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Community-Based Partnered Research: New Directions in Mental Health Services Research

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Abstract

Objective—Community-based participatory research has the potential to improve implementation of best practices to reduce disparities but has seldom been applied in mental health services research. This article presents the content and lessons learned from a national conference designed to stimulate such an application.

Design—Mental health program developers collaborated in hosting a two-day conference that included plenary and break-out sessions, sharing approaches to community-academic partnership development, and preliminary findings from partnered research studies. Sessions were audiotaped, transcribed and analyzed by teams of academic and community conference participants to identify themes about best practices, challenges faced in partnered research, and recommendations for development of the field. Themes were illustrated with selections from project descriptions at the conference.

Setting and Participants—Participants, representing 9 academic institutions and 12 community-based agencies from four US census regions, were academic and community partners from five research centers funded by the National Institute of Mental Health, and also included staff from federal and non-profit funding agencies.

Results—Five themes emerged: 1) Partnership Building; 2) Implementing and Supporting Partnered Research; 3) Developing Creative Dissemination Strategies; 4) Evaluating Impact; and 5) Training.

Conclusions—Emerging knowledge of the factors in the partnership process can enhance uptake of new interventions in mental health services. Conference proceedings suggested that further development of this field may hold promise for improved approaches to address the mental health services quality chasm and service disparities.

Keywords

Community-Based Partnered Research; Mental Health; Disparities; Implementation; Dissemination

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Introduction

In the last decade, policymakers, providers, the public, and the research community have paid increasing attention to the quality chasm or gap between the advances in clinical research and the realities of real-world practice.[1] McGlynn and colleagues, for example, found that only 55% of persons with a chronic health condition received appropriate care; quality of care for depression was close to this average, while substance abuse was about 10%.[2] There has also been increasing attention to disparities in access to, quality of, and outcomes in psychiatric care for ethnic minorities and other vulnerable populations.[3–11] Because mental disorders exact a high toll on individuals and families,[12] efforts to address quality gaps and disparities have important clinical, social and policy implications.

It is widely known, however, that traditional information dissemination approaches to transport evidence-based interventions into practice have failed to substantially close the quality gap or reduce disparities.[13,14] Reasons cited for the limited impact of evidence-based interventions in vulnerable communities include: 1) they do not account for community and cultural context, such as the infrastructure realities of safetynet service systems or community cultural norms; 2) they focus on individuals without using community resources to support implementation; 3) research findings are primarily disseminated through scientific journals, not to communities; 4) the gold standard for clinical research, the randomized clinical trial, emphasizes internal validity over external validity or generalizability, and often excludes vulnerable populations.[15–17]

Community-based participatory research (CBPR) is one approach to address such shortcomings of traditional research and information dissemination methods, by engaging diverse community stakeholders in developing and evaluating programs that are embedded and sustainable within the local community and cultural context.[18–27] CBPR has been recommended as a paradigm for increasing the relevance of clinical research through public participation and community engagement.[28–30] Experts in management sciences have recently emphasized action research[31,32] and engaged scholarship,[33] which follow some principles and methods that overlap with CBPR. In CBPR, key community stakeholders are full participants in research design, conduct of the research, analysis, interpretation, conclusions, and communication of results.[34] In this way, CBPR shifts authority for action to the community, and the community-academic partnership.[18,21,24]

Community-based participatory research holds promise as an approach to address the quality gap and service disparities for theoretical, practical, and ethical reasons. Populations more involved in research may be more likely to be committed to its use. Such involvement may increase attention to life circumstances and cultures of participants in intervention design, which could yield more acceptable interventions for that population. For example, consideration of how culture is expressed in local norms and interpersonal interactions has been proposed as critical to developing more respectful and effective community health interventions in mental health.[35] Further, research may be more feasible if community members are involved in its development. Active participation of the user population in research development and implementation increases autonomy, and inclusion of individuals from underserved populations as research leaders can increase social justice and equity in the research development process.[27,36,37]

