Achieving Health Equity through Community Partnerships: Innovations in Community-Based Participatory Research

Meeting Report of the 28th Annual International Symposium of the Center for Translational and Basic Research (CTBR) in partnership with Weill Cornell Clinical and Translational Science Center (CTSC).

The full-day symposium took place on Monday, April 13, 2015 at The Kaye Playhouse at Hunter College of CUNY.
Achieving Health Equity through Community Partnerships: Innovations in Community-Based Participatory Research

Overview

Hunter College's Center for Translational and Basic Research (CTBR), along with Weill Cornell Clinical and Translational Science Center (CTSC), chose to focus their 28th Annual International Symposium on innovative ways to engage community member participation in research. Community-Based Participatory Research (CBPR) is a collaborative approach in which researchers and community partners work together to design, implement and disseminate the findings of research studies that address topics important to the communities of interest. CBPR partnerships aim to build trust and equitable relationships that will result in scientifically sound research that is relevant and meaningful to the community members. Befitting the collaborative nature of CBPR, this year's symposium consisted of complimentary panels with academic researchers and community members presenting together rather than individual speakers. Attendees were introduced to the history of CBPR by the founder of the Detroit Community-Academic Urban Research Center, a pioneering institution that has had an enormous impact on the development and promulgation of CBPR and its underlying concepts. Three panels followed highlighting CBPR efforts in Detroit as well as efforts in New York. The day was capped off by a keynote presentation by the founding Director of the Center for Health Equity, newly established by the New York Board of Health.

Sponsorship

This conference and meeting report were made possible with support from the Weill Cornell Clinical and Translational Science Center (CTSC), Hunter College of the City University of New York, the National Institutes of Health, National Institute of Minority Health and Health Disparities – 8 G12 MD007599-27 and the Clinical and Translational Science Awards – 2UL1TR000457-06.
The Detroit Community-Academic Urban Research Center

In her introduction, Liz Capezuti, the Director of the of the Center for Nursing Research at the Hunter-Bellevue School of Nursing, called the Detroit URC "the best exemplar of a community based health partnership in the United States." The keynote presentation that opened the symposium amply demonstrated how the Detroit URC came to fill that role over its twenty year history. Barbara Israel is an academic researcher at the University of Michigan interested in the social and physical determinants of health and health inequities, and Angela Reyes founded the Detroit Hispanic Development Corporation to help the at-risk youth in her community. Together, they described the research partnership they forged twenty years ago and how it works today. In the panel discussion following their keynote address, they were joined by community member Zachary Rowe and nursing professor Barbara Brush to further expand upon how academic-urban partnerships are established and maintained. All of the panel members spoke of the benefits and challenges inherent in these partnerships, and all agreed that though the challenges are hardly trivial they are usually outweighed by the benefits. They described the structural components of their Center that facilitates, and more importantly, sustains long-term partnerships.

NY Community Advocates and Academics

The day's first panel of New York City community advocates and academics focused on two very different populations - youth with, or at risk for, HIV and women with physical disabilities - and how CBPR has been harnessed to address their very different needs. The Complementary Strengths Research Partnership was born out of Jennifer Tiffany's idea that building programs with strong youth participation, and heeding the voices of the participants, could stem the tide of HIV. She and her partner in this venture, Rebecca Gallagher, developed a scale to rate the efficacy of various types of youth programming based on how much the kids feel actively involved. Youth participants as well as program staff and researchers collaborated on the scale that has since been used by other community based organizations throughout the city to judge their own efficacy. Then Marilyn Saviola spoke about her lack of access to health care. It is not due to poverty, racism, or poor public policy; she is in a wheelchair, and literally often cannot access doctor's offices and diagnostic machines. She created the Women's Health Access Program to make sure that women with physical disabilities can get the medical care they need. Along with her academic partner, Hunter College School of Nursing Professor Anita Nirenberg, they have developed and implemented curricula for nursing and medical school students to understand the unique challenges faced by those with physical disabilities in obtaining quality health care.
Palliative Care and Pain Relief in Older Adults

The symposium's last panel highlighted two other advocate-academic partnerships in New York City, one focused on reducing health disparities among chronically ill older adults in East and Central Harlem and the other addressing pain disparities at the community level in senior centers. Daniel Gardner, an Associate Professor of social work at Hunter College, and Fay Rim, the Chief of the Department of Pain Medicine and Palliative Care at Metropolitan Hospital Center, teamed up to look at the disparities in palliative care and hospital use faced by older adults of color in East and Central Harlem and identify interventions to better meet their needs. Cary Reid, the Director of the Cornell Columbia Translational Research Institute on Pain in Later Life at Weill Cornell Medical College, and Evelyn Laureano, the Executive Director of the Neighborhood Self-Help Older Persons Project (SHOPP) in the Bronx teamed up to adapt an extant Arthritis Self-Help Program for use by older Hispanic and African Americans. The older members involved helped shape the program by giving feedback directly to the researchers assessing it.

The Center for Health Equity

This past September, Aletha Maybank founded the Center for Health Equity within New York City's Department of Health. It is the newest such center in the country. There exist vastly different health outcomes between neighborhoods in our city, and this office aims to close that gap. Neighborhoods that have historically been poor and filled with minority residents - primarily black and Hispanic residents - suffer from higher rates of death by diabetes and AIDS and infant mortality, increased hospitalizations due to asthma and drug abuse, and decreased lifespans compared to their more affluent white neighbors. Maybank insists that these disparities in health are a result of racism, injustice, and bad public policies, not biology. She has resurrected a system of neighborhood offices, initiated by a collaboration between the Department of Health and the American Red Cross between the world wars, to engage local community members to take active roles in promoting and improving their own health outcomes.
A Community-Based Participatory Research Approach Aimed at Achieving Health Equity

Speakers:

- Barbara A. Israel, DrPH, MPH, Director, Detroit Community-Academic Urban Research Center
- Angela Reyes, MPH, Executive Director, Detroit Hispanic Development Corporation

Highlights:

- CBPR is a paradigm shift on the part of researchers - rather than viewing study populations as unfortunate subjects to be examined and helped, these populations are viewed as individuals with useful knowledge and strengths to be harnessed.
- CBPR is an approach, not a method. Researchers must be willing to learn about and validate a community's history and culture in order to enter into a research partnership with that community.
- The Detroit URC is one of the first and best examples of an organization that fosters many CBPR partnerships.
- The Healthy Environments Partnership, only one of many fostered by the Detroit URC, identified community specific contributors to cardiovascular disease risk and implemented walking groups which have cut that risk.

