

## Community based research partnerships for co-constructing participatory forms of social justice research and action

Jean Schensul

### Abstract

Questo contributo esamina due forme di co-costruzione di conoscenza e azione che hanno entrambe un impatto su questioni di giustizia sociale in contesti comunitari, la Participatory Action Research e la Community Based Participatory Research. Definisce la CBPR come alleanze tra organizzazioni comunitarie e partner universitari per il cambiamento; e la PAR come ricerca guidata dalla comunità per la costruzione di alleanze e per l'advocacy. Il documento descrive alcuni esempi di entrambe, illustrati attraverso il lavoro dell'Institute for Community Research, un'organizzazione di ricerca indipendente basata sulla comunità. Suggerisce argomenti sul motivo per cui gli antropologi dovrebbero considerare la formazione di organizzazioni di ricerca basate sulla comunità e i loro vantaggi nel condurre CBPR e PAR per affrontare le questioni di giustizia sociale. Rileva inoltre i vantaggi della collaborazione tra tali organizzazioni e le università per estendere la portata delle università e le risorse per la risoluzione dei problemi delle comunità. Il documento sostiene un maggiore coinvolgimento degli antropologi sia nella CBPR che nella PAR.

This paper examines two forms of co-constructing knowledge and action both impacting on social justice issues in community settings, Participatory Action Research and Community Based Participatory Research. It defines CBPR as alliances between community organizations and university partners for change; and PAR as community-led research for alliance building and advocacy. The paper describes examples of both illustrated through work of the Institute for Community Research, an independent community based research organization. It suggests arguments for why anthropologists should consider the formation of community based research organizations and their advantages for conducting CBPR and PAR to address social justice issues. It also notes the advantages of university collaboration with such organizations to extend university reach and community problem solving resources. The paper endorses greater involvement of anthropologists in both CBPR and PAR.

**Parole chiave:** urbano, ricerca, partecipativa

**Keywords:** urban, research, participatory

Anthropologists prefer to use terms that differentiate scholarship from action and research from practice and to publish articles that document, critique and evaluate "action", or change efforts. There is a small though compelling literature on PAR/CBPR conducted by anthropologists both within and

beyond the university (Cammarota and Romero, 2009; Campbell and Lassiter, 2010; Contreras and Griffith, 2011; Gubrium and Harper, 2016; Hyland and Bennett, 2005; Hyland and Maurette, 2010; Hyland and Bennett, 2013; Pink, 2004) limited by the constraints of anthropology departments that restrict time and support to work on policy or practice related issues especially if faculty are untenured (Schensul and LeCompte, 2016).

### **The urban setting for PAR/CBPR**

With approximately 70% of the globe urbanized, inequality is a significant urban problem. Patterns of social, racial, economic and cultural inequality vary across countries and urban environments as a consequence of different laws, policies and regulatory actions, local economies, labor force migration and in-migration and formal and informal means of spatial bounding within cities and metropolitan regions. In every country, concentrations of urban residents are readily identified as sharing common cultural characteristics, ethnic/racial designation, country of origin, income differential, documentation status and other factors. Many of these populations often both suffer and protest the consequences of marginalization, stigma, discrimination and economic exploitation that are the focus of much CBPR/PAR work around the world. Anthropology can and should be especially appropriate for PAR and CBPR work since ethnography establishes local and other connections and encounters and studies local problems viewed in a broader social and political context. However, anthropologists are not always trained to advance their work further, by building research/action partnerships to assess and address those problems.

To avoid the problems posed by the academy, my colleagues and I, an interdisciplinary team of anthropologists, social epidemiologists and ecologists, have developed a community-based research organizational model that supports collaborations between NGOs and private citizens representing marginalized communities to use research as a means of addressing complex social and health problems stemming from structural inequities. The collaborative process that links researchers and community organizations results in the co-creation of knowledge, problem solutions and opportunities for working together to promote more responsive, inclusive and equitable societies. The paper

describes this model, embodied in the work of the Institute for Community Research (ICR), and the urban contexts in which it evolved (Schensul, 2010). I discuss two approaches ICR has used in the co-creation of knowledge and action: Participatory Action Research (PAR) and Community Based Participatory Research (CBPR), give several brief examples from ICR work in the U.S. and India for each, and summarize their similarities and differences, challenges and opportunities. I note the advantages of a community base for CBPR and PAR and benefits to anthropology departments for linking to such organizations to extend their capacity for these approaches.