Despite these potential advantages, the application of CBPR to mental health services research has been relatively recent. Wells and colleagues proposed a conceptual model to integrate mental health services and CBPR principles in intervention design[27] and Bruce et al[38] summarized relevant literature for affective disorders. Based on this model, pilot studies blending CBPR principles and mental health services research methods were

developed,[18,39–42] and these experiences also informed the documentation of a variant of CBPR, community-partnered participatory research (CPPR) that emphasizes equal community and academic coleadership of research.[21,43] However, there is continuing uncertainty about whether interventions using CBPR principles lead to better health outcomes or sustainable community change, as relatively few CBPR studies are interventions or use strong randomized designs.[44] Despite the growth of community-based health intervention projects in the social and behavioral sciences, there is still no systematic, rigorous approach to assessing community capacity and systems change within a local cultural context.[45] Awareness of both these limitations and possibilities prompted leaders of several mental health services research centers to convene a joint conference. The goal of the conference was to explore the promise and challenges in developing the CBPR interface of fields and methods, as a follow-up to the proposed model of integration[27] and preliminary development of experiences with partnered research in these centers. This article describes the conference and the lessons learned.

Conference Design

Planning

The executive planning committee for the conference included academic and community partners from four National Institute of Mental Health (NIMH) Centers: UCLA/RAND, Washington University in St. Louis, Cambridge Health Alliance (CHA)/Harvard Medical School, and Georgetown University. The executive committee planned the conference in phone calls and follow-up emails. Different centers took responsibility for sections, maintaining a balance in leadership among centers and between community and academic leaders. The executive committee developed a conference website and an evaluation design including digital recording of almost all sessions, transcriptions of recordings, and note-taker/recorders to provide immediate feedback. The committee invited other partnering research groups and also asked each center to nominate partnerships for participation as well as additional programs and centers for geographic balance. Costs of the conference were covered by discretionary funds of the participating centers; we did not use separate conference grants. Research procedures for the evaluation were approved by the IRB of the host institution (RAND).

Participating Research Partnerships

The executive committee also invited investigators from the research center at Cornell and research programs affiliated with the UCLA/RAND Center in southern United States (University of Arkansas, University of Mississippi, Tulane University, and Tugaloo College) so that participating partnerships were drawn from four census regions of the United States. Each center followed its own procedure to select partners and projects according to its CBPR goals and available budget. Participants included staff from NIMH and other National Institutes of Health (NIH), the Robert Wood Johnson Foundation, the Substance Abuse and Mental Health Services Administration (SAMSHA), and an expert consultant in CBPR (Dr. Nina Wallerstein). Community partner attendees represented an array of agencies, including nonprofit health organizations and community associations, for-profit health consulting and healthcare organizations and providers, schools, county and state health and human service departments, faith-based programs, and educational institutions (Table 1). Nearly 80 people attended over two days, with approximately 40% community partners and 60% academic partners participating.

Conference Structure

The two-day conference was held on July 24–25, 2006 at the RAND Corporation in Arlington, Virginia. Day 1 of the conference opened with an introduction and overview. The

structure of the conference included a series of plenary sessions and breakout groups centered on themes related to the CBPR experience (eg, Sharing a Vision, Building Relationships, Evaluating our Partnerships). Facilitators used mutually identified topics to guide discussion in each content area: challenges, strategies (successful and unsuccessful), community and academic research priorities, lessons learned, partner contributions to improving services and scientific advances.

All breakout groups were followed by summary sessions with report-backs from participants, and synthesis of information among all conference participants. Day 2 of the conference opened with comments from staff of NIMH (Dr. David Chambers) and SAMSHA (Dr. Crystal Blyler), concerning their priorities for partnered research and application of CBPR principles in services, respectively. The topics of the breakout groups for Day 2 were guided by feedback from the experiences of the participants during Day 1. One executive committee member (Wells) circulated among groups, summarized the feedback across groups at the final plenary discussion, and led a discussion of next steps and future directions. The executive committee issued an invitation for follow up planning efforts. Loretta Jones, from Healthy African American Families, closed the conference with a ceremony where each participant took a key and considered what doors (eg, partnerships, vulnerable populations) to open up in their communities.

Analyses

All audiotapes from the workshop breakout groups were transcribed for analysis. The executive committee for the conference including academic and community partners that volunteered to participate in follow-up efforts at the conference divided into workgroups, largely falling along lines of individual centers, with 2–4 community and academic members per group. Each work group analyzed the transcripts taking one to two breakout groups. A priori questions were used by the reporters of the breakout groups to synthesize the discussions of that day. They were also asked to develop themes, examples and an overall synthesis. Groups were given flexibility in how community partners participated (eg, full review, working in pairs with academics, reviewing academic comments and editing them). Issues raised in these sessions were summarized by note takers selected by the group.