Rationale for a CBPR Approach

Environmental stressors - like unemployment, violence, and poverty - are proven risk factors for poor mental and physical health. Members of low income communities and communities of color disproportionately bear the brunt of these stressors and the diseases they enable. Yet members of these communities have not historically benefitted from traditional "drive-by" research. In this model, academics parachute in, demand access to at-risk populations without ever bothering to even try to understand the cultural milieu of those populations, and finally leave community members feeling used - without any more useful tips or information than they had before the research began. Such research studies rarely generate useful health interventions for the populations they are ostensibly helping, since they are often designed in ignorance of that population's mores and needs. Rather, they all too often only serve to engender a strong distrust of academics on the part of the population being studied. Because far from being mere fodder for research studies, these populations are comprised of individuals with knowledge, skills, and expertise.
Community-Based Participatory Research (CBPR) seeks to address health inequities by harnessing the strengths of the population under study. It is not a research method; it is an approach whose principles of inclusiveness can be applied to a number of research methodologies. It is best suited to those studies that aim to identify determinants of health and health disparities; those that hope to better understand specific communal concerns; and those designed to implement or evaluate potential health interventions and policies. CBPR balances research and action for the benefit of all partners - the academic researchers as well as the community members enrolled in a study. Key principles of CBPR include involving all of the partners in all decisions involved in the study design and disseminating any findings to all of the partners. This way, everyone involved can walk away with satisfactory feelings of responsibility and ownership.

**Detroit Community-Academic Urban Research Center (Detroit URC)**

The Detroit URC was established in 1995 as one of three urban research centers in the United States. (The other two were in New York and Seattle.) Its stated goals are to foster and sustain CBPR partnerships in Detroit focused on promoting health equity; to promote the CBPR approach to research studies and conduct CBPR studies; to enhance the community’s capacity to promote health equity through advocacy; and to translate research findings into new policy. The Detroit URC has supported ten partnerships that have engaged in thirty research studies, and in all of them, community members are active in the decision making that goes into designing a research study. They have won grant money and published research reports; but just as importantly, they have forged strong connections between the African-American and Latino communities in Detroit, improved the health of the members of those communities, and have developed an unprecedented sense of trust between the members of those communities and the University of Michigan.

**The Healthy Environments Partnership**

The Healthy Environments Partnership is just one program run under the auspices of the Detroit URC. It is a partnership between the Detroit Hispanic Development Corporation, the Eastside Community Network, the Friends of Parkside, community members at-large, the Henry Ford Health System, the Institute for Population Health, and the University of Michigan School of Public Health that has been in place since 2002. This partnership aims to "examine aspects of the social & physical environment that contribute to racial & socioeconomic inequities in cardiovascular disease (CVD), and develop, implement & evaluate interventions to address them."

HEP was funded by the NIH in 2000, and was originally intended to be only a survey; it did not initially include an intervention. But five years of basic research resulted in policy changes and intervention recommendations. In the year 2000, cardiovascular mortality
rates in Detroit were about one and a half times the national average, and they were even higher in low income areas of Detroit. HEP studied the impact of air quality, access to groceries, land use, and the built environment on cardiovascular health. All of these social and environmental factors, in addition to individual lifestyle choices, can affect health. For example, liquor and convenience stores are much more prevalent in these areas than are grocery stores; the people there therefore predominantly have access to high fat, high salt foods with poor nutritional value, which promote obesity, which promotes CVD. Moreover, poor sidewalk conditions, the lack of police presence, traffic, and stray dogs all conspire to limit people's physical activity, again raising their risks for CVD.

Like all CBPR projects, HEP has its own Steering Committee made up of community members and researchers. The committee meets monthly to design the study parameters, to collate opinions from community members who don't sit on the committee (gleaned from focus groups and town meetings), and to reflect on their progress. Based on the above findings, the steering committee recommended that people form walking groups. This would serve to increase their physical activity, and the group structure would provide safety and support. The committee came up with an ingenious staggered design wherein some groups started walking a few weeks later than others; this provided sedentary groups to act as controls for the groups who started walking first while still allowing all of the study participants to reap the benefits of the recommended intervention. The walking group intervention resulted in reduced cholesterol levels, blood pressure, body mass index, blood glucose levels and depressive symptoms among participants.

References


http://www.detroiturc.org/about-cbpr/cbpr-principles.html

http://hepdetroit.org/en/hep-overview
Panel Discussion: Detroit Community-Academic Urban Research Center

Panelists:

- Barbara L. Brush, PhD, ANP-BC, FAAN, Professor, Division of Health Promotion and Risk Reduction, University of Michigan
- Barbara A. Israel, DrPH, MPH, Director, Detroit Community-Academic Urban Research Center
- Angela Reyes, MPH, Executive Director, Detroit Hispanic Development Corporation
- Zachary Rowe, BBA, Executive Director, Friends of Parkside

Moderator:

- Liz Capezuti, PhD, RN, FAAN, 2015 Symposium Committee Chair, William Randolph Hearst Foundation Chair in Gerontology, Assistant Dean for Research, Director, Center for Nursing Research, Hunter College School of Nursing

Highlights:

- CBPR partnerships take a lot of time, especially at the beginning when the details surrounding decision-making and other processes are laid out. But this time spent on process at the outset is indispensable in establishing trust and getting results later on.
- The Detroit URC runs the Community-Academic Research (CAR) network to help community based organizations and academics with similar interests and goals find each other.
- CBPR has real challenges, like establishing trust between academics and community members and working together in the face of significant cultural differences. But they are outweighed by the benefits, like policy changes, health interventions, and the relationships that can grow despite the cultural divide.

