### The Trustworthiness of Research: The Paradigm of Community-Based Research

Catherine Jordan, Susan Gust, Naomi Scheman

#### **Abstract**

The authors — a scientist, a community activist, and a philosopher and former university administrator — describe issues of trust surrounding traditional versus community-based research. We draw on our experiences in a research collaboration that engendered trust, created sound scientific data, and made real social change. We describe GRASS (Grass Roots Activism, Sciences and Scholarship) Routes, an initiative we have undertaken to promote trustworthiness as a core virtue of research, researchers, and research institutions.

Questions about trust and trustworthiness are very much in the air these days, from evaluating the evidence presented as reasons for going to war to weighing the claims made about global warming; from genetically modified plants and animals to the nutritional benefits and harms of various diets. Research universities, especially public ones, which are dependent on state funding and have special responsibilities to the citizens of the state, have important roles to play in ensuring the trustworthiness of much of the information on which we all rely. While much of the fiscal crisis currently facing public universities is the result of more general economic woes, there has been, even when the economy was booming, a steadily declining commitment to support for higher education on the part of most states.

We suggest that one explanation for this decline is a growing climate of cynicism of authority in general and research-based expertise in particular. We will argue that the mistrust of researchers, their claims, and their institutions stems from the ethos (the characteristic and distinguishing elements) of the conventional practice of the scientific method itself. As a response to the current cynical climate we argue for a fundamental shift in the academic research culture; one that takes the ethos of community-based research as the preferred approach to instilling trust in the research enterprise. Terminology in this area is diverse and contested and our use of the broadest term, "community-based research," is in some ways better captured by the more explicit terms used by some researchers, such as "community-based participatory research" or "action research." Those terms, however, generally refer to social scientific and directly policy-oriented research, while our argument will be that the practices and norms we discuss are not at all limited in scope and can be equally applicable to basic scientific research.

We do not, of course, want to suggest that all research ought to be community-based, not even in the most expansive of the many ways one can interpret the term. Rather, we argue that the core community-based research value of trust should serve as a criteria by which research more generally is conceptualized, practiced and evaluated, much as the norms and practices of laboratory science have implicitly or explicitly played that role.

Despite the sense of many members of the university faculty that they have little or nothing in common with their colleagues in different colleges, there are ways in which it is important to think about the university as a whole. For one thing, that is how researchers are most often thought about by the public with which they interact: when one research group approaches a community, the spirit in which they are received will have a lot to do with the actions and attitudes of others who preceded them. And, as administrators are coming more and more to recognize (largely as a result of well-publicized lapses in research integrity), the role that universities play in lending credibility to the claims made by academic researchers carries with it an obligation to cultivate and sustain a research climate of social and ethical responsibility.

Several years ago the University of Minnesota was required as a condition of clearing its "exceptional status" with the NIH (imposed as a consequence of a transplant surgeon's marketing of an anti-rejection drug without FDA approval) to initiate training in the "responsible conduct of research" for all members of the university community involved in any way in research activities. Subsequently, a similar requirement has been imposed nationwide. This creates an opportunity for a serious exploration of just what beyond regulatory compliance might be meant by "responsible conduct of research." It is far from clear that this opportunity is being seized and the present essay (and the initiative out of which it springs) is an attempt to open up this conversation. We feel that this conversation is one that must take place at all levels of the academy. In fact, we believe that the manner in which this question is answered will be of critical importance in determining the role that universities and university-affiliated researchers will play in the 21st century. We have taken on the task of convincing our colleagues of this.

We approach this project from three distinct perspectives: Gust is a longtime community activist and organizer in the Phillips Community of Minneapolis. The Phillips Community is one of 11 communities defined by the city of Minneapolis and is also a state planning district. Jordan is a research and clinical pediatric neuro-psychologist whose research has focused on neurotoxicology and development. Scheman is a philosopher and former administrator working in feminist and other liberatory epistemology, whose intellectual skills lie mainly in integrating ideas and articulating them for others who may make use of them. Our conviction about the broadly transformative possibilities of the ethos of community-based research is rooted in the work of two reflective practitioners (Gust and Jordan), with at least one foot apiece firmly grounded in the needs and values of the community and of science, respectively, whose reflections became entwined with those of a philosopher (Scheman) who was using trustworthiness to provide a conception of scientific

objectivity that would work in a diverse democracy (Scheman, 2001). Together we have arrived at what we feel is a critical axiom: The value of research is a direct and primary consequence of its "trustworthiness."

Trustworthiness is what makes it rational for people to accept research findings — to build future research upon them, to utilize them to inform public policy, and to use them to guide individual choice and community action. The standard explanation for why lay people ought to believe what experts tell them rests on the paradigm of laboratory science. This paradigm is considered the research methodology that best controls for the subjective biases, confounding variables, and other sources of "noise" that are said to undermine the objectivity of research. However, this control is meant to reduce or nullify the effect of much of what we care about if we take social, ethical, or political trustworthiness seriously. That laboratory science serves as a paradigm can be seen in the premium placed on the researcher's ability to separate both the object under investigation and the investigator from the contexts in which they naturally occur. The former is extracted, purified, placed in a sterile environment, and otherwise isolated from confounding variables; the latter is decontaminated, white coated, rubber-gloved, stripped of conflicts of interest, and, in reports of the research, masked behind impersonal prose. That these norms of detachment, call them the "standard norms," are seen as definitive of objectivity creates problems for research on human beings in general, but especially for community-based research. In fact, community-based research rather than acknowledging the norms and attempting to apply them as strictly as possible, blatantly flouts them. Instead of attempting to retreat to disinterested disconnection the ethos of community-based research calls on researchers to move toward responsible connection. Objectivity understood as trustworthiness requires of researchers not detachment but, far more rigorously, responsible engagement; not the pretense of being a disinterested observer but the commitment to listening to and learning from a diverse group of individuals and communities who have a stake in the research product. Far from shrinking from this unorthodox rejection of the traditional paradigm, we propose that if we view trustworthiness as fundamental to the concept of objectivity, community-based research is a better way to realize objectivity than research that attempts to emulate the standard norms.