Those notes and syntheses were used by the executive committee to further aggregate the qualitative data across breakout groups. Repeated themes, appropriate to the *a priori* questions that guided the conference and those that were generated within the discussion groups, were then extracted by the executive committee without use of software. Then, the first and second authors further distilled the themes by aggregating those themes that percolated in several breakouts so as to minimize repetition. Our approach followed a comprehensive synthesis around the identified themes to allow for details and examples that would elucidate the richness of the groups' discussions.

Results

Themes were identified in five main areas: 1) partnership building; 2) implementing and supporting the work of community-based research partnerships; 3) developing creative dissemination; 4) evaluating the impact; and 5) training. Findings were also synthesized into recommendations for the field.

Partnership Building

Primary themes that emerged included the importance of transparency regarding incentives for different stakeholders to come together, partner priorities and the timeline of the project (Table 2). Creative examples were given by participants of ways in which they managed

shifting priorities of participants over the course of the partnerships. For example, the Witness for Wellness project had a policy in which participants could get "on and off the bus" as they were able to participate, making a shifting membership explicit and recognizing that such shifts are not an indicator of failure. Developing a sustainable infrastructure for the partnership and for the service initiatives launched through the partnership was a major concern since funding for research was time-limited. The resources required and the labor intensity of partnered research was a constant theme, as these factors can curtail or enable participation. The data collected in evaluating partnered research are often qualitative, which is very labor intensive, and innovation is required to capture actual process and outcomes in a time sensitive way.

Implementing and Supporting the Work of Community-Based Research Partnerships to Improve Quality of Care

Beyond establishing the partnership, specific challenges in implementing and supporting the research were noted by participants (eg, improve the quality of mental health services). To be successful in the work, it is necessary to marshal community support, transform university and community agency policies, develop ongoing trust and commitment among members, and balance the professional demands of the work (Table 3). The implementation of partnered research can often affect the organization of how a partner does business. Examples were given in which organizational policy change was the primary goal of the research collaboration, as in the School Systems Enhancement Project where CHA and the Graham and Parks Alternative Public School documented changing systems in a public school to improve the mental health and functioning of immigrant children. Another grant-funded partnership led to a broader, long-term commitment by a school of social work to forge agency partnerships for educational and service-improvement purposes.[46] Other examples were given in which change at the systems level were initially unintended, such as how planning for a partnered research pilot concerning depression services led to new contracts between the Los Angeles County Department of Mental Health and community-based organizations.[47]

Developing effective work to improve quality of care was viewed as requiring sufficient time and effort of the partnership, even when that effort was not fully compensated by funding or available resources. For community organizations, it was noted that this often meant participating in meetings and dissemination activities without a specific budget. For research staff, the time to build a strong partnership and develop a trusting relationship with community members was viewed as competing with other activities (eg, writing articles, teaching courses, submitting grant applications) that are, according to department chairs, more salient for career advancement.

Developing Creative Dissemination Strategies

A key theme was the importance of knowledge transfer in the development and implementation of a dissemination plan of the findings. Without a dissemination plan, research has little impact in the real world.

Innovation and development of new strategies to disseminate information on the partnership and partnership process was also emphasized. Dissemination of data on outcomes of interventions and partnered research efforts were viewed as essential to foster buy-in for community-partnered research (Table 4). Suggestions included using a partnered process that builds community capacity to analyze and publish findings.[48] Another level of dissemination discussed was efforts to create a manual with lessons learned from the research and community engagement process to standardize steps leading to partnered research and improved quality of care.[49]

Evaluating the Impact Including Evaluating the Partnerships

Improving the quality of science was noted as important so that the field of CBPR is improved and accepted, and interventions adopted and enhanced. Under the theme of evaluation, the concern was that the partnership itself often lacks an evaluation (Table 5). The groups recommended that partnership evaluation be institutionalized, and that funding go to the development of a best practices model for evaluating partnerships. Some major issues to evaluate were balance of power (in terms of who controls the money), lack of equality, lack of respect for community experience and capacity, shifts of power during the project that are appropriate to partner interests and strengths, and sharing leadership in grant submissions.

