Integrated Health Care for African Americans with Serious Mental Illness Who Are Homeless In Chicago’s Edgewater-Uptown Neighborhood

Specific Aims

People with serious mental illnesses such as schizophrenia and bipolar disorder suffer significantly higher physical health morbidity and mortality than the general population (WHO, 2005). They are also much more likely to be homeless compared to other adults. Minority ethnic status further compounds disparities in this group with the rate of illness and death among African Americans who are homeless with serious mental illness at catastrophic levels. We propose to understand the intersection of these conditions and ameliorate their impact on the lives of African Americans in Chicago’s Edgewater-Uptown neighborhood, an area shown in census data to be among the most challenged in these regards in the United States. Policy experts and advocates call for integrated care -- the strategic combination of mental and physical health services by a single team of providers (IOM, 2012) -- to deal with this problem. CBPR for integrated care is poignantly relevant to establishing and acting on integrated health care among African Americans who are homeless with serious mental illness (hereafter referred to as African Americans with lived experience for reasons of brevity). People who are homeless are among the most disenfranchised of communities in America. Being African American with serious mental illness only furthers alienation from the political process and established community. Note we distinguish “established” community from the socially meaningful community of people who are homeless; perhaps without boundaries but, consistent with the mission of NIMHD, a collective with recognized and shared identity. CBPR provides the mechanisms by which the community of African Americans with lived experience assume a partnering role in describing the health condition through research; use this description to identify and develop an effective intervention for influencing it; bring resources to implement the intervention, albeit it on a pilot basis; and test its impact. Success in Phase 1 will lead to a Phase 2 application, where CBPR will yield a more rigorous test of the intervention at a broader level.

This proposal represents a partnership ideally situated to accomplish the goals of the proposal. It includes leaders of Heartland Alliance for Human Needs & Human Rights AND the Center on Adherence & Self-Determination. Heartland Alliance began its service to the City of Chicago in 1888 helping to set up health and related social systems for immigrants and other newcomers to our City. Jane Addams expanded some of its programs with the founding of Hull House in 1908. Heartland Health Outreach (HHO) is Heartland Alliance’s health care arm and offers primary care, oral health, and behavioral health services in over 120 locations throughout the Chicago area including a state-of-the-art primary care and oral health center in the Edgewater-Uptown neighborhood. In 1985, HHO launched Health Care for the Homeless, a national demonstration project supported by the RWJ Foundation and the Pew Trust. Health Care for the Homeless includes a consumer advisory board, people with lived experience who provide feedback and guidance to all levels of the program. Prominent among Health Care for the Homeless consumer concerns are programs for its members with serious mental illness. The CBPR mission described herein provides an excellent opportunity to specifically advance the health care needs of African Americans with lived experience in Edgewater-Uptown.

HHO will partner with investigators from the NIMH-funded (P20) Center on Adherence and Self Determination (CASD) at the Illinois Institute of Technology (IIT) whose mission is to develop, advance, and conduct rigorous research addressing the question why people do not seek or fully avail healthcare services (Dr. Patrick Corrigan, P.I.); co-PIs are at Yale, Penn, Temple and Rutgers. Central to our efforts is a focus on self-determination and the role CBPR plays in defining health problems, developing appropriate interventions, and implementing these interventions in real world settings. Dr. Karen Batia, HHO executive director, has been CASD co-investigator since the Center’s inception. The partnership proposes the following aims:

- Establish a Community Advisory Board (CAB) co-chaired by this proposal’s PI (Corrigan) and co-PI, Mr. Raymond Burks, an African American with lived experience and a member of HHO’s Consumer Advisory Board. The CAB will be responsible for all facets of the research as well as parallel planning, education, outreach, and dissemination efforts. CAB will comprise African Americans with lived experience and other key stakeholders.
- The CAB will conduct a community needs assessment to identify the disease or condition for intervention research using mixed research methods developed by the CASD Research core. We seek to do this, in part, using innovative mobile assessment technologies developed by CASD investigators.
- Results of the needs assessment will yield development of a corresponding intervention grounded in integrated care.
- A pilot will be conducted to examine feasibility, acceptability, and impact of the intervention as well as the CBPR experience among the CAB.
RESEARCH STRATEGY

SIGNIFICANCE

People with disabling psychiatric disorders show inordinate rates of co-occurring physical illnesses that are often further disabling or lead to death (Martens, 2001; WHO, 2005). This group shows higher incidence and prevalence in cancer (Schanzer et al., 2007), cardiovascular and respiratory illness (Badiaga et al., 2009; Diez-Roux et al., 1999), gastro-intestinal disorders (Weinreb et al., 1998), neurological disorders (Hwang et al., 2008; Laporte et al., 2006), and orthopedic illnesses including those due to accident (Takano et al., 1999). People with serious psychiatric disorders are also over-represented among the homeless population. A meta-analysis of 29 prevalence studies in Western countries indicated frequent DSM-diagnoses among people who are homeless: psychotic illness (12.7%), major depression (11.4%), and personality disorders (23.1%) (Fazel et al., 2008). Homelessness hugely compounds morbidity and mortality (Cheung & Hwang, 2004; Morrison, 2009). A review of 50 years of research indicates far greater rates of tuberculosis, asthma, bronchitis, and HIV/AIDS among people in homeless shelters (Martens, 2001). Ethnic minorities are over-represented among the homeless (U.S. Department of Housing and Urban Development, 2010). African Americans, compared to Caucasians, are three times more likely to experience homelessness (Greenberg & Rosenheck, 2010), susceptible to worse physical and mental health as a result (Folsom et al., 2005). Making matters worse, the health care system for homeless African Americans with serious mental illness is severely lacking (Horvitz-Lennon et al., 2009; Richardson et al., 2003). Although some markers suggest America’s economy is in recovery, unemployment remains troubling, especially in urban areas and low SES neighborhoods within these cities (National Alliance to end Homelessness & Homelessness Research Institute, 2012). The social service network meant to rectify this disparity is challenged by significant budget deficits in many states, deficits that are often addressed by diminishing human services (NASMHPD Research Institute, 2011).

