehensive knowledge of dementia related diseases (CNADC); and a 38-year history of responding to the acute needs of Korean Americans (KACS).

During this partnership building phase, our goals are to:

- 1) Establish a strong working relationship and infrastructure,
- 2) Involve stakeholders in exploring the attitudes about Alzheimer's Disease and barriers to seeking help among the Korean American community,
- 3) Build our collective capacity by holding educational workshops, and
- 4) Develop culturally appropriate research tools for future use in implementation.

At the conclusion of the partnership building phase, KACS and CNADC will be prepared to conduct a CBPR needs assessment of Korean American seniors in Chicago who are at risk for developing Alzheimer's disease as the population continues to age. KACS hopes to use the data from this research to develop culturally appropriate programs and services for Korean Americans who are suffering from or at risk of developing Alzheimer's disease; CNADC hopes to expand their understanding of the cultural effect on conceptualizations of Alzheimer's disease, as well as develop a CBPR approach to conducting needs assessments that can be replicated in other ethnic communities.

Implementation Grants

Evaluating Coordination of Care for the Suburban Uninsured: The Access Du Page Cohort Study

Kara Murphy, Access DuPage, and Melissa Simon, Obstetrics & Gynecology, Feinberg School of Medicine

Founded in 2002, the DuPage Health Coalition, composed of civic and community organizations and its Access DuPage Program (AD), have become the primary advocates for a strong healthcare safety net to address the needs of growing populations of low income, uninsured residents in DuPage County. Now enrolling 12,000 uninsured residents, AD assigns primary care clinics to serve as medical homes. Since 2005, Drs. Endress, Simon, Feinglass and Ms. Murphy have been working together to build a community-based research capacity, focused on behavioral and health services research for medically underserved populations. Our collaborative has received an NIH RO3 Partners in Research and an NIH R24 cancer navigation grant. This CBPR seed grant project expands this partnership to health policy research with three main purposes: 1) to conduct an evaluation of AD and the extent to which enrollees achieve coordinated care characteristic of a patient centered medical home, including ratings of access, satisfaction and unmet needs; 2) to build community-based research capacity and survey research expertise; 3) provide preliminary data and expertise for a longitudinal cohort study to evaluate upcoming state and federal changes in health care provision for the uninsured. The proposed n=200 survey will measure uninsured enrollees' baseline, pre-AD enrollment medical care experience as compared to their 6 months post-enrollment experienced. This approach responds to requests by community leaders for a never previously done evaluation of AD program effectiveness and benefits. The study is designed to test the relative efficiency (cost and attrition rate differences) of two baseline recruitment techniques, in person versus telephone interviews (n= 100 each), with six month telephone follow-up of all subjects. This analysis of the dynamics of cohort recruitment and survey reliability would provide essential preliminary data for a larger scale evaluation of the Affordable Care Act in Illinois.

People with Disabilities Speak Out on Health Care Disparities: A qualitative study of Medicaid beneficiaries' primary care experiences

Judy Panko-Reis, Access Living of Metropolitan Chicago, and Susan Magasi, Medical Social Sciences, Feinberg School of Medicine

Recent cost containment legislation enacted by the State of Illinois will move half of the Medicaid beneficiaries from traditional fee-for-service delivery systems into mandated managed care by 2015. Community partners at Access Living have grave concerns that these measures are being implemented at the expense of Medicaid beneficiaries with disabilities, a group who already experience disparities in healthcare access and outcomes. In spite of known barriers to healthcare access and outcomes, there is a lack of local data that document Medicaid beneficiaries' primary healthcare needs and priorities.

Access Living is partnering with health services researchers in the Feinberg School of Medicine to conduct a qualitative community-based participatory research study to address the following specific aims:

- 1) Examine the primary healthcare experiences and needs of Medicaid beneficiaries with disabilities on Chicago's Southwest Side.
- 2) Establish community directed priorities for advocacy, policy change, and research.

We will use qualitative methods, including focus groups and nominal group techniques within a town hall setting, to achieve the project goals. We will recruit a maximum variability sample of 90 Medicaid beneficiaries with disabilities from Chicago's Southwest Side to participate in 9 focus groups stratified by impairment type. We will use a 2-phase analytic approach and constant comparative methods to examine healthcare needs and barriers experienced by Medicaid beneficiaries as a whole and by impairment group. Focus group findings will be

disseminated to consumers, providers, and local and state policy makers at a town hall meeting. Town hall participants will engage in nominal group techniques to identify priority areas for advocacy and research.

We have developed an organizational structure characterized by our commitment to healthcare equity, open communication, and consensus based decision making to ensure the success of this project and build the team's capacity to conduct rigorous research that informs healthcare advocacy and public policy.