This panel of academics and community members affiliated with the Detroit URC was tasked with explaining the real nitty-gritty of how CBPR gets done. They addressed how partnerships are established and sustained, and they discussed the benefits and challenges of the approach to all partners involved, on the individual, organizational, and communal levels.
Developing, maintaining and sustaining CBPR partnerships

Zachary Rowe, a founding member of the Detroit URC Board, started the proceedings by outlining how partnerships are initiated and developed. First and foremost, he said, is deciding who gets to represent the community. "That's a toughie," he noted, but over time he said that they learned to start small, involving only a few highly regarded community based organizations (including faith based organizations) and leaders. Academic partners can be engaged after the support of community members is assured. Once a prior history of positive working relationships is in place, subsequent partnerships become easier and easier.

One theme that came up time and again was that these partnerships take a lot of time. All partners get frustrated, because no one wants to focus on the process of how things get done; people want results. But Angela Reyes stressed that the time spent on process at the outset is essential in establishing the trust between partners that has allowed these relationships to last, and even flourish, over the years. All partners must find a way to work together amid ethnic, cultural, social class, and organizational differences - not only between academics and community members, but often between different community based organizations that may have conflicting, or at least different, priorities. These partnerships often use informal democratic processes and consensus decision-making to define a productive, collaborative, and equitable partnership. Zachary spoke of the 70% rule, wherein each individual on a steering committee must be able to get their minds 70% behind any decision. Basically - can you live with this?

Building the capacity of community and academic partners to engage as equitable partners

Even if everyone has the best of intentions, the Detroit URC provides training activities to all partners - populations in Detroit and researchers at the University of Michigan, only forty-five minutes away - to maintain successful partnerships. Many community members and community based organizations are wary of engaging in academic research. Their past experience, if any, may have entailed researchers wanting to come in and survey their activities vis a vis diabetes, or domestic violence, or obesity, or whatever; researchers would come in and out with their questions, but then disappear. Not only did they not give anything back to the community, they took valuable resources - notably time - from the community members they studied. CBPR workshops show these populations a different model, where community members are involved in every aspect of the research study, from hiring to budget development. They get paid for their time and effort, and they get authorship of papers coming out of the study. Once the Detroit URC makes them aware of these rights, they might be more willing to participate in research.
The Detroit URC also runs the Community-Academic Research Network (CAR-Network), which matches community-based organizations with researchers based on the interests of both parties. Both sides can apply on the URC website, which also contains profiles and a searchable member directory. The CAR network currently includes 137 community and academic members interested in collaborative research in Detroit, and it catalogs and disseminates research topics identified by leaders of community-based organizations and academic researchers as being of interest. The Detroit URC also holds informal social gatherings for members of the CAR network.

**From the aya collaborative to the partnership for family health and housing**

Barbara Brush, an Associate Professor of Nursing at the University of Michigan School of Nursing, wanted to understand the effects of homelessness on children. She also wanted to know what services were being provided to the homeless, and why some families could escape from homelessness but others were caught in its cycle, periodically reappearing in shelters. In 2009, she had a $3000 NIH grant to do so. But the needs of the homeless were unknown, and she wanted to make sure that the problems she was studying were relevant. Once she got a grant from the Detroit URC she renamed the study, initially called the aya collaborative after a West African term for fern, to The Partnership for Family Health and Housing. Now everyone knew her focus. And her pilot data, reported in 2010, was able to transform policy directives.

**Benefits, Challenges, and Questions**

All four members of the panel agreed that the benefits of CBPR outweighed the challenges. And they also all agreed that one of the primary challenges of engaging in CBPR is the huge investment in time it requires. Interestingly, both academics and community members cited access to the others' world as a benefit. They noted that CBPR enhances the relevance and use of data, and it enhances the quality and validity of research. It provides valuable resources for the communities involved, and it increases trust and bridges cultural gaps between partners. While acknowledging these benefits, the panel members were not shy about identifying the challenges as well. The spoke honestly about how difficult it can be to establish and maintain trust, to agree upon goals and objectives, and to balance task and process with research and action. It is also very difficult to always follow agreed-upon CBPR principles.

Audience members had a lot of questions about the dynamics within a research partnership - notably, what if the partners want to break up and "see someone else"? Barbara Brush admitted that sometimes, the mission of a community based organization does not exactly match the mission of the collaborative. But these relationships are not
exclusive; new partners can be brought in, as long as they are vetted. And she said that just like in any relationship, communication is key. Zachary Rowe ended by pointing out that reciprocity over time is what matters; each partner knows the other is accountable, and that they will each get something out of this in the end.