### **A brief History of PAR and CBPR**

PAR and CBPR have much in common though they offer different approaches and methodologies for community problem solving readily adaptable for use in the academy and beyond. PAR and CBPR share common roots in the work of Kurt Lewin, a psychologist (Adelman, 1993), Sol Tax an anthropologist, in the US (Tax, 1975), and somewhat later, Paulo Freire an educator in Brazil (Freire and Shor, 1987). Influenced by current intellectual streams they embraced the basic notion that people experiencing social injustices or inequities and their consequences should be central to their solution. They also believed that these problems could best be tackled through structured inquiry by social scientists in partnership with the people most affected by them. Finally they recognized that stakeholders should act in concert to undertake action to solve the problem, with actions stemming from the data integrated with some form of promotion of social, cultural or structural change. Later researchers involved in revolutionary actions with rural poor in Latin America and in the US based civil rights movements of the late 1960s and 1970s took up the banner and applied various forms of CBPR/PAR in their work (Fals-Borda, 1987). By the 1980s, Participatory Action Research (PAR) had become the primary approach to engagement of social science researchers with locally informed community activists and activism, standing in contrast with organizing approaches that emphasized policy analysis or mobilization of populations against single issues. PAR also came to be defined as community-led, meaning that community activists learned to conduct research on issues that affected

them, and act on the results, where the role of the researcher became one of facilitation and collaboration, not of leadership. Though used with adults it became very popular in work with young people both in the US and globally. By the 1990s, YPAR, endorsed by university centers (e.g. CUNY graduate center, Cornell, University of Victoria, BC) was used by educators, youth activists and newly minted social science PhDs to engage young people in change efforts in schools and communities (Camarota and Fine, 2008; Etmanski, Hall and Dawson, 2014). It grew to become an established approach for involving youth in co-creating youth oriented interventions in special education, health and mental health, violence prevention and many other activities (Blum-Ross, 2017; ICR and DPH, 2014; Iwasaki *et al.*, 2014; Kohfeldt, Chhun, Grace and Langhout, 2011; Lesser, De La Rosa, and Ramirez, 2015)

CBPR is an approach that like PAR evolved from the same fertile ground as PAR/YPAR (Wallerstein and Bernstein, 1988) yet differs from PAR in that rather than supporting lay researchers to use research for action, it most often supports the collaboration of university trained researchers and community organizations and groups to solve social, educational and health problems together (Wallerstein and Duran, 2006). As articulated by public health researchers, despite endorsing the idea that partners or stakeholders conduct all aspects of a study and its resulting action together, CBPR usually retains the independent roles of the researchers and the community organizations capitalizing on the best of both worlds while engaging in full understanding and participation in a study (Israel, Eng, Schultz and Parker, 2012; Israel *et al.*, 2006; Israel, Schurman and Hugentobler, 1992). CBPR can be effective with basic research sans intervention, but works especially well when coupled with interventions, especially those that simultaneously address policy or norms change, group or collective efficacy, and individual efficacy (Wallerstein and Duran, 2010). Most anthropologists are not trained to conceptualize or conduct social, or health interventions; thus not many anthropologists are involved in CBPR work (Lambert-Pennington, 2010; Okraku, Vacca and McCarty, 2017).

CBPR most often links researchers with community organizations and informal alliances. In a typical CBPR effort, the topic emerges in a dialogue between organizations and researchers about critical community issues (e.g. as environmental pollution,

food insecurity, HIV prevention or COVID-19 protections) and raise researchable questions. The study design then must be researchable, i.e. a question has to meet funding criteria, organizational criteria and researcher capacities. Finding and negotiating a researchable research question takes time, patience and good will on all sides. Building a research model helps to refine the research question and develop a consensus on the study. Researchers must be able to work with communities to select a design that is scientifically rigorous, and consistent with organizational reach and capacity for recruitment and data collection. It requires an open mind and an agreement to search for additional skills if all those required are not yet embedded in the study team. Data analysis in a CBPR project usually is the responsibility of the researchers, but it is generally agreed that results review and querying should involve all partners. Similarly all partners should discuss and act upon the implications of the results for science and organizational practice or policy advocacy (Israel *et al.*, 2006).