Although trust is at the heart of community-based research, it is neither easily come by nor easily sustained in the face of challenges from all sides, most importantly from the grass roots communities it needs to engage and from the scientific communities it needs to persuade. Through the lenses of our experiences at the University of Minnesota and in a Minneapolis neighborhood, we want to articulate the issues of trust surrounding traditional approaches to research and community-based research and to explain how a particular university/community research collaboration engendered trust, created sound scientific data, and made real social change. We then want to outline the principles and some of the projects of an initiative we have undertaken to use what we have learned about trust building to promote trustworthiness as a core virtue of research, researchers, and our research institution. We want to note that our perspectives are rooted in our commitments to economically disadvantaged, racially and culturally diverse, inner city community activism; traditional, empirical scientific

method; and public, land-grant research university administration. We will not attempt to generalize to different contexts (rural communities; qualitative, survey or humanistic research methods; or private universities, for example), though we do hope that our discussion will be useful for those who work at such sites.

## The Context: The Phillips Neighborhood Healthy Housing Collaborative

Jordan and Gust have been working together for nearly 11 years in a community-university collaborative, the Phillips Neighborhood Healthy Housing Collaborative. The collaborative was initiated in 1993 by community leaders who invited the University of Minnesota, local businesses, community-based organizations, a foundation, and, eventually, local and state health department personnel to join forces to address Phillips Community lead poisoning concerns. The collaborative has sponsored two federally funded community-based research projects. The DREAMS Project, funded by the Maternal and Child Health Bureau, studied the developmental effects of lead poisoning in Phillips children from eight months to 48 months. The Phillips Lead Poisoning Prevention Project, funded by the Maternal and Child Health Bureau and the Centers for Disease Control and Prevention, studied the efficacy of an intensive, culture-specific, peer education program in maintaining low blood lead levels in Phillips children from birth to age three years.

In forming the collaborative, the community did not initially set out to use research as a tool for achieving its environmental health goals. The academics convinced the neighborhood activists that essential data were needed before any credible campaign could be mounted by the neighborhood to effect change in public policy and enlist politicians and health care professionals in an effort to effectively deal with the problem of lead poisoning. The necessity of a well-conceived research project (including a control group) was not initially well received by the residents and activists in this newly formed collaboration. It took several years to come to agreement regarding the design of the research project because of mistrust and a host of barriers including cultural differences, feelings of "less than," prejudices on both sides, varying norms and practices surrounding the concept of volunteerism, different problemsolving styles, and varying approaches to dealing with conflict. Yet it was the very practice of working through the issues that seemed to separate us that allowed us to build not only a sustainable collaboration but also two grant-funded community-based research projects that spanned five years of data collection and four years of dissemination (e.g. Hughes, Jordan, Roche, and Shapiro, 2003; Jordan, 2001; Jordan, Hughes, Roche, and Shapiro, 2004; Jordan, Hughes, and Shapiro, 2003; Jordan, Lee, Hampton, and Pirie, in press; Jordan, Lee, and Shapiro, 2000; Jordan, Yust, Robison, Hannan, and Deinard, 2003; Phillips Neighborhood Healthy Housing Collaborative, 2000; Robison, Jordan, Hughes, Zelinsky-Goldman, and Shapiro, 2003).

Phillips Community, a large, economically disadvantaged, and ethnically diverse urban community, has served as the incubator for the thoughts discussed by Gust and Jordan

in their own voices, in sections below. Out of their experiences in Phillips came an understanding of the widespread mistrust of research by communities and the skepticism directed toward community-based research by researchers trained in the standard norms. They also developed passionate beliefs about the benefits of community-based research to communities and to the research enterprise.

# Trustworthiness and Community-Based Research: The View from the Community

As individuals within communities, we all intuitively know that we are affected by research, but we do not often contemplate this fact. We mostly let research happen and either reap the benefits through, for example, more and improved choices, treatments, policies, and technology, or, on the negative side, complain about inadequate designs, unfair policies, or high costs. As in the political process, we do not fully use our rights and expertise as citizens to participate in the research process or in the forming of research-based policies; that this is a possibility may not even occur to many of us. Yet, while we may abdicate our responsibility out of apathy or ignorance, we are left at some level with the awareness that we are truly excluded, do not know how to get involved, do not believe our opinion would be appreciated, and do not even know if we truly have valuable expertise. Yet, just as in the political process, the research process would undoubtedly be better at meeting our basic human needs or improving the overall health of our communities if more of us knew how to be thoughtfully involved and respected in the process.