References

http://www.detroiturc.org/the-network.html


Panel Discussion: New York City Community Advocates and Academics - Part 1

Complementary Strengths Research Partnership Access and Education around Healthcare for Women with Physical Disabilities

Panelists:

- Jennifer Tiffany, PhD, Director, Outreach and Community Engagement, Bronfenbrenner, Center for Translational Research, Cornell University
- Rebecca Gallager, MSW, Director of Youth and Adolescent Services at Lutheran Family Health Centers' Project Reach Youth
- Anita Nirenberg, PhD, RN, PNP, FAAN, BC, AOCNP, Professor & William Randolph Hearst Foundation Chair in Clinical Nursing, Hunter College School of Nursing
- Marilyn Saviola, MS, Vice President, Independence Care System

Moderator:

- Carla Boutin Foster, MD, Associate Professor of Medicine, Associate Director of the Center for Multicultural and Minority Health, Joan and Sanford I. Weill Department of Medicine Weill Cornell Medical College

Highlights:

- The Complementary Strengths Tool, born out of the Complementary Strengths Partnership, determines if community based organizations are doing a good job developing their youths' assets so they refrain from engaging in risky behavior.
- People with physical disabilities do not receive adequate health care.
- As a community advocate railing against injustice and trying to establish and maintain productive partnerships, one's best tool is not anger but education.

The day's first panel of New York City community advocates and academics focused on two very different populations - youth with, or at risk for, HIV and women with physical disabilities - and how CBPR has addressed their very different needs. Panelists were asked to talk about the benefits and challenges they've experienced with their CBPR work, if they would or have engaged in other partnerships, and any advice they would give to a researcher or community member who wanted to embark on a new partnership.
Complementary Strengths Research Partnership

The Complementary Strengths Research Partnership was born out of Jennifer Tiffany's idea that building programs with strong youth participation, and heeding the voices of the participants, could stem the tide of HIV. However, it was very difficult to assess the efficacy of such programs. As Rebecca Gallagher, her partner, quipped about her own programming at Project Reach Youth: "We think we're doing good work - but how do we really know?" In 2005 the two landed an NIH grant to find out. Their goal was to generate a scale to rate the efficacy of various types of youth programming based on how much the kids feel actively involved. The Complementary Strengths Research Partnership includes Cornell, the New York State Department of Health, and New York City after-school programs. Tiffany and Gallagher developed and validated their new scale and have distributed it to community-based programs that can now use it to monitor the quality of their own youth programming. Previous assessments often only looked at the types of programs the kids attended, and how long they spent there, but they did not really try to assess the quality of the kids' experience. In this partnership, youth participants, program staff, and researchers all worked together to develop and fine-tune the twenty questions that comprise the new scale. Importantly, the youth participants were involved in all aspects of the study, from hiring decisions to data evaluation. The partnership's work has demonstrated that participation in engaging and compelling after school programs can in fact reduce high risk behaviors in individual kids and can even improve the youth environment as a whole in terms of everyone's sexual health and behavior. Hopefully such programs will be potent tools to promote adolescent sexual health, reduce HIV risk among youth, and enhance their feelings of social connectedness. And as an added bonus, the whole endeavor helped to develop the research and leadership skills of the kids that took part.

Access and Education around Healthcare for Women with Physical Disabilities

Anita Nirenberg had been a practicing oncology nurse for years, she said, and it had never occurred to her that women in wheelchairs would have trouble getting mammograms until she was asked to join in the Women's Health Access Program partnership with Independence Care System. Nursing education has been revamped recently to address the health disparities between racial and socioeconomic groups and end of life issues, she noted, but it has not yet addressed the needs of people with physical disabilities who often do not receive adequate health care.

Her partner Marilyn Saviola was arguably the most compelling presenter of the day. For Marilyn and other women in wheelchairs, "lack of access to health care" means something quite different than it does when referring to members of inner city minority communities.
For her it is quite literal: she often can't get into the exam room, let alone onto the exam table or situated in front of a mammography machine. And physicians often don't have - or are not permitted to take - the extra time that physically examining her requires.

The barriers to Saviola attaining standard medical care are manifold. The design of the equipment - think of that mammogram machine - is often problematic; there is a lack of education, so most medical professionals don't even know that this is an issue; and once it is brought to their attention, she found that many had a "not my problem" sort of attitude. Evidence of this last sad fact is that once she got funding from the Susan G. Komen foundation to embark on a study to eliminate or at least alleviate some of the issues, it took five and a half months to find a facility in New York City willing to partner with her. But when asked what advice she'd give to other advocates, Saviola quipped that "anger is good as a stimulus, but not your best tool as an advocate." To make your passion productive, she said, the best tool is education - to recruit driven, committed people as your partners. Due to her equanimity, her Women's Health Access Program now has four sites as well as facilities for gynecological exams.

Women with physical disabilities do not suffer from higher rates of breast cancer incidence than the general population, but they do have higher breast cancer mortality rates. This is partially because the barriers to screening them means their disease gets detected later, but also because they are not treated as aggressively, they are barred from participating in clinical trials, and very little research has been done on them. Twenty-five years after the Americans with Disabilities Act was passed to prevent discrimination against this population, they still have restricted access to basic medical care.

References

http://www.projectreachnyc.org/

http://www.icsny.org/

Panel Discussion: New York City Community Advocates and Academics - Part 2

Community Access to Palliative Care: Reducing Health Disparities among Chronically-Ill Older Adults in East and Central Harlem
Addressing Pain Disparities at the Community Level

Panelists:

- Daniel Gardner, PhD, MSW, Professor, Silberman School of Social Work, Hunter College
- Fay H. Rim, MD, Chief, Department of Pain Medicine and Palliative Care at Metropolitan Hospital Center
- Mannery Cary Reid, MD, PhD, Professor in Geriatrics, Weill Cornell Medical College
- Evelyn Reyes Laureano, PhD, LMSW, Executive Director, Neighborhood SHOPP

Moderator:

- Daniel Herman, PhD Professor and Associate Dean for Scholarship & Research Hunter College Silberman School of Social Work

Highlights:

- Seniors who are poor or part of minority groups have severely diminished access to hospice use, palliative care, and treatment options for musculoskeletal pain, such as that stemming from arthritis.
- In order for CBPR partnerships to work, academic researchers and community based organizations often must be brought together by mutually trusted third parties.
- Age, just like culture, can be a barrier in researchers' relating to study partners and participants and must be taken into account.