Both PAR and CBPR pose challenges for university faculty, especially anthropologists because they require support from their institutions (time and resources), extensive interaction with local communities, cross disciplinary collaboration, and multiple IRB and other institutional constraints. On the other hand, NGOs – nonprofits or businesses with a social entrepreneurship mission – offer many advantages as a base for such work. They often have a clear social change mission. They are not subject to the salary and qualification constraints for the university hiring process and can hire and pay people from the local community based on the importance of their work rather than their academic credentials. In addition, they can develop their own personnel policies that are more responsive to the needs of community personnel. And they can respond rapidly to administrative procedures, have lower overhead costs, and can use indirect costs to further immediate organizational needs and mission directed purposes. NGO-based IRBs though uncommon, are not difficult to form and can be composed of professionals and people directly from communities collaborating in research, who better understand community based ethnographic and intervention research and who share ethical stances that are more sympathetic to protecting communities and participants, and less oriented to protecting research institutions from lawsuits. Their ability to

hire personnel reflective of and directly from the communities which they collaborate garners trust in those communities and ensures that the knowledge generated is closer to community realities and more likely to be immediately useful as well as scientifically sound. These organizations may not be identified as belonging to any given community but because of their mission, style of work and emphasis on relationships they have close personal and professional ties with multiple communities that enable them to access communities for research purposes more readily, and leaves them open to responding to community requests for research and program development (Schensul, 2015). The Institute for Community Research offers one example of a research NGO functioning independently yet linked to other community and academic institutions.

### **The Institute for Community Research as a PAR/CBPR research center**

The Institute for Community Research (ICR), named in 1988 has been directed from the outset by anthropologists committed to integrating research with social activism. ICR's mission was crafted as «the conduct of research to promote equity and justice in health education and cultural resource allocation in a diverse multi-ethnic globe». ICR is both an organizational innovation and a community intervention insofar as its mission calls for collaboration with community partners in the development and introduction of *intentional social change efforts into an ongoing system* (Hawe, Shiell and Riley, 2009).

ICR is located in the state capital of Connecticut, one of the three most impoverished and segregated communities in the state and fairly typical of cities across the U.S. It is characterized by gaps in transportation, limited opportunity structures for local residents and a very high level of unemployment among urban youth of color, leading to involvement in the informal economy and the continuous potential for associated violence, arrest and imprisonment. The class divide is seen in the differences between those who live in gentrified downtown or suburban housing and work in business, banking, insurance and health services in the city center, and those living in the city's impoverished neighborhoods, a situation I referred to as "urban apartheid" (Schensul, 1997) or segregation by design. Magnet and charter schools have drawn resources away from

the general public school system, furthering already existing educational disparities across ethnic/racial groups strained by ever decreasing resources. Surrounding municipalities, both working and middle class, retain control over their essential resources (schools, police services and health departments), and have used a variety of strategies to keep low income people out. Because of limited interaction, suburban families often hold strong negative stereotypes of urban residents, viewing them as threatening to the social and economic order. Over the years there have been multiple efforts to address these racial/ethnic and class biases and fractures in the social fabric of the city and nearby suburbs. ICR viewed this setting as a prototype for global urbanization and as an incubator for the development of local and global approaches to address its structural inequities and resultant health and other disparities.

To do so, ICR evolved a holistic multilevel approach to social change driven by ecological, social and cultural theories drawn from anthropology that incorporated different strategies for community building in the United States: 1) Use of mixed methods community research partnerships for addressing community problems through research and interventions (CBPR). 2) Creating a program of PAR training for social change (PAR); 3) Developing community partnerships, some with universities, and alliances for health research and prevention (Radda and Schensul, 2011; Schensul, 2015); 4) Supporting heritage and emerging community artists to promote community voice, health and cohesion. ICR's global reach included building CBPR centers in Sri Lanka and Peru and CBPR efforts to prevent HIV in South Asia (Mauritius, Sri Lanka, India), China, and Vietnam. ICR has strong research infrastructure including its own IRB and administrators familiar with funding sources and regulatory responses, and its own PhD and MA level trained research staff. As an independent organization it retains close working relationships with U.S. and international universities, which are critical to enable cross sharing of technical capacity, library resources and intellectual capital. Programs of CBPR and PAR/YPAR have been in existence since 1988. Below I discuss the ICR approach to CBPR and PAR/YPAR with several examples drawn from the US and India that illustrate how the organization builds collaborative studies with community and university partners to conduct research for action.