The consequence of this "research disenfranchisement" is that traditional research, like "politics as usual," has come to be mistrusted. Reasons for this mistrust include:

- Traditional researchers are perceived as undertaking a project primarily for their own personal, professional, or institutional gain. The fact that they might actually care about how their work contributes to the common good or that they may care about the community is hidden from the view of the community and the research "subjects" through the practice of detachment.
- Being a cooperative subject in a traditionally designed study requires one to be subordinate to the researcher. In communities of color, economically disadvantaged geographic communities, or communities of specific concerns, this feeling of subordination is compounded by other feelings of being "less than" in areas such as education levels, economic class, employable skills, disease or impairment. Why should one choose to associate with another individual or institution when that association contributes to a feeling of decreased self-worth?
- Traditional researchers do not often share their findings with research participants in a way that would allow participants to use the information. The perceived and sometimes stated reason for this neglect is that the research is too technical or too preliminary for consumption beyond the scientific literature. In addition, researchers sometimes simply get too busy to follow-up on promises to provide summaries of findings to participants. The community gets the message that we are not to be considered as equals or peers; that we are not smart enough to understand the

- research, let alone put it to good use; and that research, however popular in scope, is really for the advancement of the individuals and the institutions that conduct research, who apparently don't have the time or interest to communicate results to those who made the research possible.
- As we see it, the primary issue is power: who has it and who gets to use it. In a democracy, power is shared; we all have it and have the right to use it. But in traditional research, the thinking seems to be that the research will be more sound, more valid, more "trustworthy" if one entity (the researcher) has more power over another (the "subject"). Why should communities become involved with researchers or institutions that appear to be acting primarily in their own self-interest, reinforce participants' awareness of their relative powerlessness, and take no action to share the franchise and privilege that the researchers clearly possess?

Consequently, although we acknowledge that research shapes our lives, from the design of the cars we drive to the methods available to us to birth our children, it seems reasonable, even rational, from a community perspective to mistrust researchers, their methods, and their findings. We strongly believe that community-based research, when done well, holds the key to overcoming the mistrust left in the wake of years of traditional research and to achieving the dramatic, positive change that is possible when everyday citizens act in partnership with progressive researchers using rigorous scientific methods.

Community-based research is, by definition, good for communities. Its goal is to address issues that communities have defined or recognized, in a manner that allows them to act on the resulting information. Through community-based research, communities are empowered both because their resources and assets are recognized and strengthened and because the expertise of researchers and the resources and power of a university are brought alongside their own political will. The capacity of the community is increased through skill-building and economic security because its members are employed whenever possible to conduct the research. In the Phillips Community projects, the community-based research model benefited the community in the following ways:

- Resident leaders learned and taught specific skills and transferable techniques to level the playing field between residents and nonresidents. For example, we used no titles, only first and last names; we celebrated each other's life events; we socialized with each other's families during annual picnics; and we paid residents a stipend for attending collaborative meetings to acknowledge that they were offering their expertise and experience just as the researchers were offering theirs.
- Community residents were as valued as the researchers because we were teachers as
  well as learners, just as the researchers were. This reciprocity helped residents value
  their nontraditional skills, intuitive knowledge, and learned experiences and to see
  them as of equal importance to the more formally acquired knowledge and skills of
  the researchers. Some residents experienced considerable boosts in self-esteem and
  were able to make improvements in other areas of their personal and professional
  lives.

- Generally, compared to faculty participants, residents were collectively more
  accepting of conflict and able to express anger because conflict is part of our daily,
  community life. Since conflict is often a necessary component of change, residents'
  comfort level with conflict meant that we could sometimes make changes more
  openly and swiftly than the researchers. The researchers valued this capacity and
  some made concerted efforts to improve their own ability to deal openly with
  conflict.
- Residents were also more easily accepting of their own and each other's intuitive
  knowledge and the use of emotional expression as a way of forming and sustaining
  the collaboration. Therefore, they often were able to take leadership in designing and
  sustaining the collaborative model. Researchers and other nonresidents were able to
  learn ways of integrating their personal and professional lives through these
  collaborative relationships while still maintaining the boundaries essential for a
  research project.
- Community residents increased their knowledge about lead poisoning and about the
  value of the scientific method because the researchers taught and modeled the
  principles of scientific integrity and rigor. This information increased residents'
  ability to protect their children's health and to evaluate and use scientific data in
  order to make individual choices.
- Community residents filled the majority of the staff positions on the two research projects. These residents, representing the ethnically and culturally diverse demographics of the community, received comprehensive training, were paid living wages, and received health benefits. Numerous resident employees were able to transfer the skills and experience acquired to subsequent positions that advanced their vocational goals.
- Parents who received lead poisoning prevention education through the lead
  prevention project commented that their positive relationship with their peer teacher
  and the project as a whole helped them to feel valued, to complete the three-year
  participation commitment, as well as to make the behavior changes necessary to
  maintain a lead-safe environment for their child.
- In the dissemination phase of this project, the community as a whole was valued by presenting the resulting data within the community before disseminating the information to academic journals. Community residents and researchers have partnered in presenting data both to journals and to the community media.
- The credibility gained by the community through successful completion of two multi-million-dollar research projects and sustaining an ongoing collaboration with the University of Minnesota, despite many cultural differences and systemic barriers, has facilitated our ability to change local public policy around environmental health issues. The city of Minneapolis now has a comprehensive, inter-agency, public-private partnership to address the childhood lead poisoning problem and other childhood environmental health issues.

### **But Is Community-Based Research Good Science?**

There is a perception that community-based research is a methodology in and of itself, and that it is more qualitative or "soft" than traditional research. Although community-

based research has been used more extensively in the social sciences, any discipline can employ a community-based research approach. It is important to state that community-based research is an approach to a research process that does not dictate the methodology. Methodology is called for by the research question; basic or bench science could be part of a community-based research initiative. Community-based research is understood by its practitioners to benefit the research at all stages, including conceptualization, design, implementation, dissemination, and application, and thereby to strengthen the validity and utility of the results. However, it is sometimes criticized by professional colleagues, administrators, grant reviewers, and journal editors as inferior to approaches employing the standard norms, in which researchers control and conduct all phases of the project, and researchers, participants, and the issues studied are distanced from each other as much as possible.