Researchers and advocates have distinguished among types of homelessness: episodic (in and out of shelters), transitional (relatively short term brought on, for example, by temporary, unforeseen unemployment), or chronic (often defined as more than a year) (Lee et al., 2010; U.S. Department of Housing and Urban Development, 2010). Add to this are concerns of the precariously housed: people imminently at risk for homelessness, frequently doubled up with others who have minimal housing. Research has shown each type interacts with effects on health and, therefore, need to be incorporated into research models (Eyrich-Garg et al., 2008). The egregious impact of homelessness on health, therefore, is not limited to adults. Children of homeless families are shown to have higher rates of asthma, nutritional inadequacy, behavioral developmental, emotional, and mental disorders (Coker et al., 2009; Grant et al., 2007). African American children have disproportionately higher prevalence rates in family homelessness studies (Coker et al., 2009; Warf et al., 2009).

Chicago’s Edgewater-Uptown Neighborhood. One experience, notorious in Chicago mental health lore known as “bus therapy,” explains Edgewater-Uptown’s troubled role in this problem. People released from Chicago Read State Hospital in the 60’s through 80’s were put on a city bus to Edgewater-Uptown with a week’s medication and recommendations to seek care once arriving. Edgewater-Uptown was a desirable setting because earlier in Chicago history it was a tourist destination with large, single-room occupancy (SRO) hotels. As tourism moved elsewhere, these hotels became flophouses for the disenfranchised with serious mental illness. Overtime, Edgewater-Uptowns economic plight worsened, SROs closed, and many in this group ended up on the streets. The continuum of care is better but the impact on the community was significant. Edgewater-Uptown has one of the highest collections of people with mental illness who are homeless in the 9.6 million Chicago Metropolitan area. Findings from HUD’s (2010) Annual Homeless Assessment Report to Congress estimated that 1.59 million people across the country spent at least one night in a homeless shelter. From 2006-2010, Chicago experienced a 28.4% increase in shelter use and a 40.4% increase in people who were unsheltered. Illinois was one of 19 states reporting increases in their homeless populations and a 5% increase within the near future is expected given the financial climate (National Alliance to End Homelessness & Homelessness Research Institute, 2012). Some researchers have suggested that as high as 50% of the homeless are African Americans (Johnson, 2010; U.S Conference of Mayors, 2002).

The safety net in Edgewater-Uptown is largely funded by the State of Illinois, Cook County, and City of Chicago. Unfortunately, all three governments have significant budget deficits and, to varying degrees, sought balanced budgets by decreasing social and human services. The Illinois per capita budget deficit is higher than that of any other state. As a result, Illinois lawmakers recently passed a budget that cuts $1.6 billion from the state’s FY13 Medicaid budget. The impact of such cuts will largely affect adults with disabilities living in poverty, a disproportionate percentage who are African American. The State, for example, has reduced funding to its Department of Mental Health by 15% from 2009-2011 (NAMI, 2011). County Mental Health
Services have always been a small part of the service system except for services offered by the County Jail; Cermak Hospital in the jail continues to be the greatest single provider of psychiatric services in the Metropolitan Area. The City just closed 6 of its 12 municipal mental health clinics (Chicago Mayor’s Office, 2012). Finally, among the cuts to the Illinois’ FY13 Medicaid budget was the elimination of General Assistance, a category designed to cover outpatient medical services for the state’s poorest residents. As a result, 9,160 individuals, disproportionately African American, will lose this benefit effective July 1, 2013.

What Compounds these Alarming Disparities

Often with homelessness and serious mental illness come other conditions (5 reviewed here) that may co-occur in many African Americans in poverty. (1) People who are homeless with serious mental illness show very high rates of co-occurring substance use disorders (Greenberg & Rosenheck, 2010). (2) People who are homeless are also often involved with the criminal justice system with frequent arrests leading to potentially treatment-interrupting involvement in court, prison, and/or probation/parole (Greenberg & Rosenheck, 2008a,b; Warf et al., 2009). (3) Conversely, relative to the general public, people who are homeless are at least twice as likely to be victims of crime (Maniglio, 2009; Whitbeck et al., 2007). Domestic violence in particular, leads to inordinate homelessness among single parent families (Baker et al., 2010). (4) People who are homeless have often unsuccessfully graduated from foster care (Dworsky & Courtney, 2009). Many state agencies including the Illinois Department of Children and Family Services fail to provide transitional services needed for young men and women leaving foster care (Allen & Vacca, 2011; Culhane et al., 2011; Park et al., 2012). (5) People who are homeless and/or with serious mental illness often engage in unprotected sex practices which lead to HIV/AIDS or other sexually transmitted diseases (Halcón & Lifson, 2004). African Americans who are homeless are likelier to engage in prostitution and unprotected sexual behaviors (Edwards et al., 2006; Mutchler et al., 2011; Salazar et al., 2007). In ALL cases, these co-conditions lead to grossly higher rates of morbidity and mortality.

The challenge to understanding health among African Americans who are homeless and with serious mental illness is sorting out the relationships between these conditions as co-variates versus causal agents. Medical anthropologists have made sense of this phenomenon with the idea of syndemics which serves as a theoretical foundation for our proposal. Syndemics represent the synergistic interaction of two or more coexistent diseases or conditions and its consequent, exponential burden of disease (Singer, 1994; Singer & Clair, 2003). Common to the conditions of concern in this proposal is the egregious impact of poverty, unemployment, and social disadvantage. The challenge of the Community Advisory Board responsible for the CBPR outlined herein will be discerning among these conditions to define specific causal agents specifically relevant to co-occurring health disorders.

What we found through a preliminary needs assessment. In Preliminary Investigations of the Research Section of this proposal, we describe focus groups conducted with the Heartland Health Outreach (HHO) consumer advisory board to inform the goals and direction of this proposal. Briefly, African Americans who have been homeless with serious mental illness living in Edgewater-Uptown resoundingly echoed the concerns outlined in the research findings above. Namely, physical health problems and subsequent death are at catastrophic levels among their peers; integrated services reflecting the unique needs of others in the community are lacking. Past efforts to craft these kinds of services often failed to incorporate the voice of the population in need: one focus group participant commented, “We need to make sure we don’t just set up more bureaucracy and red tape!” CBPR has the potential for making a major impact on their neighborhood.