### **Community Based Participatory Research (CBPR)**

ICR has conducted many CBPR studies with multiple partners in relationships that endure over many years. For example, HIV research and intervention and policy promotion began at ICR in the early 1990s, expanded in the US and globally and now to alliances in New York City and Vietnam. ICR basic and applied research on emerging adults and substance use began in 2002 and is continuing with the same and new partners (Diamond *et al.*, 2009; Moonzwe, Schensul and Kostick, 2011; Schensul *et al.*, 2000). Similarly, ICR partnerships with older adults began in 2002 with research on HIV, depression, flu vaccine uptake, polypharmacy, oral hygiene improvement and are continuing with loneliness, oral health and COVID-19 studies (Schensul, Reisine, Grady and Li, 2019). Two examples illustrate CBPR at ICR, one initiated by faculty seeking expertise unavailable at the university, and the second initiated by ICR with a university in Mumbai India. Both examples extend university and community capacity through collaboration, by utilizing the resources of both settings to accomplish immediate health goals and longer term policy and practice changes.

### **Flu Vaccine Uptake in older adults**

ICR had established research relationships with senior housing managers and organizations serving older adults, and had conducted research on the health of older adults over a decade. This study began when a vaccine scientist from the University of Connecticut School of Medicine approached ICR to collaborate to promote flu vaccine uptake in older adults as a means of avoiding serious negative consequences of flu in people 65 and over. The public health vaccines expert, Janet McElhaney, was internationally recognized for her work on influenza vaccine for older adults and ICR offered an excellent base for a public health intervention. Together we received funding to test a psychosocial individual and group approach to dispel myths and misunderstandings about flu vaccine and vaccine uptake with a diverse population of older adult residents in two large income-subsidized apartment buildings. The team consisted of the PIs from ICR and UCONN School of Medicine, a bilingual ICR coordinator with IRB expertise, a Latino artist and group facilitator, UCONN medical student interviewers, a peer



health committee of volunteer building residents, a volunteer control building, a home-visit nurses' organization providing vaccinations onsite and an agency advocating for older adults that reimbursed participants without insurance for vaccination.

After obtaining the support of building staff and volunteer resident oversight committees in the two study buildings we invited volunteers in the experimental building to work with us to build educational curricula responding to residents' concerns about flu and flu vaccination. A diverse, bilingual group of 10 diverse residents worked with the research team, to integrate scientific sources with residents' ways of understanding. Together we created a fact sheet of FAQs and illustrative cartoons designed by the ICR artist with answers tailored to resident concerns. Subsequently, the residents made a film entitled *I got mine, did you get yours?* for use in resident run campaigns (flu fairs).

More than 200 residents who attended one or both of two "flu fairs", heard a presentation by the flu vaccine expert, asked questions, saw the film, heard testimony about vaccination experiences from committee members, and participated in committee generated flu related games and activities. Flu vaccinations were available at the end of each fair.

The results of a pre-post survey comparing treatment and control buildings showed significant improvements in knowledge, attitudes and flu vaccine uptake in the treatment building with Hispanics faring better than other groups in part because they had less initial knowledge of flu and vaccination importance. The university/community study team then generated plans to expand the study to other buildings in other cities and to promote vaccination education among Hispanic older adults (Schensul, Radda, Coman and Vazquez, 2009) and residents went "on the air" with their film.

There were two primary challenges in this project. The first were the presence of anti-vaccination residents in the treatment building who wanted to promote natural approaches to strengthen the immune system over vaccinations. They eventually agreed that the approaches were complementary, and were willing to combine their approach with our resident-led pro-vaccination

approach during the fairs. The second was the presence of an African American pro-vaccination advocate promoting onsite vaccinations in the control building which increased the rate of acceptance in that building, reducing the strength of the study intervention outcome. At the same time it illustrated how important internal advocates can be in improving public health actions in buildings or communities.

The second example shows how the CBPR approach can be extended from an NGO, ICR to a university in another country.