This mistrust of community-based research likely stems from the cultural rift between academics and lay communities. Academics, and particularly scientific researchers, are socialized to view themselves as the experts and are trained to view issues narrowly, with precision, and in a reductionistic manner. Communities value the larger picture, the context, the relevancy and applicability of information, and the manner in which they are treated in the process of research. The criticisms that result focus in part on the belief that community-based research requires sharing power and decision-making authority with non-researchers and to address the sometimes competing demands of the community will compromise the rigor of the research. A second set of criticisms focuses on the potential for bias, because the research participants or others in the community close to the research issue have input into design, implementation, and data interpretation. Finally, community-based research is sometimes viewed as locally limited and not generalizable to a broader population or to other locales.

The first two criticisms do not apply when community-based research is done appropriately. As part of the sharing of expertise within the collaborative relationship, researchers must communicate why the scientific method or particular research process will produce findings that will be valuable to the community and why this approach will increase their power to make change. If it's true that the research will be better when, for example, the researchers are detached from the interests that lie behind the research situation, they ought to be able to make that case, and they are obliged to do so. If they can't of if they insist on a model of scientific practice that they can't explain and justify, then there ought to be serious questions about the rationality of placing trust in them. Attention to scientific method, elements of research design, threats to validity, sources of bias, and risks of going beyond the data when interpreting findings is vital because it is rational to place greater trust in research and researchers that attend to these matters than in those that don't. Especially when coupled with researchers' demonstrated respect for communities and concern for the consequences of their research, we have found that community members come to recognize the need to be guided by the researchers when necessary on matters of research integrity. This process of education and justification is likely to be time-consuming and frequently contentious but the reward is that academic and community collaborators can become

co-investigators committed to creating a well-designed project, to preserving the rigor of the research design, and to accurately interpreting data.

The third criticism, concerning the alleged lack of generalizability of research findings, can apply to community-based research, just as it can to any form of research, depending on the topic and research design. But there is nothing about community-based research that makes its results necessarily less generalizable. For example, in the lead poisoning work in the Phillips Community, findings regarding peer education efficacy and developmental effects of lead poisoning are certainly generalizable to other diverse, urban populations, which happen to be just the populations most relevant to the topic. Moreover, the richness and texture of local data can provide insights into the complexities of the phenomena under investigation that traditional approaches to research could only attribute to noise or random error. (This point will be discussed further below.)

It must be acknowledged that conducting community-based research surely does require more work than traditional approaches in order to control for threats to validity, rigor, and potential bias. That work is often in the form of building trust; trust of the community's expertise and trust of the researchers' intentions, knowledge and training; and of the scientific method. Though not directly applicable to all sorts of research, the respectful engagement that characterizes community-based research provides a paradigm of what trustworthy research looks like. This engagement occurs at all stages of the research. Advantages of the community-based research model at each phase of the research process are presented below, using illustrations from the Phillips Community experience, with the aim of demonstrating why the extra investment required by community-based research is worth it and why colleagues, grantors, public policymakers, and editors should trust the information produced via community-based research approaches.

Conceptualization — Conceptualization is the process of framing the right research question. Research questions can be designed in a way that increases meaningful understanding of a phenomenon or provides only partial, superficial or narrow understanding, appropriately handles confounding variables or ignores their presence, and increases applicability of findings or restricts it. The conceptualization stage is one of the most important determinants of whether research findings will have relevance and impact. Community-based research is an ideal approach for increasing the depth of understanding contributing to the conceptualization process.

There are many research questions that tolerate, or even require, use of the standard norms. However, when you apply the standard norms to research with people and communities, particularly research that will inform public and social policy, you risk drawing incomplete and narrow conclusions. A standard norms approach to research creates artificial constriction of the scope of investigation in that it deliberately controls for the influence of some of the factors that may be most important in understanding how the complex human world works, and it eliminates valuable sources of expertise readily at hand that can be obtained by including nonacademic

stakeholders in all stages of the research. The process of co-conceptualizing a research question with community collaborators possessing their own expertise greatly increases the likelihood that the research question will be framed in a manner that considers the many complexities and interrelationships involved, provides information that informs the scientific knowledge base, and delivers information on which the community can take action and the community can use to understand itself. Community members have considerable "local knowledge" to share with researchers concerning how a phenomenon might work in their community and often have their own hypotheses about the root causes underlying issues to be studied. A collaborative research approach means that researchers will have greater trusted access to community-held information and knowledge. This information allows researchers to understand the topic more deeply, to identify more potentially confounding variables, to generate more alternative hypotheses, and to try out research hypotheses against a wider range of critical perspectives.

In the Phillips collaboration, neighborhood residents assisted researchers in conceptualizing lead poisoning and its effects as one set of variables within a complex web of factors and issues related to substandard housing, environmental discrimination, eviction, fear of homelessness, poverty, social justice, inadequate education, health care access and quality, etc. As a result, the questions asked and the data gathered, particularly in relation to the developmental effects of lead poisoning, address multiple biological, demographic, environmental, home, parental, and community variables. Collection of detailed data on variables that may be involved in such complex interactions is allowing for sophisticated modeling of predictors of children's developmental outcome.