Alienation and Disenfranchisement

People who are homeless are among the most disempowered of our citizens (Boardman, 2006; Gangamma et al., 2008; Phelan et al., 1997). Sociologists sometimes refer to them as the invisible population: people who fall below the radar of community influence because of their social disadvantage. People with serious mental illness show similar levels of alienation and distance from their communities (Pelletier et al., 2009). Advocates and researchers note this kind of absence of power undermines both groups’ influence on the community health agenda (Bhui et al., 2006; Kidd & Davidson, 2007). Continued experiences of disenfranchisement and disempowerment lead to apathy and demoralization (Corrigan & Rao, in press). People with serious mental illnesses and other social disadvantage develop a sense of why try (Corrigan et al., 2009). “Why try to get a job: I am not able.” “Why try to get good health care: I am not worthy.” Once again, race only seems to worsen the picture. Both qualitative and quantitative research shows African Americans who are homeless often report a prominent sense of alienation from community and the political process (Washington et al., 2009). Compounding this: African Americans who are homeless are typically without work and income thereby lacking ways to influence the economy. Without a home, they lack an address and the benefits of association.
The Promise of CBPR. CBPR is uniquely situated to advance the health priorities of African Americans with lived experience (to remind the leader: African Americans with lived experience are African Americans who are homeless with serious mental illness). At its essence, CBPR is an activist approach to science recognizing that only an empowered community is able to fully understand and act on challenges of that community (Kidd & Krall, 2005; Lewin, 1946; Minkler & Wallerstein, 2008). CBPR is a strengths-based approach recognizing that solutions lie as much in describing the resources a group might call on to address a problem as description of the problem alone (Wallerstein & Duran, 2006). CBPR provides a Community Advisory Board the procedures for reaching real world goals. In the process, CBPR yields sustainability through system change and capacity building. Our proposal will provide the resources to support the Community Advisory Board (CAB): salary support for key CAB members, venues for work, financial resources for data gathering and analyses, method and content experts to provide information for CAB deliberations, and clinics for the eventual testing of the intervention. CBPR fosters sustainability beyond the limits of a project like this by building and fostering working relationships among local governments, providers and people in need.

Two important questions about CBPR are examined in this proposal. First as suggested earlier, “homeless” seems to challenge notions of community in CBPR. By virtue of their alienation, people who are homeless do not seem to constitute an organization or discrete community like, for example, Native American Tribes or ethnic community organizations that are partners in other NIMHD CBPR efforts. Existing research, however, contradicts this concern showing that homeless people comprise unique and diverse communities; communities that have worked collaboratively with researchers seeking to improve their capacities and resources (Ravenell et al., 2006, 2008; Washington et al., 2009; Yeich, 1996). Three phenomena further challenge concerns of CBPR with homeless. First, an ad hoc aggregation of people who are homeless in Edgewater-Uptown may be the genesis of a viable organization that will shepherd health care change for African Americans who are homeless and with serious mental illness. Second, there are advocates with lived experience in Chicago and Edgewater-Uptown who have formed service organizations that can be the foundation on which this new organization emerges. HHO already serves this purpose in Edgewater-Uptown. Third, racial identity among African American participants will further cement the CAB.

A second important question is whether serious mental illness might undermine a CBPR process. For example, do the cognitive dysfunctions often observed among people with serious mental illnesses and some substance use disorders undermine participation in the partnership process? This is an important empirical question that will be examined in the proposal. However, previous CASD research leads to a hypothesis here: with appropriate accommodations, people with serious mental illnesses are able to fully participate in and add to the CBPR process (Corrigan & Shapiro, 2010).

Central to the CBPR process is partnership between researchers and people with lived experience to describe problems of physical illness in this group and develop a corresponding integrated care intervention. Good CBPR does not occur in a vacuum. There are already a slew of evidence-based approaches to public health concerns that might inform the Community Advisory Board through the CBPR process. The goal here is not to restrict the direction the CBPR process might take. Rather, it is to remind us that CBPR occurs in the ground of existing knowledge. The Center on Adherence and Self-Determination at IIT is largely funded to examine why people do not seek out or otherwise obtain integrated services. We propose integrated care as the frame onto which the specific intervention will be developed and superimposed (IOM, 2012). Candidate interventions which the CAB might select to enhance integrated care include:

- **Shared decision making (SDM).** SDM evolved out of practitioner and patient recognition that interventions are more effective when derived collaboratively (Corrigan et al., in press; Corrigan et al., 2012). SDM is a fairly well-developed and evaluated approach to influencing medication adherence for such medical conditions as cancer (van Leeuwen et al., 2004), heart disease (Morgan et al., 2000), and GI disorders (Greenfield et al., 1985). It has been tested for psychiatric illnesses (Ludman et al., 2003; Malm et al., 2003) and substance abuse disorders (Joosten et al., 2009). SDM has three components (Drake et al., 2010). (1) Assist decision-making by helping people examine costs and benefits of health options; e.g., how does one’s anti-hypertensive medication help and hinder symptoms, functioning, and quality of life. (2) This kind of assessment is facilitated by individual and group education so patients better understand their disease and corresponding treatments. (3) SDM is fundamentally a counseling enterprise with key processes such as empathy, genuineness, and promotion of self-efficacy (Miller & Rose, 2010). Dr. Corrigan is currently partnering with HHO in a NIMH-funded study to examine both implicit and explicit processes related to SDM.

- **Peer navigators.** The health care system can be formidable to the educated and overwhelming to those alienated and disenfranchised from the mainstream. Peer navigators are one way public health experts have
sought to diminish the sense of disempowerment within hospitals and clinics. Peer navigation has different forms but typically includes a partnership between patients and paraprofessionals from their community, often referred to as community health workers. Component practices and principles might include: (1) navigating tasks, which consist of identifying and mitigating barriers to service; (2) facilitating tasks, which include finding relevant resources; and (3) maintaining systems, which include strategies meant to impact service systems to better meet needs (Griswold et al., 2010; Parker & Thorson, 2009). Dr. Matthews on the research team of this proposal has completed NINR-supported research on patient navigation among and African American population.