### **Alcohol and HIV Risk in India**

In the mid 2000's alcohol use was accelerating in India along with rates of HIV infection. The National Institute on Alcohol use and Abuse (NIH/NIAAA) was funding international studies of alcohol and HIV risk internationally. Faculty at the International Institute for Population Sciences, a government university in Mumbai, were interested in a collaboration to learn community based research methods, and together we mounted a five year program of research, publications, and policy change. We built partnerships with a network of local Mumbai NGOs working on alcohol related issues and interested in promoting policy changes around alcohol use and de-addiction. My colleagues engaged several national ministries responsible for HIV and substance use who could integrate the results into their policies and regulatory procedures. The study was advised by a group of national statistical and policy experts. To conduct surveys, observations and in-depth interviews with people involved in the alcohol and sex trades, we engaged with three deemed-slum communities near the university by talking with political parties, religious institutions, alcohol sellers and other key gatekeepers. In addition to IIPS faculty and advanced MPhil and PH.D. students, the study involved researchers from ICR, UCONN faculty with methods skills, and a student statistician.

The India and US PIs built a curriculum integrating qualitative/ethnographic and quantitative and GIS training, which we used to train the India all male study team. The students collected observational and in-depth interviews on alcohol and its intersection with sex from multiple stakeholders and administered an ethnographic survey to more than 1200 men in

the three communities. Data were analyzed by researchers in the US and India, with face to face meetings in both countries. Results were disseminated in local communities by using data to build street theatre scripts with local performance groups for presentation in the study communities on HIV risks associated with drinking. We planned and held two international conferences, one to bring together epidemiologists, historians and ethnographers to frame alcohol research in India and the second to bring together interventionists in HIV and alcohol, to talk with each other and government HIV policy makers, resulting in inclusion of alcohol into the HIV prevention portfolio. The conference provided the basis for a joint Indo-US special issue of the journal *AIDS and Behavior* on the history, epidemiology, culture and interventions related to alcohol and HIV distributed at the second international conference in Delhi as a study monograph (Jean Schensul, Singh, Gupta, Bryant and Verma, 2010; Singh *et al.*, 2010).

This study raised awareness of alcohol's contribution to HIV risk in local communities, strengthened ethnographic research at IIPS, changed government policy and paved the way for a later study to reduce drinking among men who were HIV infected. The success of this project rested on the collaboration of ICR via CBPR and mixed methods experience and an Indian university's biostatistical expertise, with shared learning for all parties.

### **Participatory Action Research (PAR/YPAR)**

PAR can be conducted from either a university or community base, and there are some examples of university programs that have supported both PAR and YPAR in the U.S. at Cornell, City University Graduate Center, University of South Florida and Berkeley. They depend on dedicated faculty members or students and are usually conducted in partnership with community organizations that have links with youth or adults locally or in countries in the global south. They tend to be viewed as education for advocacy, rather than as producing scholarship and lead to fewer peer reviewed publications. Thus they are held in lower esteem. Most PAR projects are more closely aligned with the social justice/social change goals of local community organizations wherever there are marginalized populations.

These organizations have greater and more sustainable reach though they too suffer from limitations of instructional personnel and financial resources. ICR as a community based research organization has conducted PAR with both adults and youth. Though the methodologies are similar, the approaches vary by developmental stage and age.

### *PAR with Adults*

ICR's PAR projects with adults over the years have included a resident led critique of the US census ethnic racial designations (Schensul and Schensul, 1992), urban women's concern about lack of voice in political decision-making in their city and state (Pelto and Schensul, 1987), parents concerned about child readiness for elementary school, mothers concerned about substance abuse prevention with young children, and community activists concerned about the uses of evaluation data for neighborhood development (AECF, 2016).

PAR methods utilize the toolkit of mixed methods group or team ethnography, which lends itself well to understanding self and others and to identifying the structures and processes, allies and powerbrokers that facilitate or offer barriers to change (Ozer, Ritterman and Wanis, 2010; Phillips, Berg, Rodriguez, and Morgan, 2010). Both PAR and YPAR are based on group processes, designed to reinforce individual growth, group cohesion and action toward a common goal usually stemming from structural inequities and experienced disparities in education, health, resource access and political voice. Typical PAR steps include solidifying individual and group identity through reflection and dialogue, building group cohesion through problem identification, stimulated by observations, photography, conversations, listing and ranking topics; and building a conceptual model, using either linear modeling (cause-consequence) or an eco-systems analysis to understand the complexity, political infrastructure inequitable distribution of power and resources and other primary perceived causes of a problem (Schensul *et al.*, 2004). Critical analysis is an essential component of most, though not all PAR processes. While some PAR processes end with unpacking and analyzing the research model based on the understandings of the group itself (Cammarota and Romero, 2011; Cammarota and Romero, 2009; Fine, 2009), in the ICR approach, outreach to the community