**Design** — Design is the process of creating ways of testing the research question so that it can be answered definitively and in its entirety. This is the stage when plans are made for how to recruit participants and sustain their participation, how to reliably deliver an intervention if the study is an experimental one, how to measure variables of interest in a standardized and controlled way, how to analyze data, and how to protect the project from situations that would compromise the ability to draw accurate conclusions. The expertise of community members can be invaluable in these efforts. Community members know how they would want to be approached to participate in a project, what would allow them to trust the intentions of the research, and what incentives would motivate them to join and continue participating in the study. They can anticipate when questions, measures, or procedures would be offensive, threatening, or culturally insensitive. And they may be able to predict when situations in their community might pose a threat to the validity of the project. For example, Phillips Community residents informed researchers of the city's policy to make birth records public only for children of married couples. Had we implemented birth record searches as a primary recruiting mechanism we would have introduced significant selection bias.

**Implementation** — Implementation is the process of setting the design into motion. It is the actual recruitment of participants, application of an intervention if called for,

collection of data, and analysis of data. Community partners can provide information that facilitates implementation and avoids situations that would threaten the feasibility of the study. For example, Phillips Community residents informed researchers of the city's policy to condemn homes contaminated by lead, forcing families to move, sometimes to shelters or the streets. We were thus able to predict that our project might result in increased condemnations because of our frequent monitoring of blood lead levels and that this might deter participation. We were able to take preventive steps including working with collaborative residents to change the city's policy and create a "safety net" providing lead-safe transitional housing and advocacy for families affected by high lead levels.

Community-based research projects typically hire individuals from within the community to conduct much of the research during the implementation stage. The project benefits through improved recruitment rates, lower attrition, increased compliance, improved accuracy of reported information, and fewer cultural and language barriers. These all strengthen the validity of the data. In the Phillips lead poisoning projects, program evaluation focus group participants stated that they might not have joined the project if a researcher, social worker or nurse had approached them, because residents mistrusted these professions and found them to be judgmental in the past (Jordan, Lee, Hampton and Pirie, in press). Community staff was not suspected of having an ulterior motive (such as career advancement) and their personal experience as a community member or as a parent (or as a parent with a lead exposed child) added to their credibility. Researchers observed that community staff was able to establish warm relationships with participants because they shared similar experiences, culture, and language. The connection with a peer seemed to maintain participants' involvement and compliance. The sharing of more personal information, than would have been the case had participants been interviewed by academic researchers, was vital to the collection of accurate data on confounding variables. Community staff established trust and rapport with participants and were therefore able to project confidence in the researchers' intentions and the appropriateness of the project's goals and ethics.

Interpretation — Interpretation is the process of constructing a story to explain the results. It is the process of making meaning out of information, often numbers, that seem disconnected and abstract. This stage requires the ability to integrate various pieces of information, generate possible explanations for how they work together, and anticipate the implications of various explanations. Because individuals tend to view such information through their own lens, whether research training, disciplinary expertise, or lived community experience forms that lens, this stage is vulnerable to tunnel vision and personal investment. This is as true of the researchers as of the non-researchers. The participation of all collaborators in this process provides a system of checking the accuracy and rationality of interpretations against each other. Rather than create subjectivity, this part of the community-based research process tends to create a balance between various "takes" on the data, and therefore, greater objectivity. Consideration of multiple and sometimes diverse interpretations of the data can lead to appreciation of the complexities inherent in the object of investigation and prevents oversimplification of the model constructed to explain the phenomenon.

Co-author Gust, the primary community research collaborator, participated in discussions with researchers regarding the interpretation of the data from the lead education project. Her expertise in commercial and residential construction and remodeling as well as her knowledge of the history of housing practices in her neighborhood allowed us to more effectively understand the sources of lead contamination within the homes of our participants. In addition, she, far more effectively than the researchers, was able to understand the implications of the results of the project for policy change recommendations.

Dissemination — Dissemination is telling the story to an audience. In traditional models of research, findings are reported in the scientific literature as the primary (or sole) method of dissemination. Sometimes the media may pick up on research data or investigators may seek out the media, resulting in broader dissemination. However, for the most part, traditional researchers tend to target their research reports to their peers. The result is that the translation of research data into public knowledge or practical application is very slow and non-deliberate and is typically out of the control of both academic researchers and community members. In community-based research, the results of research projects reach a wide and diverse audience because many people have become stakeholders in the data, possibly including community members, policymakers, organizations, as well as scientists. As stakeholders, these groups and individuals are not only interested in receiving the information resulting from the study, but likely to participate in further dissemination of information within their own circles.

After the completion of the lead prevention education project in Phillips, community members and researchers collaborated in writing an insert for the neighborhood's newspaper. This 12-page document not only featured articles by researchers concerning the findings of the study; but also included articles by community residents addressing their personal experiences as participants in the project and the importance of the community-based research model in reducing lead poisoning in the neighborhood, creating accessible information for the community, increasing the skill-base and leadership potential within the community, and empowering the community to take action on the information provided via the research. The insert was published prior to any scientific journal articles in order to communicate respect for the community as the primary stakeholder in the resulting information. Years later we continue to receive calls from readers seeking to use this information in their professional work or personal decision-making.

**Application** — Application is using the data to guide decisions and to make changes. In traditional models of research, there is little focus on how research findings will be put into practice by others. In fact, the research process typically ends after dissemination, except when the researcher or other investigators utilize research findings to inform the generation of additional research questions. A fundamental tenet of community-based research is that information resulting from a research project is used to make change, such as in social programming, environmental regulation, medical practice, public health policy, or law enforcement. Having results applied

within such arenas provides feedback about the data's ecological validity and can raise additional questions for the community to investigate that ultimately lead to a more complete understanding of the topic of study.

Information accumulated throughout the Phillips lead prevention project and through data analysis has been utilized by Department of Health programs and non-profit agencies to design a comprehensive, interagency, public-private lead poisoning prevention program that combines educational and environmental approaches to prevention of lead poisoning.