**Mobile health technologies.** Both the WHO (2011) and NIH (2012) embraced mobile technologies like SmartPhones as an innovative approach to dealing with real-world challenges to health care. CASD co-I Dror Ben-Zeev developed Mobile Assessment for Treatment for Schizophrenia (MATS), a PDA-based system shown to have significant impact on social functioning and treatment seeking (Swendsen et al., 2011). The MATS uses daily prompts and a tailored response system to guide participants towards research goals. A separate project showed the feasibility of this kind of technology (Ben-Zeev et al., 2012); contrary to naïve expectations, 72% of a sample of more than 1500 people with serious mental illness, many who are homeless, reported having and regularly using a mobile device. Similarly, mobile phones have been shown to be an effective way of communicating with people who are homeless (Stennett et al., 2012). Purchasing SmartPhone technology is cost efficient in many services research projects (Hendry et al., 2011).

As noted, these program candidates may provide direction for the CAB charged with defining a community-important health challenge and resulting intervention. However, central to the CBPR process, and the qualitative methods on which it rests, is the emergence of approaches not foreseen prior to the process per se. The exciting activities of the proposed project are the identification of a truly innovative approach reflecting interests and exigencies of people with lived experience from the Edgewater-Uptown neighborhood.

**INNOVATION**

Our proposal builds on HHO’s already successful Health Care for the Homeless in Edgewater-Uptown and CASD’s record of services research related to integrated care. On this foundation, our proposed project features several innovations.

- The proposed work adds to the unfortunately limited research literature on poor health and health care among African Americans who are homeless.
- It seeks to understand how serious mental illness exacerbates the health and health care options of African Americans who are homeless.
- It incorporates an explicit agenda to examine important moderators of health and health care among people with lived experience: substance abuse, involvement in the criminal justice system, foster care, and unsafe sex practices.

**CBPR is at the heart of the work in this proposal. Hence, several innovations emerge vis-à-vis CBPR.**

- CBPR is offered as a particularly relevant way to address health concerns for a disenfranchised and disempowered community: African Americans with lived experience.
- The proposal provides a venue for examining the CBPR process in this little studied sample.
- Composite studies will attempt to confirm key hypotheses:
  - People who are homeless constitute a meaningful community for CBPR and
  - Dysfunctions related to psychiatric disorders do not undermine the CBPR process.
- CBPR will generate capacity building and systems change to yield sustainable integrated programs.
- CBPR will enhance a sense of empowerment and engagement in the CAB.
- The programs generated by CBPR will be shown to foster sustainable engagement in integrated care.

**APPROACH**

**PRELIMINARY INVESTIGATIONS**

The aims, significance and approach of this study in part reflect general research lessons of CASD as well as preliminary investigations conducted by the partnership submitting the proposal. The partnership includes Patrick Corrigan who is CASD PI and been supported for more than 15 years by NIMH and NIAAA on research related to integrated care. Raymond Burks, project co-PI, is an African American with lived experience with homelessness and mental illness in the Edgewater-Uptown community. Since 2009, Mr. Burks has been the chair of the Community Advisory Board at Heartland Health Outreach during which time he fostered and sustained community connections with African Americans. Susan Pickett is Senior Scientist for
Behavioral Health at Advocates for Human Potential (AHP) and previously co-PI of the National Research and Training Center on Psychiatric Disability and Co-occurring Medical Conditions (funded for more than 20 years by the US Department of Education) at the University of Illinois-Chicago (UIC). Dr. Pickett has a 17-year history conducting federally-funded research on homelessness and serious mental illness with the minority health care programs at HHO. **Alicia Matthews** is an African American psychologist and health disparities researcher at UIC with more than a decade of CBPR-based health care research with African American and other underserved populations. The focus of her research is on identification of socio-cultural determinants of health disparities and the development of culturally targeted health promotion interventions to address them. **Steven Marcus**, is a statistician at the University of Pennsylvania and CASD co-PI where he directs our research core. **Dror Ben-Zeev** is director of the Dartmouth Thresholds Research Institute, in Chicago and expert in research on mobile technologies for the problems of people with serious mental illness. In terms of general lessons, CBPR was prominent in the CASD charter. The CASD Methods Core includes a section on participatory research and qualitative research. CBPR is written into the more than a dozen studies CASD investigators have conducted on care seeking and service utilization. The CASD executive committee includes the Associate Director of Consumer Affairs, **Janice Parker**, who is an African American with history of psychiatric disability. Table 1 lists CBPR projects of this proposals team and their implications for the proposal herein.

<table>
<thead>
<tr>
<th>Project Title and Funder</th>
<th>Lead Investigator</th>
<th>CBPR Method</th>
<th>Relevance to this NIMHD proposal</th>
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<tbody>
<tr>
<td>Stigma among employers in Beijing, Hong Kong, and Chicago (NIMH-NIAAA)</td>
<td>Corrigan</td>
<td>CAB/steering committee of employers in Beijing, Chicago, and Hong Kong using mixed methods to define hiring problems for people with mental illness.</td>
<td>Cultural translation of social concepts.</td>
</tr>
<tr>
<td>Self-stigma and care seeking (NIMH)</td>
<td>Corrigan</td>
<td>CAB/steering committee using mixed methods with people of color with serious mental illness to map out self-stigma</td>
<td>Doing CBPR with people with psychiatric disabilities.</td>
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<tr>
<td>A multi-state evaluation of consumer operated services (SAMHSA)</td>
<td>Corrigan</td>
<td>CAB/steering committee to develop cross-site protocol to examine mutual help programs for people with serious mental illness.</td>
<td>First experience with eight state effort to develop quantitative protocol in CBPR format with people with serious mental illness.</td>
</tr>
<tr>
<td>Consumer-based approaches to stigma change (CA Prop 63)</td>
<td>Corrigan</td>
<td>CAB/steering committee to describe fidelity and outcome to consumer-based anti-stigma programs.</td>
<td>Active CBPR process to coordinate consumer-based anti-stigma programs of the 300+ California programs.</td>
</tr>
<tr>
<td>African American Chicagoans’ attitudes about mental illness and care seeking (Boeing Foundation)</td>
<td>Corrigan &amp; Matthews</td>
<td>Partnership with African American community on Chicago’s Westside to describe the experience of care seeking among their culture.</td>
<td>Using local churches and other institutions to facilitate mixed methods study.</td>
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<tr>
<td>African American mental health consumers’ satisfaction with care (NIDRR)</td>
<td>Pickett</td>
<td>CAB helped develop interview protocol; African American consumer researchers conducted satisfaction interviews</td>
<td>Working with African American mental health consumers to design and implement interview protocols</td>
</tr>
<tr>
<td>Church-based family support groups for African Americans (UIC Great Cities Grant)</td>
<td>Pickett</td>
<td>Partnership with African American mental health center and African American churches to develop and implement support groups for families of adult relatives with mental illness</td>
<td>Working with African American churches to educate families about mental illness and provide culturally-sensitive support groups.</td>
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<tr>
<td>Development of a culturally targeted patient navigation intervention for LGBT adults. (NINR)</td>
<td>Matthews</td>
<td>Partnership with community based organizations, health care providers, and LGBT CAB to develop patient navigation intervention</td>
<td>Working with CAB to use principles of CBPR to address health disparities among a disenfranchised subpopulation.</td>
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<tr>
<td>Culturally targeted smoking cessation intervention for HIV+ African American smokers (NIH)</td>
<td>Matthews</td>
<td>Partnership with community based organizations and individuals impacted by HIV to develop intervention.</td>
<td>Working with African American CAB to create a culturally appropriate intervention.</td>
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Table 1: Selected CBPR projects of the Investigative Team for this NIMHD proposal
One additional project is especially notable: the Edgewater-Uptown Neighborhood Preliminary Needs Assessment done to inform this grant proposal. Using the HHO consumer advisory board, the investigators behind this proposal convened a focus group of eight African Americans with lived experience who consider Edgewater-Uptown their home (Raymond Burks, co-PI for the proposed project). Coding of the transcripts from the focus group yielded themes consistent with the goals of this project and, more importantly, which informed some of the proposed goals and methods.