through qualitative and quantitative data collection is important in building allies, recognizing obstacles, enhancing communication skills, and encountering and resolving different perspectives. Organizing, analyzing and interpreting the results are critical steps in a PAR process to ensure that every member of the group can speak authentically about the results of the study, develop and operationalize approaches to change, and hone their skills through results dissemination, public action and advocacy. These steps are interactive, and are organized to enhance knowledge, collaboration, leadership and group problem solving, building an action base. The PAR process is ongoing, as participants reflect on learned and lived experience, observe effects of their actions, reformulate their goals, and advance their goals through more data collection (Berg, Coman and Schensul, 2009; Schensul, Berg and Williamson, 2008). The following is an example that illustrates adult-led PAR at ICR.

### **The Resident Engagement Project**

This project was part of the Annie E. Casey's ten year effort to involve residents from 22 cities in the US in activities to strengthen families and involve them in neighborhood development (AECF, 2016). A key to neighborhood development was the use of large secondary data bases controlled by the city and large planning agencies, and inaccessible to community residents. With direct funding from the foundation, ICR joined forces with residents in the Hispanic and Black neighborhoods of the city to increase understanding of the uses of data through conducting their own research on topics of concern in their neighborhoods. We believed that the PAR process would arm residents more effectively to advocate for their neighborhood and constituency needs as emergent leaders excluded from the urban development process in a city where community organizing had been stifled and developers held sway over municipal decision-making.

For two years, two ICR facilitators, a Puerto Rican activist social worker and a Black anthropologist trained in community engagement worked with four PAR groups, two in predominantly Black neighborhoods in the city's North End, and two in primarily Hispanic neighborhoods in the city's south end. Residents were supported to build group identity through team building activities, and then exposed to group ethnographic methods including

in-depth interviews, focused group interviews, personal and community history time lines, neighborhood mapping, visual documentation and survey methods. Each group chose a key question and its preferred research methods. For example, one South End group conducted a survey of parents of school-aged children to determine the type of neighborhood and economic development trainings people desired, mapped key institutions that offered parent programs and trainings in the neighborhood, and interviewed key informants to explore how the quality and quantity of Spanish language trainings affected residents' economic status. A North End group employed individual-level interviews and a survey to explore how family involvement affected student performance. With their data they prepared a resource guide for parents and held group meetings for parents, which they observed, while school issues were discussed and resource guides distributed (Williamson and Brown, 2014).

Residents in all groups were involved in data analysis, synthesis, and data presentations to the public and they created action strategies. To address cross – ethnic differences and biases in a segregated city, the groups met on a regular basis to discover and discuss common concerns and issues in their neighborhoods and to present the results of their work to each other, building common ground and collaborative leadership. Typical of other similar ICR efforts, PAR was successful in bridging intra and intergroup differences both within and across neighborhoods. Each group produced several new neighborhood activists and strengthened the voices of group members enabling them to be more effective in speaking to civic groups and city administration about the issues they had identified.

Despite these accomplishments there were challenges. Facilitators required extensive classroom and on the job training in mixed methods approaches, and facilitation skills. Both facilitators had advanced degrees and faced distrust and suspicion from their own communities and had to spend more time than expected on relationship building. Finally, local leaders undercut the effort to develop independent leaders through persuading the funders to divert funding to the city, which they used to hire the best emergent leaders for other work, thereby undercutting their advocacy potential. Co-optation and marginalization are always risks with PAR work that challenges existing power structures (Schensul, Berg and Williamson, 2008).

*PAR with teens (YPAR) at ICR*

Young people experiencing disparities and keen to act in support of improved future conditions and political voice have been on the forefront of activist movements and efforts to change their communities (Jenkins, Shresthova, Gamber-Thompson, Kligler-Vilenchik and Zimmerman, 2018; Stoudt *et al.*, 2016). ICR began experimenting with YPAR as an approach to youth leadership with three long term intervention studies, an NIH/NIMH training program and state funding for work with special populations. These projects worked with Hartford African American and Latinx youth to train them to conduct group action research for prevention and community activism through their choice of topics that included teen substance use and drug sales, teen sexuality, teen mental health issues, teen violence, teen stress, unprotected sex and HIV. Teens created films (Schensul, 2016), an app to address teen dating violence, and a unique approach to research and policy change for unstably housed youth. This work produced a training curriculum for youth, Action Research for Youth Empowerment 1st and 2nd editions (2000 and 2004). In 2016 it was adapted for use with the State of Oregon Department of Health (2016). These guides integrated identity formation, group team building, collective research activities incorporating math, social science, history, computer and reading/writing skills building and results dissemination with action planning to large audiences of parents, the press and the public. One example of a longer term YPAR program to prevent illegal hustling is described below.