Training

An important theme was sufficient training in partnered research for community partners and young academic investigators (Table 6). Participants noted that such trainings would need to be offered from both perspectives: community to academic trainings, and academic to community trainings. By developing trainings and materials for partnered research, new partnerships could learn from the experience of older partnerships.

Recommendations for the Field

An end goal would be to make partnered research a mainstay approach across disciplines, if data existed to support the importance of this undertaking. This would involve creating buy-in for community engagement in research from the scientific community, community agencies, and funding agencies. Evaluation was viewed as still needed in order to be able to attribute outcomes of partnered research projects to the partnership process. Dissemination of findings once again weighed in as essential to impact the field. A shift towards conventionalizing partnered research was thought to require funding support for partnerships that were built into grant mechanisms, as well as including experienced CBPR researchers and community members as members of grant review panels.

Structuring the Partnership—The groups recommended forming partnerships as a win-win situation. Understanding and communicating the goals and needs of the community along with those of the investigators is vital not only as the partnership is getting structured, but also as it progresses. To achieve a shared vision of the partners, it is necessary to develop strategies to better understand each other's worlds, including engagement of community members in research activities to understand what research has to offer and for researchers to sit on community advisory boards to learn about what the community has to offer.

Setting Up the CBPR Project—One important component in the early stages of a CBPR project is to make expectations about the role of each group clear from the early phases of the project (pre-grant period), so that groups are not disappointed with the tasks and process as it unfolds. Simultaneously, the partners should outline the objectives from the very beginning in goals for community and for academic institutions. Becoming aware of the funding agency's agenda is critical to ensure success. Also relevant is to require a partnership evaluation, along with other evaluations relative to implementing the partnership and improving the quality of the science and dissemination. The groups also recommended paying attention to the end user to make sure that the generated information has relevance.

Developing Creative Dissemination—A crucial aspect of CBPR is the efficient dissemination of methods to evaluate program outcomes and partnership success. Effectual dissemination entails both breaking ideas and process into small pieces to identify what can

be done on a daily basis to share lessons learned, and also put the pieces together to collaborate and disseminate the lessons learned. The groups also discussed the importance of assisting media in framing encounters that happen on a daily basis from a mental health perspective and from a social activism perspective so that mental health has a more prominent role in the media. Another recommendation was the development of a toolkit on how to adapt and disseminate evidence-based practices in the community to establish community validity.

Training—Different workshops should be provided to train young investigators in CBPR methods, including processing the data so that they are useful to the community groups and agencies.

Discussion

The themes and topics identified in the meetings at this conference underscore the emerging knowledge regarding the process of CBPR and the factors that contribute to or limit its success in mental health services research. They demonstrate the components of the CBPR process that are critical to its success as well as those where continued work is needed to address inherent tensions in the partnership process, in the development of a standard evaluation process, and strategies to address institutional constraints. In addition, the conference themes suggest that community partnered research can contribute to improved interventions with greater contextual and cultural validity that may result in better quality of care for diverse populations. Throughout the conference themes a clear blueprint for enhancing the strategies that facilitate development and implementation of effective mental health interventions emerged. Some have recently argued that close attention and analysis of the process and implementation of an intervention should precede measurement of the actual health outcomes,[50] given that these factors may substantially improve chances that a new intervention might have an effect.[51] Evidence suggests that community involvement enhances intervention quality, and that the most rigorous research designs in community partnered research are also associated with the strongest health outcomes.[44] Continued attention to embed community partnered strategies as part of a rigorous intervention process could enhance efforts to uptake interventions and improve the quality of care.

Particularly when addressing issues of mental health disparities, attention to issues of research process and implementation as part of the intervention process appear to be closely tied to subsequent improvements in quality of care. For example, a community-based participatory project with Aboriginal people in Canada found that the partnered approach was critical to overcoming barriers to mental health service provision, and that local management and delivery of quality of mental health services improved dramatically.[52] Although this study did not track specific mental health outcomes, the barriers to delivery of care were effectively addressed through a participatory approach, making the next step of evaluation of mental health outcomes possible. Others have applied partnered research strategies to encourage uptake for physicians in administering evidence-based practices – another way in which community-based strategies that target process and implementation issues can lead to improvements in quality of mental health care.[53]

Community participatory strategies can also improve quality by assessing the specific components of partnered research that lead to sustained improvement in the community after the research has ended. In particular, efforts towards training and developing multidisciplinary partnerships within the community have the potential to build infrastructure to support sustainability of clinical research findings. The conference themes identified many training topics focused on increasing the capacity of participants

(researchers and community) to learn to work from each other, deal with bureaucracy, manage institutional review boards, and learn best practices and cultural awareness.