- People with lived experience have high rates of health problems in many spheres including diabetes, cancer, respiratory illness, dental health, and nutrition, leading to high rates of unnecessary death.
- Health care is worsened by insufficient clinics, housing, and employment requiring a multi-tired plan to address disadvantage at several levels.
- Case management in integrated care is essential. BUT, beware the potentials of case management. It can lead to bureaucracy and red tape. Peer case managers, the group believed, is an innovation that might significantly promote integrated care in Edgewater-Uptown.

**RESEARCH DESIGN AND METHODS**

Consistent with the NIMHD RFA on CBPR, our research and development activities are divided into two sequential parts:

- **Part 1 (Year 1): establish CAB, develop CBPR processes, define problem, develop intervention:**
- **Part 2 (Years 2 & 3): conduct study to assess intervention’s feasibility/impact and CBPR process.**

**PART 1 (YEAR 1): ESTABLISH CAB, DEVELOP CBPR PROCESSES, DEFINE PROBLEM, DEFINE INTERVENTION:**

During Year 1, co-PIs Corrigan and Burks will use HHO and CASD’s network to establish the Community Advisory Board, develop its organizational framework, begin CBPR to fully define the health problem, continue CBPR to identify community strengths and resources, and use products of problem definition and community strengths/resource summary to develop intervention plan. The primary goal of year one is PLANNING AND DEVELOPMENT.

**Formation of the Community Advisory Board**

We decided to frame the CAB per se in a steering committee and subcommittee structure. Subcommittees would be charged with some of the essential duties of the CBPR process. We tentatively identify three: Community Engagement (responsible for fully communicating with key Edgewater-Uptown constituencies about CAB/CBPR decisions and products), Design & Measurement (responsible for collecting recommendations for mixed method efforts to define the health problem and intervention, followed by defining the pilot evaluation), and Data Management (responsible for guiding the CAB in gathering, managing, analyzing, and interpreting all data of the project). These committees are meant to be populated by at least five members including a majority of people with lived experience, to convene all three years of the project, and
to be co-chaired by a person with lived experience and a CASD colleague from the Steering Committee. Additional committees may be developed by the Steering Committee as needed. The Steering Committee will be responsible for all decisions of the project and will be co-chaired by co-PIs Burks and Corrigan.

Key to the CBPR process is selection of steering committee and sub-committee members. Two principles will guide this process. First, members must be stakeholders invested in homelessness and serious mental illness in the Edgewater-Uptown neighborhood. We use stakeholder decidedly recognizing people with lived experience being central players here but others might be additionally important in the CBPR process; e.g., family members of people with lived experience, service providers, and/or community advocates. We expect selected stakeholders to be diverse: certainly all African American but also diverse for gender, sexual orientation, and other issues discerned at start-up. We will request Steering Committee Members to fulfill a three year term and be paid for their work and travel (as laid out in the Budget). The Second Principle: size of committees must be carefully considered to assure consensual decisions can be made in a timely manner. Our experience suggests a total number between six and ten; the CAB will decide total N at start-up. Many of the procedural activities of the CAB will be conducted by CBPR staff including people with lived experience hired as research assistants for the duration of the project.

The CAB operates IN the Edgewater-Uptown Community. It does this by selecting people with lived experience from this community. It also does this by constantly reminding itself of its charge and seeking feedback from Edgewater-Uptown as the project progresses. The CAB also operates with the resources of HHO and CASD. HHO will provide the support and history of its clinics, services, and community advisory board through the CBPR process. Similarly, CASD will provide technical support and resources through its investigators, Research Core, and Office of Consumer Affairs.

Governance and Process

HHO and CASD already have extensive principles and policies that guide respective CBPR activities of the past, policies from which the Steering Committee might consider at start-up. Three are notable here:

• Decision by Consensus: HHO and CASD colleagues with CBPR experience have mastered skills to make sure decisions represent consensus and not simply majority vote. These skills represent the commitment to necessary time and information so all participants in the Steering Committee are fully informed about the decision. It also recognizes plasticity and varied cultural styles in the decision process.

• Mutual Cross Training: CBPR recognizes the need for ongoing training to fully inform CAB members, training meant to be bidirectional. CASD members of the project have had experience conducting user-friendly seminars on research methods so all CAB members are informed about research design and data management decisions of the process. HHO and affiliated people with lived experience have developed seminars for cultural sensitivity and facilitation to educate CASD investigators without lived experience. Innovative processes will be used to facilitate training. For example, windshield tours will be used to educate CAB (e.g., CASD) members without lived experience (Taylor et al., 2006).

• Full Transparency and Communication: All information developed by the CAB will be publicly available (except for information protected via assurances of confidentiality to research participants). A website will be developed where minutes and other documents will be posted; it will also include a discussion board for community exchange. Project staff will have a call-in line where people might query about the project.