The final panel of the day highlighted two other advocate-academic partnerships in New York City, one focused on reducing health disparities among chronically ill older adults in East and Central Harlem and the other addressing pain disparities at the community level in senior centers. As in both of the preceding panels, participants were asked about the benefits and challenges associated with their CBPR work, if they would or have engaged in other partnerships, and what advice they would give to a researcher or community member who wanted to embark on a new partnership.
Community Access to Palliative Care

In the last ten to fifteen years, according to Daniel Gardner, palliative care has grown in hospitals. However, this is much less true of public hospitals, like Metropolitan Hospital Center. Fay Rim, the Chief of the Department of Pain Medicine and Palliative Care at Metropolitan, describes it a community hospital. that delivers care to underserved populations that lack access to any other care, like black and Latino older immigrants. It does not look at anyone's ability to pay. Gardner and Rim teamed up to look at the disparities in palliative care and hospital use faced by older adults of color, primarily in East and Central Harlem, and identify interventions to better meet their needs. Their study hoped to determine how much palliative care can alleviate pain and enhance quality of life, and to identify any barriers minority seniors may face in accessing palliative care within their communities.

Both Gardner and Rim stressed that this CBPR project, while immensely fulfilling, is difficult. Gardner noted that it can slow down grant applications and publications, reinforcing points made by previous presenters that this type of research takes a lot of time. And he pointed out that cultural competence applies to age as much as to community; his population, of patients ranging in age from sixty to their nineties, is a diverse one, and relating to them requires a learning curve. Rim said people in underserved communities like hers often think: this will never work, so why bother? It is this type of attitude that can stymie CBPR endeavors before they even get off the ground.

Addressing Pain Disparities at the Communal Level

Cary Reid, a geriatrician and the Director of the Cornell Columbia Translational Research Institute on Pain in Later Life, started his presentation by stating unequivocally that CBPR enhances productivity: he has submitted more grants, published more peer-reviewed papers, and given more presentations because of it. He is such a convert that he has even developed a course in CBPR for graduate students at Weill Cornell. His partner Evelyn Laureano, the Executive Director of the Neighborhood Self-Help Older Persons Project (SHOPP) in the Bronx, noted that CBPR fits right into their mission to "help people help themselves."

The problem that Reid and Laureano are combating is that advancing age and being a member of a minority group increase the risk that musculoskeletal pain will be undertreated. Chronic musculoskeletal pain is a major cause of disability and suffering. There is an effective Arthritis Self-Help Program (ASHP), but it is not accessible to many who need it - for example, those who are functionally illiterate and therefore have trouble reading the lengthy Arthritis Foundation book. The goal of their CBPR project was to adapt
ASHP for optimal use, especially in older Hispanic and African Americans. To achieve it, the investigators from the Cornell Institute for Translational Research on Aging teamed up with Neighborhood SHOPP Casa Boricua (Hispanic adults), the Central Harlem Senior Center (African Americans adults), the Riverdale Senior Center (non-Hispanic Americans in the Bronx), and the NYC chapter of the Arthritis Foundation. They were brought together by a "matchmaker" that had credibility with all parties.

SHOPP serves 5000 clients a year through its three senior centers and outreach to the homebound elderly. Laureano was able to incorporate the ASHP into her other programming, and the members involved helped shape the program by giving feedback directly to the researchers assessing it. The participating groups met weekly for six to eight weeks, and generated over eighty recommendations to improve the program. The researchers incorporated about half of the recommendations into an amended program, including restructuring the class format to maximize learning; modifying specific program elements, like the reading materials, so they are appropriate for each learner group; and facilitating the maintenance of treatment gains. The innovative wellness programming that resulted from the collaboration yielded superior retention and attendance as compared to the original, unmodified program and retained the original's improvements in physical and psychological function and pain relief. Moreover, the participants felt totally empowered that researchers for Cornell were seeking and heeding their opinions. This project, alas, was not sustained - the grant funding climate remains tight - but they did manage to successfully launch a new pain management project as a result.

References


Siegler EL, Lama SD, Knight MG, Laureano E, Reid MC. Community-Based Supports and Services for Older Adults: A Primer for Clinicians. J Geriatr. 2015;2015. pii: 678625.
Achieving Health Equity through Community Partnership: Building the Capacity to Act

Speaker:

- Aletha Maybank, MD, MPH, Associate Commissioner, Founding Director for the Center for Health Equity, NYC Department of Health and Mental Hygiene

Highlights:

- Disparities in health are a result of injustice and bad policies, not biology.
- Each neighborhood in NYC has a history that affects the health of its residents.
- The Center for Health Equity's mission is to strengthen and expand the NYC Health Department’s efforts to ensure that all NYC residents have equitable access to opportunities to achieve their full health potential. They advance this mission by fostering partnerships, supporting community power, and building organizational capacity to address the social, environmental, and systemic factors that contribute to health inequities in NYC.

Geographic income inequity yields geographic health inequity

New York City is extremely diverse. While this is certainly one of the city's greatest strengths, it means that clinicians and public health officials may make assumptions that might not apply equally to all residents and this can be a challenge. For instance, overall positive health trends do not necessarily mean there will be reductions in health disparities; more targeted action is needed to achieve that. In September 2014, Aletha Maybank founded the Center for Health Equity within the NYC Department of Health and Mental Hygiene because there are disparate health outcomes in different neighborhoods, and she wants to close that gap. It is the newest such Center in the country.