**Addressing Teen Hustling**

A three year national grant provided the basis for a program in which a group of 40 Hartford African American and Latino high school youth explored the reasons for “hustling” (selling semi-legal and illegal products to generate income). The youth believed that hustling was prevalent in their communities and might become the only option for them in the future. They had personally seen the both the advantages and disadvantages of obtaining illegal income – much needed cash on the one hand and the risk of exposure to drug dealers, the police and jail sentences on the other. The 40 youth who decided to conduct the study wanted to learn more about why youth hustle, and to use

the data to advocate for more legitimate means of developing work and careers for themselves and their peers.

In an eight week full time program, youth assessed themselves and their group on multiple intelligences which provided the basis for their choice of methods of data collection (e.g. linear logic versus movement or artistic expression). They also learned about gender, sexuality and racial/ethnic bias, all important in both doing research with their peers and analyzing and interpreting the results. Using their own photographs and group discussion about priorities they eventually came to consensus on the topic of hustling, and learned how to use and construct an ecological model to illustrate the multiple factors (financial situation, family and peer influence) that were associated with teen hustling. In accordance with the YPAR curriculum, they unpacked or identified the subcomponents of the “dependent variable”, teen hustling, and the factors that predicted it (the independent variables). Building a model helped them to articulate the “culture of youth hustling” and it guided their data collection.

Next, methods learning stations offered youth an opportunity for hands on engagement with options for data collection. They eventually chose in-depth interviewing, pile sorting, mapping, visual research, and survey methods. Working in groups, they developed their methods and evolved a coherent set of strategies for collecting the data in community settings with adult support. They also learned how to present their design to the ICR IRB. The in-depth interviews used with stakeholders were based on questions that evolved from the vertical models (unpacking the predictive factors), and meant to verify and add new dimensions to the model. The photography group collected photographs related to teen hustling and composed them to match a case study collected by one of them from a teen hustler. The survey group went through ten systematic steps to develop a survey on topics in the model that they administered to 135 other youth in programs throughout the city. A fourth group conducted pile sorts on hustling and risk and a fifth group gathered data from an additional 50 youth on hustling sites locations and items hustled there. Each group was coordinated by a team consisting of an experienced facilitator, and interns, and the project was



overseen by two anthropologists who had developed the YPAR approach at ICR.

Each methods group analyzed their data, and amalgamated it into a larger story of teen hustling which was written and presented by youth in the ICR exhibit space to a broad spectrum of the public. Subsequently these and new groups of youth used the information to advocate for more employment money for youth, at state and city levels, and to promote job banks and work incentives in their high schools. Using a pre-post case/control design, outcomes for the PAR group were positive for avoidance of marijuana and school attachment at the individual level compared to a control group (Berg *et al.*, 2009). This project was successful, but time and labor intensive, requiring both ongoing staff training in group facilitation, methods and data analysis, and the negotiation of opportunities for youth to engage productively with state and local stakeholders and politicians (Morgan *et al.*, 2004).

### **Discussion**

Despite generally successful outcomes, both PAR and YPAR offer several crosscutting challenges regardless of whether programs are conducted in a community organization or from an academic base. First, the facilitators must have a combination of research design and methodology skills and experience, and group facilitation skills. These skills are not usually taught in anthropology departments and are often learned on the job or through mentorship. Second, both require the ability to facilitate strong relationships among the often very different members of the study team through research and other techniques. These skills are sometimes taught by educators, psychologists and social workers but rarely in anthropology departments. Third, the work requires creating and implementing research methods that are engaging, developmentally appropriate, reinforce team work and are relatively easy to carry out and analyze. Fourth, both approaches depend on researchers who are community-wise, committed to teaching new skills above and beyond research, and are prepared to find ways of generating research and action successes.