Making Sense of the Health Condition

After organizational structure and operations are established, definition of the health condition is the dominant agenda of Year 1. Mixed methods model we have developed elsewhere (Corrigan & Shapiro, 2010) will be used. These occur in two stages: qualitative generation of health concerns from the community of African Americans with lived experience and subsequent quantitative cross-validation of priorities.

Qualitative Identification of Health Concerns: We will conduct focus groups and key informant interviews of people with lived experience and other stakeholders, all from Edgewater-Uptown. Focus group format will be determined by the CAB addressing questions about participants in terms of stakeholder status, diversity (e.g., gender and sexual orientation), and number for thematic saturation. These will be augmented by one-to-one key informant interviews with the CAB identifying these informants. The interview guide will be fully developed by the CAB but specific issues might include:

• What mental health problems are of concern to people with lived experienced in Edgewater-Uptown?
• What physical health problems are of concern?
• How does homelessness influence these concerns?
• In what ways does access to the current Edgewater-Uptown health system fail to meet these needs?
• How does being African American affect physical and mental health concerns in Edgewater-Uptown?
Focus groups and interviews will be co-led by an investigator and African American with lived experience, with at least one in the pair having significant experience in conducting similar focus groups. Focus groups and interviews will be recorded yielding verbatim transcripts. Transcripts will be coded using Atlas.ti v6.0 for qualitative data management and a grounded theory approach (Peek et al., 2008). Descriptions and definitions reflecting Edgewater-Uptown health concerns will emerge from iterative thematic analysis by independent raters.

Qualitative findings from focus groups and key informant interviews will be triangulated with information gathered from THREE additional data gathering efforts. Identification of important themes related to health is a function of context; focus groups conducted in settings removed from the community *per se* sometimes miss this context. For example, respondents might forget about the particular harm of spreading germs when sharing a homeless shelter with a person coughing because of respiratory disorder. (1) To address this concern, windshield tours (Taylor et al., 2006) will be conducted with small groups of people with lived experience through key contexts of Edgewater-Uptown. With a skilled interviewer, two to three people with lived experience will visit key settings (identified by the CAB) and discuss their health concerns. (2) Ten people with lived experience will be given smartphones and cued four times per day for a week to provide their immediate concerns about health. Research participants will be called and asked a series of questions from the interview guide to obtain their perspectives *in vivo* about Edgewater-Uptown health concerns. (3) These findings will be juxtaposed to archival data which Edgewater-Uptown providers and the Chicago Department of Public Health regularly collect: e.g., the Edgewater and Uptown Community Health Profiles for 2006 included in the Appendix of this proposal.

The qualitative phase will also include assessment of two other issues: community resources and community readiness. One of the concerns of much CBPR health research is focus on community failings and not accomplishments (Minkler & Wallerstein, 2008). Consideration of strengths helps to frame the task as hopeful and achievable. It also helps to identify resources that might be adopted to accomplish the intervention (Corrigan et al., 1995; Wallerstein & Duran, 2006). One model described six dimensions to community strengths and dimensions: existing change efforts, community knowledge, leadership, community climate, knowledge, and resource prevention (Edwards et al., 2000), which have been transposed into useful assessment strategies (Jumper-Thurman et al., 2003; Plested et al., 1999). Using these strategies, the CAB will add queries to the focus group interview guide reflecting these dimensions. Plested and colleagues (2007) have used findings from considerations of these dimensions to make judgments about community readiness. Adapting individual and community readiness to change models (Prochaska & DiClemente, 1983; Rogers, 1983), Plested et al believed communities vary in their preparedness to implement change plans from relative denial of the problem to full confirmation and plans of action. The Plested et al readiness model is beneficial because it suggests community organizing strategies that might be implemented for neighborhoods that are “stuck” in moving forward (cf., Edwards et al., 2000 for a menu of options). The Plested group admits no simple algorithm between dimensions and readiness exists, instead providing recommendations for qualitative assessment guidelines that will help to inform the CBPR process.

**Quantitative Cross-Validation of Health Concerns:** Qualitative assessment facilitates a discovery process where breadth of possible health concerns relevant to a community emerges. Despite being CBPR-directed, the broad description is often unwieldy and does not neatly crosswalk with development of a corresponding intervention. Subsequent goals then are to cross-validate qualitative findings on a larger sample, using these data to establish the priority of mental/physical health concerns of Africa Americans with lived experience in Edgewater-Uptown. Specific questions and format to do this will be decided by the CAB after qualitative data have been analyzed but, based on our experience (Corrigan & Shapiro, 2010) may include considerations of:

- **Survey platform:** This may include online and/or paper-based formats. We have found large segments of the population are computer literate, even people who are homeless. Computer terminals at homeless shelters, laptops, and/or mobile technology might be used to help research participants access questions.
- **Specific questions:** Typically, the quantitative arm of our mixed methods efforts have asked research participants to rate the relevance and importance of information in order to establish a priority from themes that emerged in the qualitative arm. The CAB will select among these kinds of items to prioritize health concerns. The challenge in drafting items here is to capture health conditions beyond simple diagnoses (hypertension), reflecting the subtlety in meaning that emerged in the qualitative process (e.g., “heart trouble that comes from no diet and exercise”). Also, based on earlier work, the CAB might decide to assess co-variates to make sense of priority ratings; e.g., the research participants’ history with homelessness, mental
illness, physical illness, and health care systems. We expect to obtain responses from 100 with lived experience, a suitably powered sample to conduct regression analyses useful for making sense of priorities.

- Data analyses: The scientists and people with lived experience comprising the Data Management Committee will examine central tendencies of data to determine which health concerns re-emerge as priority. We will also conduct regression analyses to determine whether priorities are associated with additional diversity demographics (e.g., age, gender) or personal homelessness, illness or health history.