In summary, the public has come to mistrust traditional research paradigms in which research "subjects" are placed in relatively weak positions of power that parallel societal power structures and in which participants or communities rarely hear back from researchers much less directly benefit from the research process or its findings. Community-based research holds much promise in the eyes of community members because it equalizes power, addresses a need the community identifies as important in a manner the community defines as acceptable, directly benefits the community by addressing the need and supporting the economic, skill, and leadership development of the community, and increases the capacity of the community to utilize resulting information to take action. Yet community-based research is often mistrusted within academia and the systems that support it, mainly granting agencies and journals. It is argued above that the community-based research approach benefits the research at every stage of the research process and that typical criticisms of decreased rigor, bias, and lack of generalizability are not warranted. Heightened understanding within academic communities of the benefits of the community-based research approach to the research itself, as well as the increased impact of the research on society's problems, should result in increased trust of community-based research. With greater trust we may see a willingness to apply the ethos of the community-based research process to more traditional research methodologies and a shift in the research cultures within academia, granting agencies and journals.

# Community-Based Research as a Model for Institutional Change: GRASS Routes

In 2000, Scheman, a philosopher and feminist epistemologist, was introduced to Gust and Jordan because of her interest in the importance of trust to the mission of research universities, and in the part played by demonstrated commitments to social responsibility and social justice in grounding trustworthiness. At the time the three began working together, Scheman was about to become an associate dean in the graduate school. University administration provided her, through work with Gust, Jordan, and other faculty, administrators, and community members with a unique laboratory in which to practice "applied epistemology" by exploring issues of trust and trustworthiness and ways of overcoming increasingly prevalent mistrust on the part of diverse publics. She has argued that such mistrust stands in the way of the creation of truly objective knowledge and that this (very traditional) goal will come into reach

only when diverse communities become full collaborators in research as well as respected critics of it (Scheman, 2001).

The three authors first worked together on a conference, "Designing Research for Change," held at the University of Minnesota in February 2001, as part of the president's series of events in recognition of the university's sesquicentennial. The conference brought together university researchers, community members, policymakers, and funders to map the barriers they perceived to genuinely collaborative research and to begin to strategize ways of overcoming them. The participants identified barriers to community-based research and, specifically, the challenges to forming the respectful, trusting community-university partnerships that are essential for this work to successfully occur. The work of the conference participants laid the ground for the authors' subsequent development of GRASS (Grass Roots Activism, Sciences and Scholarship) Routes, an initiative to support preparation for and facilitation of community-based research at the University of Minnesota, and to help extend the ethos of community-based research as intrinsic to the university's research mission. The development of GRASS Routes has coincided with the work of the university's Council on Public Engagement, which helped to raise the profile of and to better prepare the ground for community-based research as one among many ways in which the university, in its teaching, research, and service missions, can more fully engage with diverse communities. It has been gratifying to discover just how timely the ideas from the conference and GRASS Routes are, not only locally, but nationally, as many people and institutions grapple with the changing face of the public research university and its relationships with the publics that are called upon to support it and that it is intended to serve.

In response to the energy and enthusiasm of the participants in the "Designing Research for Change" conference, and their rich ideas regarding barriers to community-based research, Jordan, Gust, and Scheman developed GRASS Routes with the aims of bringing together and making accessible the forms of knowledge that reside in diverse locales, from community to laboratory, in the conviction that together they will show the way from research need or idea through to the dissemination and use of research findings. This initiative has received financial support from the university's Academic Health Center, graduate school, and central administration. The activities of GRASS Routes focus on four major areas of need identified by conference participants.

First is the need for education of faculty, graduate students, and community members in methods and skills of collaborative research. Second is the locating of intersections, the matches of interests and abilities between community groups and university researchers. Third is the need for mentorship of collaborations to ensure sustainability. And fourth is the dissemination of research findings, within the community and more broadly, thereby making them available where they will do many sorts of good: empowering the community for change, informing and influencing public policy, and raising the profile of collaborative research within the university and in academic journals.

Several sets of activities have been conducted or planned to address each area of need. For example, a faculty development seminar series was aimed at providing practical skills; teaching principles of community-based research and its parallels, community-based education or service learning; preparing faculty for typical hurdles; assisting faculty in solving problems in their community-based work; and more generally, increasing the appreciation of trust, power, and privilege as the fundamental issues to address within partnerships. As a result of this faculty development series, it is expected that faculty will increase their community-based work and will serve as ambassadors, promoting the ethos of community-based research within their own disciplines and academic units, integrating concepts into their teaching and mentoring, and recruiting additional faculty and students into this work. GRASS Routes is also developing a series of Responsible Conduct of Research forums on the ethics of community-based research.

A network of university and community members are being recruited to serve as guides, available to meet with community members in their own locales, to help navigate the enormous complexity that makes up the university's research capacity. These guides will help communities frame their ideas and questions; search for faculty with relevant expertise, time and interest; and facilitate introductions of community leaders to these potential research partners at the University.

All collaborations run into problems along the way, and short-term assistance from others who have witnessed or weathered such storms can help to deal with miscommunication, mismatched expectations, conflicts of personality or style, and inevitable stretches of frustration and explosions of anger. GRASS Routes has provided mentorship to an interdisciplinary faculty/student initiative within the Academic Health Center as they designed a community learning experience within a local community clinic. In addition, networks of experienced university faculty and community members will be recruited to serve as mentors to collaborations wanting assistance forming trusting relationships or resolving problems.