Both PAR and YPAR raise important questions for self-reflection about hierarchies of power and resources manifested in

potential clashes related to knowledge development, ownership and disposition. Opportunities for self-examination and recalibration also occur when, for example, results deadlines clash with delays in community data collection or analysis or conflicts occur around decisions stemming from cultural or contextual misunderstandings, or difficult-to-reconcile needs of researchers versus community based organizations. It is here that the intersectionality of community-based research organizations like ICR can help to resolve seemingly irreconcilable cross-institutional or interpersonal differences. YPAR raises additional considerations. These include the need to tailor the approach to developmental level by creating enjoyable interactive learning approaches; considering human subjects issues when youth conduct research with other youth; ensuring personal, social and physical safety issues during the research process; and finally, paying attention to psychosocial, cognitive, and learning gap problems that can disrupt youth cohesion and productivity especially when working with youth in marginalized communities of the north and south. Special tensions revolve around prioritizing YPAR as an educational process versus as a means of producing rigorous research results or gaining awareness of self/others through an issue of concern versus acting to change it, and the multiple and complex demands of the youth facilitator role as collaborator, teacher, facilitator, counselor and authority figure.

Debates in the CBPR field focus on power and control over time resources and funding allocations, ownership of information, and dissemination and use of research results. Neither faculty nor CBO staff may have time to participate in rigorous community-based research because of other responsibilities or departmental requirements. Both faculty and CBOs may have differences of opinion as to how much involvement CBOs want or should have in the design of a study and the analysis of the data. The question of what knowledge, skills and capacities remain on both sides when the study is over and the sustainability of the relationships between researchers and CBOs over time should be addressed at the outset. University ethics review requirements may supersede those of research NGO human subjects research requirements, adding time and additional costs to study initiation. At the same time university ethics review boards may not fully understand or consider community

research contexts, missing important human subjects concerns. Finally, the challenge of managing resources to ensure equitable allocation of funding across partner institutions that supports the real cost of the study must be negotiated throughout the life of a study. Many of these issues must be addressed regardless of whether the base for a CBPR or PAR project is an organization like ICR or a university. Finally, while both CBPR and PAR/YPAR can be conducted from a university base, both require extensive, consistent and sustainable community connections. These connections can best be generated when organizations like ICR act as research negotiators, linking universities and communities by choosing both community and university partners compatible with community interests, and by virtue of their place and space, ensuring the voices and equitable participation of communities in the research and decision-making process.

PAR and CBPR have become “the people’s science”, integrating reflections on identity, and negotiation of power, knowledge and resource sharing between researchers and the communities partnering with them to achieve community futures. In sympathy with the community development approach both PAR and CBPR have been able to stand alone, join forces, or act as an initiating force for community development. At the same time, the primary focus of PAR is to train communities to use research as a means of enhancing their ability to advocate for themselves on an issue based on scientific evidence. The primary focus of CBPR is to coordinate researchers and community entities to generate and implement research based potential solutions to community problems. PAR transfers research technology for advocacy and organizing; CBPR develops collaborative research based solutions to community problems. Separately they can be effective; together they are an indomitable force for community change.

The models we have described here emerged in the U.S. context where funding for CBOs and NGOs is widely available and funding for research collaborations can be obtained by research NGOs alone or in collaboration with community and university partners. Though financial and support structures may differ, there are multiple examples of community organizations involved in various forms of CBPR/PAR across the globe. International NGOs such as Population Council and the International Center for Research on Women work with both university colleagues

and NGOs/CBOs on the ground. There are also many examples of university based cross-disciplinary research centers that have more flexibility and outreach capacity than departments and schools. Europe has a longstanding tradition of science shops or other models in which communities work with universities to accomplish needed community tasks which has now become a global model linked through Living Knowledge: the International Science Shop Network (<https://www.livingknowledge.org/>). Universities, research NGOs and CBOs with research interests each have unique capacities. Approaches like the ICR model thus may take different forms in different locations depending on infrastructure, local needs and local political considerations. Building on the Living Knowledge/citizen science approach, it is possible to envision regional and global networks of cross-institutional partnerships dedicated to community-based research for concurrent science enhancement and the promotion of social justice through community participation and community voice.

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**Jean J. Schensul**, Ph.D. Senior Scientist and Founding Director,  
Institute for Community Research, 146 Wyllys Street, Hartford,  
CT. 06106. [Jean.Schensul@icrweb.org](mailto:Jean.Schensul@icrweb.org)