### Developing an Intervention

The challenge in intervention development is balancing innovative and emerging aspects of CBPR with some sense of what current evidence from the literature suggests is an effective intervention. We propose integrated care as the broadest of frameworks -- i.e., single team provision of both primary and behavioral healthcare in community-friendly settings currently operated by HHO -- on which the CAB will develop and superimpose an intervention which the CAB determined reflects the health concern that emerged from mixed methods project. We outlined candidates for this intervention earlier in the proposal: shared decision making, peer navigators, or mobile health technologies. We see two interactive processes to develop this “superimposed” intervention: mutual cross training so all CAB members understand possible existing interventions and strengths/constraints assessment of Edgewater-Uptown vis-à-vis these interventions. Investigators want to provide a clear and unbiased summary of evidence-based strategies that have been used to address the health care intervention that includes consideration of the costs and benefits of any strategy and, when available, information about the cultural impact of the intervention. The “evidence-base” is meant quite broadly here to include traditional medical interventions but also (and perhaps more importantly) allied health, complementary medicine, faith-based, culture-based, self/mutual help, bibliotherapies, and other interventions. The iterative process will lead to definition of an intervention and beta versions of a service manual as well as fidelity instrument. The service manual will outline principles, practices, and needed resources to implement the intervention in Edgewater-Uptown. The CAB will use guidelines from the Texas Cancer Council to evaluate the cultural sensitivity of materials developed here (Guidry & Walker, 1999).

**Part 2 (Years 2 & 3): Pilot Study that Assesses Intervention Feasibility and CBPR Process**

Part 2 has two goals: pilot test the intervention and document the impact of the CBPR process. Both evaluation efforts will be led by the co-PIs (Corrigan and Burks) with all decisions made by the CAB steering committee. The steering committee may rely on CAB and other ad hoc committees to collect information or make proposals for segments of this process. As in most CBPR planning, we cannot explicitly propose all aspects of evaluation efforts herein because we are uncertain as to the direction the CAB CBPR may take. However, we outline domains of consideration for the intervention and CBPR evaluations.

### Evaluating the Intervention: Feasibility, Accessibility, Acceptability, Impact

The CAB Design and Research Committee will make recommendations to the Steering Committee with extensive feedback from African Americans with lived experience in Edgewater-Uptown. It will draw on the experiences and technologies of CASD’s Research Core as needed. We seek to conduct both process and outcome evaluations of the intervention to address the following questions:

- **Is the intervention feasible?** Using available resources (likely the intervention to be conducted by African Americans with lived experience), is the intervention able to be implemented to the targeted population faithful to protocol.
- **Does the targeted group of African Americans with lived experience find the intervention satisfactory and acceptable?** Do they find component services of the intervention accessible? Do other stakeholders report the intervention acceptable and satisfactory?
- **What kind of impact does the intervention have?** Since the focus is physical illness among people with lived experience, we expect impact to be assessed at several levels outlined in a CASD core conceptual model: increased service seeking and engagement, better targeted physical health, better wellness, and improved quality of life (Corrigan et al., in press).

The CAB will seek to design an evaluation in the first three months of year 2, ready to go into the field in month 18 of the project. The CAB will consider the following additional issues:

**Sample and Recruitment.** The CAB will need to specify inclusion and exclusion criteria for people with lived experience in Edgewater-Uptown. Consistent with other CASD and HHO research, we expect exclusion criteria to be minimal, instead seeking to test the intervention on the broadest array of African Americans with lived experience. The CAB will need to work closely with its Research and Design Committee to determine a reasonably powered target sample which might be feasibly recruited into the evaluation. Based on prior work, we might seek N=30 per cell. Additionally, working with people with lived experience can offer logistic challenges for evaluation; most noticeably loss to follow-up assessments. CASD and HHO have a well-
developed follow-up communication system used in prior research which has yield attrition rates less than 15% for people with lived experience. Given this system and the size of the population of people with lived experience in Edgewater-Uptown, we are confident we can obtain and sustain the research sample.

Design. The CAB will consider design issues to make conclusions about the intervention’s impact. Minimally, we expect the CAB to consider a repeated measures design: baseline and subsequent impact assessments. Based on other work on integrated care, the CAB needs to consider length of intervention to reasonably yield a significant effect; e.g., 4 to 8 months. Length of intervention needs to be balanced with allotted time for the pilot. The CAB then considers the schedule of assessments therein; e.g., 0, 3, and 6 months. Services research typically includes a comparison group in attempting to make objective conclusions about impact. State-of-the-art designs are typically random controlled trials but some groups, especially those disenfranchised by the health system, find these approaches objectionable (Corrigan & Salzer, 2003). Alternatively, a matched control group might be recruited, though in this case, there would be a collection of people with lived experience not receiving services during the project. This is a decision the CAB will make.

Measures. The CAB Design and Measurement Committee will need to propose assessment strategies that represent the process and outcome evaluation goals of the project as outlined above. The first step will be to survey CAB and other African Americans with lived experience about examples of specific domains:

- for process: fidelity, satisfaction, acceptability, accessibility, and participation:
- for outcome: care seeking, engagement, impact on health, recovery, and quality of life.

The CAB will then seek to identify psychometrically sound measures (some developed by CASD) that have been used with this population to assess individual domains. In cases where such measures do not exist in the CAB’s opinion, the Design and Measurement Committee will draft an alternative measure (though this option will be used quite conservatively). Table 2 summarizes candidate measures which the CAB might adopt. Consistent with our other work in this arena, we expect measures to be administered in face-to-face interviews using the CASD computer assisted personal interviewing (CAPI) system.

<table>
<thead>
<tr>
<th>EVALUATION CONSTRUCT</th>
<th>NAME AND DEFINITION OF MEASURE</th>
<th>VALIDATING RESEARCH</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PROCESS EVALUATION</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fidelity</td>
<td>Fidelity Scale (FS): Using format and methods developed for other CASD research, the FS will reflect specific practices that comprise intervention. Independent rater will rate presence or absence of individual; components.</td>
<td>Michaels et al., 2012</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>Consumer Satisfaction Scale (CSS): assesses four dimensions of service satisfaction – environment, strategies, providers, and autonomy – using strategy that diminishes halo and devil effects that bias satisfaction measures.</td>
<td>Corrigan, 1990; Corrigan &amp; Jakus, 1993a,b;</td>
</tr>
<tr>
<td>Acceptability</td>
<td>Acceptability Scale: this is a to-be-developed scale that mirrors CSS structure.</td>
<td></td>
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<tr>
<td>Perceived availability</td>
<td>Perceived Availability of Services Scale: the (PASS) was developed for a previous CASD research project and includes 26 items rated on a 9 point availability scale (defined as “How likely can you obtain the following?”) representing a variety of health services.</td>
<td>Corrigan &amp; Michaels, 2012</td>
</tr>
<tr>
<td>Participation</td>
<td>Hit versus Missed Appointments: Based on CASD algorithms, this index represents the ratio of missed and hit appointments by total opportunities</td>
<td>CASD, 2012</td>
</tr>
</tbody>
</table>