Finally, funds will be raised for a small grants program that will be called the PUBLICation Fund. Grants will be given to community-based research partnerships seeking to disseminate research findings to immediate stakeholders (community residents, community-based organizations, policymakers, etc.) via nonacademic vehicles. For example, if it was important for high school students to receive information resulting from a community-based research project on sexual health, the PUBLICation Fund might grant money for the production of an interactive theater piece to be performed at high schools.

### Conclusion

Alongside the forces that push today's public research university toward corporate funding, entrepreneurial profit-making, and conservative ways of evaluating research, there is another, at least potentially opposing, trend in higher education. Colleges and universities are increasingly including what is usually called "service-learning" in their

undergraduate curricula, and some are launching broader initiatives, like the University of Minnesota's Council on Public Engagement (established by President Robert Bruininks, then-executive vice president and provost). While traditional service-learning fits comfortably under the mantle of "compassionate conservatism," instilling the value of charitable good works on the part of the privileged, many of the broader initiatives are fueled by a deeply alternative vision, which includes ideals of community empowerment, reinvigorated democratic engagement, and social justice. In the terms of such an alternative vision, "service-learning" is re-named "civic-learning," and the transformative experiences are aimed at graduate students and faculty as much as undergraduates.

We want to argue that public universities cannot afford to give up on a claim to broad-based public support, and that in order to earn such support, it is necessary to embrace the ideals articulated in that alternative vision. Community-based research is not the only way in which research universities can realize those ideals, but it is both a clear expression of them and a way to build the sort of good will and spirit of civic engagement that will make other projects more feasible. Community-based research projects, especially when embraced by the university as something to be especially proud of and to vigorously support, can do a great deal to change the image of an aloof and arrogant institution and provide grounds for those outside of it to trust what goes on within. And the core ethos of cultivating mutual trustworthiness is one that can serve as a guide even for research quite distant in approach from community-based research, much as the ethos of laboratory science has served as a paradigm of objectivity in a wide range of fields even outside the sciences.

Trust, especially trust in academic research, is among the most important resources that research universities need to draw on. Most fundamentally, research that is not trusted is worthless. Even the most basic, non-applied forms of research are meant to be taken up by other researchers and to become part of larger, shared bodies of knowledge and theory. Despite the expectation of replicability of research findings, there is no getting away from dependence on webs of trust in the work of contemporary and earlier researchers.

Beyond being taken up by other researchers, most research directly or indirectly, sooner or later, enters into a broader public context in which the trust of non-scientists is relevant, and that trust is all too often lacking. Public mistrust of academic research is a frequent occasion for faculty and administrative lament. It is intrinsically frustrating to have something one regards as valuable and useful scorned, especially by those for whom one intended it to be useful. More practically, trust in the research done at a public university contributes to the willingness of the state's citizens to support the university with their tax money (as well as to want their children to be educated there). The erosion of that trust is arguably a significant contributor to the national mood of pulling back on such support.

Universities and those who run them also ought to be, and frequently are, concerned about how well or badly, rationally or irrationally, ordinary people form beliefs. One of

the principle tasks of universities, especially in democracies, is to help to raise the general level of informed, critical discussion, debate, and belief-formation, both directly by educating some people and indirectly by educating the parents, teachers, and others who help to shape us. It seems abundantly clear that there has been massive failure somewhere along the line: most people tend to be either credulous or cynical, or some odd combination of both when it comes to most of the questions that are vital to our individual and collective well-being, whether in the realm of food safety or national security, history or economics. The blame can be spread around widely, but it's important for universities to take responsibility for their failure to consider the possibility that it might not be rational for members of diverse publics to trust academic research.

Especially public universities, out of a concern for the recognized social value of the research done there, need to attend to what typically are regarded as peripheral issues of social justice. Differences that mark inequities of power and privilege, such as race or ethnicity, class, gender, or sexual identity, affect not only the psychological likelihood of trust, but also its rationality. It is not rational to trust those who have a track record of disrespectfully treating members of a community you identify with, or whose publicly reported views about your community seem to be either lies or stupid mistakes, or who take no interest in what members of your community have to say to them or in the effects that their views about your community have on the people in it. Given the depth and pervasiveness of social, political, and economic inequality in the United States today, it needn't take malevolence or malfeasance for researchers to act in ways that give rise to such perceptions. Ordinary, orthodox scientific method is frequently sufficient, given the gulf that already exists between poor, immigrant, and/or racially stigmatized communities and "institutions of higher learning," which, whatever else they do, serve to train and educate the ruling and managerial elites and to produce knowledge useful to them.

Ironically, part of the problem lies in the norms that are designed precisely to underwrite trustworthiness, as understood from within the university: the standard norms of disinterest and dispassionate, disengaged objectivity; the cultivation of an impersonal style of writing and argument; the replacement of experience as a ground of belief with observation (measured, controlled, stripped of subjectivity or idiosyncrasy). These signs of trustworthiness, typically demanded by disciplinary training, can hardly function in the same way from the vantage point of those who see very clearly the complicity of universities in the structures of their subordination. From such a vantage point what seems to be going on is an elaborate shell game, where the interests being served may never actually be visible, but are nonetheless guiding the enterprise.

Universities have increasingly taken on, or been given, the task of certifying that research meets certain ethical standards through, for example, institutional review boards for research involving human participants and, more recently by federal mandate, of educating researchers in the responsible conduct of research. The scope of such certification and education does not, however, generally include social

responsibility, let alone social justice, among the norms of responsible research. Rather, a commitment to truth as the goal of research and protection of the individual participant is taken to be sufficient, with questions of the social consequences of research left to others (including, on the haberdashery theory of scientific responsibility, to researchers with their citizen hats on).