Inequities in health outcomes are caused by historical practices of exclusion and discrimination as well as policies that created and maintained systems reliant on unbalanced power and privilege. These led to geographic concentrations of poverty that overlap markedly with death from manageable diseases like diabetes and AIDS, hospitalizations for treatable and perhaps even avoidable conditions like asthma and drug abuse, and infant mortality. These poor neighborhoods - the South Bronx, Bedford-Stuyvesant, East Harlem, Central Harlem, Jamaica, Corona, Brownsville - are largely populated by black and Hispanic people. The lifespans of the residents of these neighborhoods can lag a full ten years shorter than that of their wealthier neighbors, only a few subway stops away.
Maybank insists that this is unfair and unjust, and that racism is the structural barrier that causes the segregation of these poor neighborhoods and the bad health outcomes within them by influencing the policies and processes that could potentially be used to dissolve these health inequities. Most Americans, individualists that we are, say that personal behavior is the biggest contributor to one’s health; but individual behaviors are shaped by the physical and social environment, which in turn is affected heavily by policy and policy makers.

The idea of health inequity is not a new one. W.E.B. DuBois recognized it and wrote about it in 1906. In 1985 Offices of Minority Health were established; these have morphed into the Centers for Health Equity. But government agencies cannot create change on their own. Maybank wants to harness young people and agitators to organize around health inequity like they have around other issues, like police brutality. Black lives do indeed matter, whether they are being lost because of gun violence or because of inadequate access to standard health care.

**New neighborhood health hubs**

Ten years ago, the NYC Health Department opened neighborhood offices as a strategy to address inequity. They are modeled after the "neighborhood health hubs" that were established between the world wars by the American Red Cross in conjunction with the Department of Health but which have since fallen into disrepair. Back in the 1930's, their stated purpose was “To avoid the confusion or duplication which inevitably results when various public and private agencies carry on health activities in the same territory simultaneously without joint planning or provisions”. In their current incarnation, these neighborhood offices are physical spaces in District Health buildings that allow for the co-localization of community-based organizations with medical service providers, diagnostic and treatment centers, and other NYC government agencies (if relevant). By fostering collective action among organizations that operate inside as well as outside of the building and with community residents, these neighborhood offices hope to change the systems in which people live and empower them through joint community health planning.

The East Harlem office is located in NYCHA public housing and focuses on people with uncontrolled asthma, diabetes, or hypertension, all of which are quite prominent in these housing developments. In order to improve the health of East Harlem residents and decrease existing disparities, government and other workers in this office help residents to adopt healthier behaviors and to attain access to health and social services. They also try to build up the capacity of community organizations to seek and advocate for healthy conditions and accessible services. If they cannot find the conditions and services they
desire, they work to create them. Similar offices in other neighborhoods addressed needs more specific to those particular neighborhoods. The South Bronx office tackled unwanted teenage pregnancy by working with community partners to connect youth with evidence-based education and contraception, and in Brownsville, in Brooklyn, the Brooklyn Active Transportation Community Planning Initiative worked with the Department of Transportation to establish bike lanes that fit in safely and appropriately with the neighborhood's traffic flow. The Department of Transportation was going to put in seven miles of bike lanes; after engaging with the community, they put in twenty-eight miles instead. Both models were so successful they have been expanded to other parts of the city, where residents of other communities can use their expertise to improve the health of their neighborhoods.

References


Media

**Opening Remarks and Keynote Speakers**
Jesus Angulo
Vita C. Rabinowitz
Julianne Imperato-McGinley

Barbara A. Israel
Angela G. Reyes

**Panel from Detroit Community-Academic Urban Research Center**
Barbara L. Brush
Barbara A. Israel
Angela G. Reyes
Zachary Rowe

**Panel of New York City Community Advocates & Academics – Part I**
Jennifer Tiffany
Rebecca Gallager
Anita Nirenberg
Marilyn Saviola

**Panel of New York City Community Advocates & Academics – Part 2**
Daniel Gardner
Fay H. Rim
Manney Cary Reid
Evelyn Reyes Laureano

**Closing Keynote Speaker**
Aletha Maybank
Keynote Speakers

Barbara A. Israel, PhD

Israel is a Professor in the Department of Health Behavior at the School of Public Health -- University of Michigan. She has published widely in the areas of: the social and physical environmental determinants of health and health inequities; the relationship among stress, social support, control and physical and mental health; and community-based participatory research (CBPR). Dr. Israel has extensive experience conducting CBPR in collaboration with partners in diverse communities. Since 1995, she has worked together with academic and community partners to establish and maintain the Detroit Community-Academic Urban Research Center. The Center involves multiple NIH and Foundation-funded basic etiologic research and intervention research projects aimed at increasing knowledge and addressing factors associated with health inequities in Detroit. Dr. Israel is actively involved in several of these CBPR projects examining and addressing, for example, the environmental triggers of childhood asthma, the social and physical environmental determinants of cardiovascular disease, access to food and physical activity spaces, and capacity building for and translating research findings into policy change.

Angela G. Reyes, MPH

Reyes is the founder and Executive Director of the Detroit Hispanic Development Corporation (DHDC). Angie has been committed to working in and serving the Southwest Detroit Latino community for over 40 years, dedicating much of her life to working with “in-risk” and gang-involved youth. Angie founded DHDC in 1997 from her living room, “because I was tired of burying children”. In an attempt to reduce the violence, the GRACE Program formed after forging a truce with the leaders of several rival gangs, and encouraging them to “retire” in return for jobs in local Hispanic-owned manufacturing companies. Ms. Reyes has since successfully integrated various services into comprehensive programs for youth, young adults and families, and developed and managed several successful programs serving the Detroit Latino community. Ms. Reyes has a Master’s Degree in Public Health from the University of Michigan, and has been the recipient of several awards for her community work. Ms. Reyes is a founding board member of the Detroit Community-Academic Urban Research Center, which was established in 1995 and involves multiple funded collaborative research and intervention projects aimed at increasing knowledge and addressing factors associated with health disparities of residents in Detroit, Michigan. Ms. Reyes is an international consultant and speaker about issues affecting the Latino community, including cultural awareness, youth gangs and violence, substance abuse, immigration, education reform, community based participatory research, policy development and community organizing.
Aletha Maybank, MD, MPH