Further, the emphasis on developing strategies for evaluation across themes provides the means for testing what components of partnered research can lead to sustainability, hence further informing the goals of long-term quality improvement in real-world settings. There is a need for standardized measures for process and evaluation outcomes for partnership, both qualitative and quantitative.[44] The conference themes suggest that development of these standardized practices and measures require innovation and creativity, as well as an understanding that measures should be flexible in adapting them for different cultures and languages.[52,54] In addition, there is a need for standardized measures to evaluate the link between partnered research and actual health outcomes. The development of such measures is in its infancy. Although there are good measures for evaluating dimensions of group dynamics within community-based participatory research,[55] there is less work identifying the constructs and measures of community-based participatory research that are linked to positive health outcomes. However, recent work is attempting to identify how CBPR can reduce disparities in depression outcomes by increasing implementation of quality improvements in underserved communities.[56] One major challenge of measuring the association between partnered research and health outcomes is the potential for lack of generalizability to other communities and settings, due to the fact that the work is often deeply embedded in specific contexts. To address this challenge, more research that includes multiple sites is needed to replicate findings across different communities using partnered research approaches.[57,58]

The conference was developed to explore how application of CBPR to mental health services research could address the research practice gap in mental health research. In that regard, the focus in the discussions on communication between researchers and community members, as well as the ideas generated for shared models of dissemination, hold potential to increase the visibility of research and the importance of dissemination in the community. By working in partnership from the beginning, CBPR methods avoid creating dynamics in the first place that lead to gaps between knowledge base and the realities of real-world practice that lead to service disparities. In particular, shared conversations about trust, power and access to research information may build a foundation for knowledge generation that is truly informed by the experiences of those the interventions are meant to affect. The promise of CBPR lies not only in its potential for improving community-based research per se, but also in its potential for improving the relevance and process of scientific investigations, dissemination and implementation of evidence-based practices in many areas. Although utilizing these principles may slow the research protocol at the front end, the expectation is that we can encourage the uptake of research findings and, subsequently, reduce mental health disparities and improve quality of care in the real world.

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Table 1

Organizations, partnerships and projects represented

Organization	Partners	Projects
Cornell's Weill Community-Based Research Partnerships in Geriatric Mental Health	Westchester County Department of Senior Programs and Services	Research Network Development Core - integrates mental health into social, nutritional, and medical activities
	Visiting Nurse Association of Hudson Valley	Home Healthcare Research Partnership - depression detection improvement, administration data for research - effectiveness & implementation studies for depression and home health care
Georgetown University's Center for Trauma and the Community	Primary Care Coalition of Montgomery County, Maryland Greater Baden Medical Services Inc Unity Health Care, Inc Prince George's Health Department, Maryland	Montgomery Cares Behavioral Health pilot (PCC and GTU Project) - culturally-sensitive behavioral health services for screening and treatment - evidence-based collaborative care services - evaluations of clinical, process, and economic outcomes
University of Arkansas	Mental Illness Research, Education, and Clinical Center	- depression intervention to assist ministers - community based outpatient clinics in partnership with other providers
UCLA's Health Services Research Center	United Behavioral Health (a health plan)	- provider incentives to improve depression care
	Healthy African American Families RAND, Drew University	Witness for Wellness - workgroups to conduct research targeting depression in Los Angeles
	Los Angeles Public School System	- school-partnered intervention for trauma
University of Mississippi/ Tugaloo College	Historically Black Colleges and Universities Faculty Development Network	- new partnership with projects in the development phase
University of Southern California	County Emergency Department	- improving depression care for medically indigent - project for depression care targeting older minorities - patient centered depression care project featuring self-management of depression and medical illness
Washington University in Saint Louis	Missouri state agencies	- improving mental health care in social services through screening, assessment, referral, and care coordination - improving community long-term care response to late life depression
Cambridge Health Alliance/ Center for Multicultural Mental Health Research	The Right Question Project, Inc.	- pilot to empower and activate mental health patients in their health care - formulating questions and focusing on key decisions of their health care