But this separation doesn't work. Those outside of the university who are taken to be objects of knowledge rather than knowing subjects, and are researched only by people who do not also listen to and learn from them, will, insofar as they are rational, be mistrustful of university-based research. The absence of their voices will seriously compromise the dissemination and acceptance of the research and, even more seriously, its very objectivity and validity.

The methodology of community-based research is grounded in the conviction that a pluralistic democratic conception of knowers enriches rather than undermines empirical scientific research. When those whose lives and communities are being researched are empowered as knowers, alongside and in collaboration with academic researchers, the knowledge that results is more complex, better supported by a wider range of evidence, less subject to unexamined bias, and far more likely to be taken up and put to use.

### Acknowledgments

We appreciate the thoughtful critique of our ideas and manuscript by Dr. Steven Hughes. Special thanks to the families of the Phillips Community who care so deeply about the futures of their children and generously gave their time, sometimes for several years, in support of the data collection phase of the projects described in the paper. The University of Minnesota investigators participating in this project will forever do our work differently thanks to the thoughtful and tenacious teachings and leadership of the current resident members of the Phillips Neighborhood Healthy Housing Collaborative (PNHHC): James Big Bear, Jody Deloria, Susan Gust, Mary Johnson, Shannon Moon, Michelle Nickaboine, and Sheila Shavers, as well as past members: Erin Bluejacket, Wendy Boppert, Lilly Bresina, Kay and Rene' Cabrera, Rep. Karen Clark, Charles (Doc) Davis, Nicole Diaz Romero, Marc Flores, Teresa Ford, Star Grigsby, Keith Johnson, Beth Hart, Gwendolyn Hill, Mary Ellen Kaluza, Leah La Chapelle, Donna Morgan, Darin Packard, Mary Parkhurst, Cathy Strobel, Deb Terwillger, Deb Whitefeather, and Cathy Winter. We also express our tremendous gratitude to the community staff members, many of who also served on the PNHHC, for their excellent work and dedication to the research. The work of the PNHHC and its contributions to the research could not have been accomplished without the tireless efforts of its staff over the years: Carol Flavin, Kim Kelker, Ed Petsche, Kim Rowe and Jermaine Toney.

#### References

Hughes, S. Jordan, C. Roche, B., and Shapiro, E. "Two Factor Parent Model Predicts Development at 36 Months In At Risk Children." Poster presented at the International Neuropsychological Society, Honolulu, Hawaii (February 5-8, 2003).

Jordan, C. "Getting the lead out: A community-university collaborative approach," *Minnesota Physician*, September 2001, 36-38.

Jordan, C., S. Hughes, B. Roche, and E. Shapiro, "The DREAMS Project: Risks and Developmental Outcomes in Inner City Preschoolers." Symposium presented at the International Neuropsychological Society, Baltimore, Maryland (February 4-7, 2004).

Jordan, C., S. Hughes, and E. Shapiro, "Maternal Risk Factors Predict Child Lead Burden." Poster presented at the International Neuropsychological Society, Honolulu, Hawaii (February 5-8, 2003).

Jordan, C., P. Lee, R. Hampton, and P. Pirie, "Recommendations from Lead Poisoning Prevention Program Participants: Best Practices," *Health Promotion Practice In press*.

Jordan, C., P. Lee, and E. Shapiro, "Measuring Developmental Outcomes of Lead in an Urban Neighborhood: the Challenges of Community-Based Research," *Journal of Exposure Analysis and Environmental Epidemiology* (10, 2000): 1-11.

Jordan, C., B. Yust, L. Robison, P. Hannan, and A. Deinard, "A Randomized Trial of Education to Prevent Lead Burden in High Risk Children: Efficacy as Measured by Blood Lead Monitoring," *Environmental Health Perspectives 111*(16), (2003): 1947-1951.

Phillips Neighborhood Healthy Housing Collaborative, "PNHHC Supplement," *The Alley Newspaper 24* (11) (November, 2000).

Robison, S., C. Jordan, S. Hughes, D. Zelinsky-Goldman, and E. Shapiro, "Can Sustained Attention Be Measured in Children Less Than 3 Years." Poster presented at the International Neuropsychological Society, Honolulu, Hawaii (February. 5-8, 2003).

Scheman, N. "Epistemology Resuscitated: Objectivity as Trustworthiness" N. Tuana and S. Morgan, eds., *Engendering Rationalities* (Albany: SUNY Press, 2001), 23-52.

#### **Author Information**

Catherine Jordan, Ph.D., is an assistant professor of pediatrics and neurology and director of the Children, Youth and Family Consortium at the University of Minnesota. She has served in a leadership capacity on the University's Council on Public Engagement.

Susan Gust, in addition to her work as a community activist, has owned a small business for 28 years that provides community development and construction management services. She has spoken locally and nationally on the merits of forming strong community partners and how to work "in community."

Naomi Scheman, Ph.D., professor of philosophy and women studies, University of Minnesota, has served as associate dean of the graduate school. She has been active in a number of initiatives to increase access and diversity across the university.

Catherine Jordan 270A McNamara Alumni Center 200 Oak Street Minneapolis, MN 55455 E-mail: jorda003@umn.edu Telephone: 612-625-7591

Susan Gust 2221 Bloomington Ave. South Minneapolis, MN 55455 E-mail: sgustsrc@aol.com Telephone: 612-724-5753

Fax: 612-724-4183

Naomi Scheman Philosophy Room 831 Heller Hall 271 19th Ave. S. Minneapolis, MN 55455 E-mail: nschema@umn.edu Telephone: 612-625-3430

Fax: 612-626-7431