Maybank is an Associate Commissioner at the New York City Department of Health and Mental Hygiene and serves as the founding Director of the Center for Health Equity. The newly created Center for Health Equity aligns efforts in advancing health equity across the city and ensures the deployment of resources to reduce health and mental hygiene disparities across all neighborhoods in NYC. The Center focuses on these key areas: leveraging community assets to better integrate primary care and public health to serve the health needs of communities; building inter-agency collaboration to implement multi-sectorial approach to addressing the root causes of health disparities; and increasing organizational capacity that strengthens the agency’s lens of addressing health equity. Previously she led the Brooklyn District Public as Assistant Commissioner where she oversaw a series of place based programs aimed at decreasing health disparities in North and Central Brooklyn including but not limited to: the Brooklyn Breastfeeding Empowerment Zone, Healthy Start Brooklyn, Healthy Schools Brooklyn, Active Transportation and Pedestrian Safety Initiatives, and Shop Healthy Brooklyn.

Panel from Detroit Community-Academic Urban Research Center

Barbara A. Israel, DrPH, MPH

Angela G. Reyes, MPH;

Barbara L. Brush, PhD, ANP-BC, FAAN

Brush is an Associate Professor of Nursing and the Carol J. and F. Edward Lake Professor of Population Health at the University of Michigan School of Nursing. Over the past two decades, her research has spanned a gamut of nurse workforce issues, including workforce diversity, nurse shortage, and nurse migration, as well as how nurses impact care provision to vulnerable community-based populations. A nurse researcher and historian, Dr. Brush has partnered with research teams at the New York Academy of Medicine, the International Council of Nurses, the Center for Health Workforce Studies at SUNY (Albany) School of Public Health, the University of Pennsylvania Center for Health Outcomes and Policy Research, and New York University to examine key workforce issues and their policy implications. Her research with homeless families in Detroit, as part of the Family Health and Housing Collaborative of which she is a founding partner, uses a community-based participatory approach to engage its members in designing, implementing, and evaluating best practice models to provide needed preventive health and social services and inform health policy decisions in this emerging and underserved cohort. She is currently a Board member of the Detroit URC and is the immediate past Faculty Director for the Community Engagement arm of the University of Michigan's Clinical and Translational Science Award (CTSA). Dr. Brush’s research has been
supported by the National Institutes of Health, the National Library of Medicine, as well as by private foundations, and has been widely disseminated.

**Zachary Rowe, BBA**

Rowe is Executive Director of Friends of Parkside, a grassroots community based organization on Detroit’s eastside which provides programs for youth, a computer learning center, health and safety projects, and linkages for residents to employment and personal development opportunities. Mr. Rowe has been involved with various Community-Based Participatory Research (CBPR) projects for more than 18 years and is a founding member of the Detroit Urban Research Center (URC) Board. He serves on the Healthy Environment Partnership Steering Committee, Community Action Against Asthma Steering Committee, REACH Detroit Partnership Steering Committee, UofM’s RWJF CSP Internal Advisory Committee (IAC) and the Michigan Institute for Clinical and Health Research (MICR) Community Engagement Coordinating Council. Currently, He is a Co-PI on a National Institute of Health (NIH) and Agency for Healthcare Research and Quality (AHRQ) funded projects.

**Panel of New York City Community Advocates & Academics – Part I**

**Jennifer Tiffany, PhD**

Tiffany serves as Director of Outreach and Community Engagement, Bronfenbrenner Center for Translational Research, College of Human Ecology, Cornell University; Executive Director of Cornell University Cooperative Extension’s NYC Programs; and as Co-Director of the Community Engagement in Research Component of the Weill Cornell CTSC. Her scholarly work centers on research translation and community engagement, with a particular emphasis on research about youth participation and HIV/AIDS. She is the Principal Investigator of the Complementary Strengths Research Project, a community-based participatory research partnership that examines the relationships among social connectedness, youth voice and participation in community-based programs, and adolescent health with an emphasis on HIV risk reduction practices. Jennifer Tiffany holds a PhD. in City and Regional Planning from Cornell University as well as a degree in nursing from Tompkins-Cortland Community College.

**Rebecca Gallager, MSW**

Gallager is Assistant Vice President, Youth and Adolescent Services, at Lutheran Family Health Centers has over fifteen years of experience in managing youth development programming in Brooklyn, New York. During this time she partnered with Jennifer Tiffany and her staff to evaluate how a youth development approach affects the outcomes of HIV prevention programming. Prior to her work at Lutheran Family Health Centers, Ms.
Gallager provided social work services to adolescents and supervised health educators and social workers in school based clinics in upper Manhattan. Ms Gallager received her BA from Wesleyan University, her MSW from New York University, and completed coursework for a PhD in Social work from New York University.

**Anita Nirenberg, PhD, RN, PNP, FAAN, BC, AOCNP**

Nirenberg is an experienced clinician, educator and researcher. Her many years in nursing have resulted in significant contributions to the science of oncology clinical practice and patient outcomes. Since joining Hunter-Bellevue School of Nursing, Dr. Nirenberg has continued to engage in interdisciplinary collaborative research and teaching activities. She was inducted as a Fellow in the American Academy of Nursing in 2013 and received the Oncology Nursing Society Lifetime Achievement Award in 2014. As the Associate Director for Nurse Practitioner Specialties, Dr. Nirenberg has been charged with improving the scholarship in the largest graduate program at Hunter-Bellevue School of Nursing. The graduates of the programs have gone on to positions in world class academic health centers and in primary care settings across the greater New York metropolitan area. As an educator, Dr. Nirenberg has experience in developing curricula for health science students around significant health issues, particularly oncology, palliative and end of life care. Dr. Nirenberg’s extensive network of colleagues at the major cancer centers among them Weill-Cornell Medical Center and Memorial Sloan Kettering Cancer Center promotes and facilitates the partnerships essential in her current position. As an engaged and recognized expert clinical scholar, she brings a leadership background in service from multiple national and international nursing and health care organizations. She has influenced direction of these organizations to set policies aimed at enhancing scholarly nursing practice and improved patient care.