Organization	Partners	Projects	
	Graham & Parks Alternative Public School	-	school system intervention to maximize mental health promoting capabilities
		-	multiple factors & system patterns leading to problem behaviors in poor immigrant children

Table 2

Partnership development challenges and recommendations

Challenge	Recommendation
Conflicting agendas among stakeholders; competing priorities (eg, financial interests, staff availability; timing).	Negotiate an initial written document detailing roles, time commitments, expectations, and goals, including ownership of data.
Community partners' needs and preferences differ from researcher's agenda; power dynamics shift over the different stages of the research.	Be flexible in expectations and rules for partnership development; recognize that conflicts may be unavoidable and effective partnership development takes time.
Ensuring long-term continuity as different stakeholders may have evolving work charges.	Make a shifting membership explicit; recognize that such shifts are not an indicator of failure.
Structural issues: institutional and funder policies conflict with partnership development; bureaucratic guidelines complicate exchange of financial resources, staff turnover, service system changes, and maintaining involvement of parties; physical distance and limited transportation deter participation.	Maintain researcher presence in community discussions both before and after the funded phase to build long-term trust despite structural constraints; work together to develop a sustainable infrastructure for the partnership and for the service initiatives launched through the partnership.
Resource and labor intensity of partnered research curtail participation in and documentation of the research.	Varied solutions based upon individual nature of partners and cultures; recognize time and resources to document the partnership process; build relationships before data collection; explore innovative means of capturing process and outcomes.

Table 3

Implementation challenges and recommendations

Challenge	Recommendation
Difficult to marshal community support, and transform university and community agency policies, to facilitate work.	Explore projects where organizational and policy change are the primary goal of the research collaboration.
Difficult to sustain mutual trust between academic and community partners and with funders of services programs and research.	Utilize community expertise to identify and prioritize problems for quality improvement; utilize academic partners for expertise on available treatments and services.
Difficult to find sufficient time and effort for the partnership, given effort often not fully compensated by funding or available resources.	Help community members and researchers see importance of investing time; be respectful of the demands for time; develop awareness of time demands in community; academic and policy circles and among funders

Table 4

Dissemination challenges and recommendations

Challenge	Recommendation
Sharing products of partnered work with all stakeholders, particularly with those that will lead to uptake of information or intervention in the community.	Encourage mutual participation in academic and community meetings and open "report backs" to the community; share publications; encourage data dissemination by the funding source; make information available in blogs, web pages, radio programs or newspaper articles.
Difficult to develop innovative strategies to disseminate information on the partnership and partnership process.	Encourage community/academic projects: partnership CD, a bibliography of resources for website, journal dedicated to partnership in research, Power Point presentations for use in both venues.
Challenging to analyze and disseminate data on outcomes of interventions and partnered research efforts to encourage community buy-in.	Build community capacity to analyze and publish findings; create manual with lessons learned from process to standardize steps leading to partnered research and improved outcomes.
Lack of credit given to community participants and lack of input on projects from all partners.	Plan joint presentations and publications for recognition of community and agency support; ensure full co-ownership of data and results.

Table 5

Evaluation challenges and recommendations

Challenge	Recommendation
Vision of benefit to the community is lost given complex nature of the research and the bureaucratic systems in which it exists.	Document best CBPR practices thoroughly: What works? What does not work? How does CBPR improve uptake of study findings? What is the added value of having community partnerships?
Lack of an evaluation of the partnership itself.	Institutionalize partnership evaluation; fund development of a best practices model for evaluating partnerships.
Lack of clear communication between partners, not listening or incorporating partner points of view, and lack of respect for different types of experience.	Link variations in communication characteristics to positive/negative outcomes, including effectiveness of partnered work, eg, an effective intervention or building community capacity.

Table 6

Training challenges and recommendations

Challenge	Recommendation
Lack of sufficient training in partnered research for community partners and young academic investigators.	Offer trainings from both community and academic perspectives; include trainings by funders; generate templates for agreements, eg, formal memoranda of understanding; less formal roles and responsibilities.