| **OUTCOME EVALUATION**|                                  |                     |
| Health Appointments   | Medical record review. With research participant consent, medical records will be reviewed for appointments with providers made and completed over preceding window (e.g., one month). Prescriptions will be documented and adherence to prescriptions will be assessed at subsequent assessments |                     |
| Care seeking          | Attitudes Toward Seeking Professional Help Scale-Revised (ATSPHS-R). The original ATSPHS is a 29-item scale that has been used in more than 150 studies. We revise for the goals of this study and will use only the 8-item Need scale and 9-item Confidence scale. | Fischer & Turner, 1970 |
| Clinical Engagement   | Service Engagement Scale: The SES is a 14- item scale comprising four factors: availability, collaboration, help-seeking, and treatment adherence. | Johansen et al., 2011; Tait et al, 2002 |
| Personal empowerment  | Empowerment Scale: This widely used scale examines multiple dimensions of perceived personal empowerment in people with serious mental illness including: self-efficacy–self-esteem, power-powerlessness, community activism, righteous anger, and optimism-control over the future. | Corrigan et al., 1999a; Rogers et al., 1997; 2010 |
| Recovery (hope)       | Recovery Assessment Scale: The RAS assesses five factors related to | Corrigan et al., |
CBPR participation might include time taken from other work, irrelevance to primary constituency, and three to overall CAB about process. In addition, all CAB members will be asked to participate in two private interviews during Year 1 to obtain qualitative information about the CBPR process. The CAB will develop the interview guide for these interviews early in its work. Consistent with AHRQ (2001) and other research recommendations (Jones et al., 2008; Mansergh et al., 1996; Sofaer & Gruman, 2003), we expect the interview guide to address key constructs in CBPR process, including perceived partnership efficiency, working group efficiency, and partner equality. After Year 1, interview transcripts will be coded by a subgroup of the CAB, key themes extracted, and findings integrated with participation data to yield a report that will be discussed with the overall CAB about process-to-date. Findings of the report will be used to inform process decisions for Years two and three of the project. Participation data as well as qualitative interviews will continue during Years two and three to fully document CBPR process at the end of the project.

CBPR Outcome. An equally important goal of the CBPR evaluation is to document its impact. Obviously, feasibility and impact of the intervention reflects this. In addition, we adopt the cost-benefit model of Shortell and colleagues (2002) to make direct sense of CBPR impact on CAB and other participants. Costs of CBPR participation might include time taken from other work, irrelevance to primary constituency, and
weakened relationships. These are contrasted to benefits perhaps including fulfilling responsibilities to constituents, promotion of helpful relationships, and improved public profile. The CAB will adapt a quantitative method used by Shortell and colleagues to develop a questionnaire assessing perceived costs and benefits which will augment the community readiness assessment (Plested et al., 2007) outlined earlier in the proposal which will be administered at the ends of years 1, 2, and 3 of the project. Data analyses will be threefold: simple description of costs, benefits, and perceived community readiness at each year; interrelationships among these indices and with the process variables above; and regression analyses examining relationships between CBPR process and outcome variables with findings from the pilot of the intervention.

**Approach Limitations**

There are limitations to the proposal that have influenced proposal decisions thus far and will be considered by the CAB through the CBPR process when the project is implemented. They include:

- A CAB that is finite (by operational necessity) in representation of important stakeholder and other groups related to African Americans with lived experience;
- A tight timeline for the goals of problem definition/description, intervention development, and testing intervention and CBPR process in a community hugely impacted by morbidity and mortality;
- Interaction with an existing service system severely hampered by waning government support; and
- Methodological concerns that result from the narrow resources including sample size and attrition.

Examination of the impact of these and other emerging limitations will be used, alongside findings from the intervention and CBPR evaluations, to inform development of our Phase II application. Despite these limitations, we are confident we have crafted a proposal that strongly addresses NIMHD goals of CBPR.

**Dissemination**

Phase 3 of the NIMHD RFA process is specifically meant to disseminate findings from earlier phases. However, dissemination will still have an important role in this project. Dissemination includes three foci here:

- intra-CAB: regular communication with the CAB of all activities and findings;
- to the Edgewater-Uptown-Uptown Community (especially our audience with lived experience); summaries of key activities especially disseminated at shelters and other settings convenient for the constituency;
- to the broader community of advocates and scientists through the already existing network of contacts which the CAB and others have established. At a minimum, this includes distribution among the existing NIMH-supported e-resources of the CASD (www.casd1.org) as well as related journals and conferences.

**Timeline**

We propose the timeline assuming the project begins at the proposed date of January 1, 2013. The timeline will be adjusted accordingly should the project begin later.

**Year 1: 2013**

**January-April:**
- co-PIs Burks and Corrigan recruit remainder of CAB.
- CAB populates committees.
- CAB develops interview for health concerns and for examining CBPR process.

**April-June:**
- Recruit and conduct focus groups regarding health concerns
- Conduct key informant interviews.
- Transcribe findings. Code and identify themes.
- Begin quantitative cross-validation. CAB interprets findings.

**June-August:**
- Identify candidate interventions. Obtain feedback from stakeholders
- Conduct qualitative interviews regarding CBPR process.

**Sept-December:**

**Year 2: 2014**

**January-May:**
- Finish development of intervention manual and fidelity criteria.
- Develop intervention design and measures. Strategize regarding recruitment.

**June-December:**
- Conduct intervention pilot: feasibility, process and outcome. Continue process and outcome assessment of CBPR.

**Year 3: 2015**

**January-May:**
- Continue/conclude intervention pilot: feasibility, process and outcome. Conclude process and outcome assessment of CBPR.

**June-October:**
- Engage CAB in iterative process to analyze and interpret findings of pilot intervention and CBPR evaluations.

**Nov-December:**
- Disseminate findings to constituency and engage in iterative feedback process. Address sustainability and moving forward including Phase II application.