**Marilyn Saviola, MS**

Saviola is a nationally recognized disability rights advocate with a 40- year history of fighting to improve the lives of people with disabilities in New York City, particularly by advocating for the rights of people with physical disabilities to live at home, in the community, as independently as possible. Ms. Saviola began her career as a Rehabilitation Counselor at Goldwater Memorial Hospital. For 11 years, she helped people with severe physical disabilities to meet the challenges of leaving the hospital to move out into the community. A post-polio survivor who grew up in Goldwater Hospital herself, Ms. Saviola brought to that position not only her professional credentials—a Master’s Degree in Rehabilitation Counseling from New York University—but also her own personal experience. From 1983 to 1998, Ms. Saviola took up the reins as Executive Director of the Center for Independence of the Disabled in NY. Under her leadership, CIDNY became a premier independent living center, recognized for its expertise in advocacy and services for people with disabilities. In 1998, Ms. Saviola brought her passion and deep knowledge of home- and community-based services to Independence
Care System (ICS), a Medicaid managed long-term care program for people with physical disabilities. As Senior Vice President of Advocacy, Ms. Saviola intervenes, often in crisis situations, on behalf of ICS members with the many systems that impact their lives. Most recently, Ms. Saviola has overseen the creation of the Women’s Health Program at ICS. Working in partnership with select health care institutions to address the numerous barriers that prevent access to care, the Program works to ensure that women with physical disabilities get the preventive, gender-specific health services they need. The Breast Cancer Screening Project for Women with Physical Disabilities was ICS’s first women’s health initiative. It has been funded since its inception by the Greater NYC Affiliate of Susan G. Komen for the Cure, which chose the Project in 2010 as “Grantee of the Year.” As a community advocate, Marilyn has brought her unique and powerful voice to the work of many advisory committees, organizations and professional associations. She has served as Past Chair of the Manhattan Borough Disability Advisory Group, Board Member or the Association of Independent Living Centers in New York, Member of the New York City Medicaid Managed Care Task Force and Board Member of Disabled in Action.

Panel of New York City Community Advocates & Academics – Part 2

Daniel Gardner, PhD, MSW

Gardner has over 25 years of clinical, administrative, and research experience in health and mental health, specializing in social work practice with individuals, families, and groups living with chronic and advanced illness. His areas of scholarship include aging, psychosocial oncology, palliative and end-of-life care, family decision making, and health disparities among underserved, community-dwelling older adults. His current research focuses on exploring and developing interventions to address health disparities in pain management and palliative care among low income, minority elders. Dr. Gardner has authored or co-authored over 30 peer reviewed articles, book chapters, or monographs. He is a Hartford Faculty Scholar in Geriatric Social Work, a founding board member of the Social Work in Hospice & Palliative Care Network (SWHPN), Research Director of the Hartford-Silberman Center of Excellence in Gerontological Social Work at Hunter College, and a Fellow of the Social Research, Practice & Policy Section of the Gerontological Society of America (GSA).
Fay H. Rim, MD

Rim is currently the acting chief of the Department of Pain and Palliative Medicine at Metropolitan Hospital. She is board certified in physical medicine and rehabilitation, pain medicine, and hospice and palliative care. She also serves as the New York Medical College hospice and palliative medicine fellowship director and is a clinical instructor in the Department of Physical Medicine and Rehabilitation at New York Medical College. Dr. Rim received her bachelor’s degree in biology from MIT and her medical degree in 2002 from New York Medical College. She did her internship at Westchester Medical Center and residency at Mount Sinai Medical Center and completed her fellowship in pain and palliative care at Memorial Sloan Kettering Cancer Center in 2007. She had worked in private practice and the James J. Peters VA Medical Center prior to joining Metropolitan Hospital.

Manny Cary Reid, MD

Reid directs Cornell’s Center of Excellence in Geriatric Medicine and the Office of Geriatric Research housed in the Division of Geriatrics at Weill Cornell. Dr. Reid’s work over the past decade has focused on the epidemiology and treatment of persistent pain disorders in older adults. This work has involved elucidating risk factors for poor outcomes (e.g., declines in physical performance), as well as the development and testing of non-pharmacologic interventions to improve outcomes, with a particular emphasis on behavioral treatment approaches for use by older adults with chronic pain. He currently serves as the Director of Cornell’s Edward R. Roybal Center for Translational Research on Aging. The goals of this center include: (1) translating the findings of basic behavioral, medical, public health, and social science research into treatments, intervention programs, and policies that improve the health and well-being of older adults who suffer from or are at increased risk for pain; (2) promoting translation of evidence-based practices, treatments, and interventions across diverse venues to improve management of pain; and (3) developing and testing innovative methods, tools, and strategies that facilitate successful translation of evidence into practice.

Evelyn Reyes Laureano, PhD, LMSW

Laureano is the Executive Director of Neighborhood Self Help by Older Persons Project, (SHOPP) an organization dedicated to empowering elders of color through advocacy, leadership training and targeted services. Dr. Laureano has a distinguished 40 year career in gerontology, in such fields as health, mental health, social services and higher education. Her accomplishments include the development of strengths-based social work practice models with minority elders, the establishment of one of the first elder abuse programs in the Bronx and prevention and wellness initiatives to reduce health disparities among elders of color.