

Ethics in Disaster Research: A New Declaration



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Abstract The opening chapter in this volume portrayed the growing urgency of disaster research, as the nature and scope of hazards shift. People already familiar with their local environment may find that a changing climate changes their risk for certain kinds of hazards (Relf, G., Kendra, J. M., Schwartz, R. M., Leathers, D. J., & Levia, D. F. (2015). Slushflows: Science and planning considerations for an expanding hazard. *Natural Hazards*, 78(1), 333–354). People moving from place to place in search of better jobs or housing may move into a hazard milieu that is new to them. Political transformations with an authoritarian bent will probably increase vulnerability amongst populations already at greater risk for experiencing a disaster and for recovering more slowly, such as those in poor housing, those with chronic illnesses, and those with Functional and Access Needs. Robust research is needed, but some critics have emerged to challenge the practice and propriety of disaster research, especially quick-response research. This chapter argues for an affirmative right to conduct research.

Keywords Disaster research ethics

Introduction

The opening chapter in this volume portrayed the growing urgency of disaster research, as the nature and scope of hazards shift. People already familiar with their local environment may find that a changing climate changes their risk for certain kinds of hazards (Relf et al. 2015). People moving from place to place in search of better jobs or housing may move into a hazard milieu that is new to them. Political transformations with an authoritarian bent will probably increase vulnerability amongst populations already at greater risk for experiencing a disaster and for

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recovering more slowly, such as those in poor housing, those with chronic illnesses, and those with Functional and Access Needs. Robust research is needed to build the knowledge base for confronting these transformations.

Yet, just at the time that robust research agendas are needed in all areas of disaster inquiry, a number of critics have emerged to question not just the practice of disaster research, but even its propriety. Recent scholars, especially in some areas of anthropology, sociology, geography, and international public health and humanitarian affairs, are assailing much disaster research, especially quick response research (e.g. Gaillard and Gomez 2015), with the argument that it should be more heavily regulated or even curtailed. The argument in general is that disaster research, particularly in cases where the researcher is not from the affected area, is disrespectful, exploitive, and deviant. An especially paternalistic strain of this growing moral panic asserts the vulnerability of people in a disaster area, in spite of the abundant evidence to the contrary. In an egregious move, New Zealand implemented a 90-day moratorium on social science research after the Christchurch earthquake, an astonishing infringement on liberty. Because ethics is an important dimension of understanding the appropriateness and suitability of scientific methods, and because of growing dialogues that call into question the propriety of disaster research (O'Mathúna 2012), it is important to discuss these in some detail. The main purpose of this chapter is to rebut the assumptions underlying this moral panic and assert an affirmative right to conduct disaster research anywhere, on any topic.

This chapter had its genesis in a workshop that was funded by the US National Science Foundation (NSF) in 2012. NSF funded the **“Workshop on Deploying Post-Disaster Quick-Response Reconnaissance Teams: Methods, Strategies, and Needs,”** focused on the state-of-the-art of quick response disaster research, which was designed to provide stakeholder feedback to NSF on their funding mechanisms for the RAPID grant program, one of the main mechanisms in the United States for funding quick-response research deployments. Participating scholars were US and international researchers who had extensive disaster research experience, and represented the social, engineering, and physical sciences. Although much of the workshop focused on the administrative details of the RAPID program and other funding mechanisms, such as timing of grants, assessing the effectiveness of the programs, and so on, ethical concerns suffused many of the subjects that were covered at the workshop. Some participants thought there should be an explicit ethics statement in every funding proposal, and that scholars should work toward a code of ethics for disaster research. Others sharply rebutted these assertions, and in general the views presented were diverse and contradictory. In breakout and general sessions as well as at breaks and at meals, participants engaged in a robust debate on ethical matters that centered on several major points of contention: (1) access to the disaster site; (2) the responsibility of researchers to the affected population in terms of providing data, analytical reports, or other products; and (3) issues pertaining to human subjects review by Institutional Review Boards. These three broadly based topical areas encompassed a number of ancillary concerns and redounded on other matters emerging in certain literatures, such as the possible vulnerability of

the affected population and their ability to provide informed consent. Together, the comments at the workshop and the growing literature on research ethics provide a view on the research ethics landscape and provide the starting point for the comments in this chapter.

Overview of Quick-Response Research

Scholars in a number of disciplines have long recognized the importance of deploying research teams to the site of a disaster to gather perishable data (Stallings 2007). Natural and environmental scientists are interested in understanding the natural processes that produce hazards in the human environment. Engineers seek to improve the built environment and benefit from knowledge of hazards that affect and are affected by man-made structures (Restrepo and Zimmerman 2003). Social scientists conduct reconnaissance research for exploratory, descriptive, and explanatory purposes (Michaels 2003) with the hope of building upon society's adaptive capacity to withstand disaster events. Data collected in reconnaissance research provide insight into linkages between the causes and effects of disasters, which are valuable in terms of developing scientific theory and useful in their potential application.

These research trips are a particularly demanding form of data-gathering that require on short notice:

1. a swift comprehension of a developing disaster situation, typically from media sources and with scanty or ambiguous information;
2. an assessment of the likely theoretical or scientific questions that can be tackled on an expedient basis;
3. if funding is needed, an urgent conceptualization of a proposal;
4. recruitment of a research team, and especially making, continuing, or renewing contacts with colleagues in the affected area;
5. completion of human subjects protocols;
6. preparation and submission of a proposal complete with budget;
7. completion of travel arrangements, including necessary documents and entry permissions, purchase and transport of equipment, and securing food, accommodations, appropriate vaccinations, and other wherewithal;
8. gaining entrée to the disaster site and relevant organizations and facilities

Quick-response or reconnaissance research probes an evanescent realm where circumstances are characterized by risk and a high degree of uncertainty, and where emergency management decisions are often made with haste and confined to the realm of bounded rationality. Perishable data, data only available for a short period of time in the immediate aftermath of an incident, are invaluable to scientists in understanding the characteristics of a burgeoning crisis (Michaels 2003).

Social scientists are interested in a wide variety of research topics, such as the entry, growth, evolution, and exit of organizations from the disaster scene, emergent

activity within the disaster affected community, disaster preparedness, influences on decision making, and social vulnerability to name a few. They collect perishable data to understand the processes that underpin the social context of disasters. Perishable data valuable to social scientists may include observations of the different activities taking place in context; unalloyed or unreserved individual accounts of these activities expressed in the moment they occur; the design and evolving configuration of facilities and personnel; instances where improvisation was necessary; volunteer and emergent non-official activities; or the names of individuals or organizations who might be contacted in a more thorough study later.

Likewise engineers are interested in obtaining perishable data to understand the context of the disaster, the causes of infrastructure failure, and the challenges of response. Such data may include observations and measurements of infrastructure damage or evolving logistics and supply chain networks. Physical scientists may also collect perishable data to develop cause and effect relationships for future application. For example, in the dynamic natural environment, subsequent meteorological or geomorphological forces may obscure geophysical evidence. Such data could, therefore, only be collected through reconnaissance research.

Reconnaissance deployments are typically inaugurated upon receipt of media reports of a disaster, whereby a research trip or proposal is developed on short notice. This demands comprehension of the disaster situation from information that can be ambiguous and/or contradictory. What limited information is available must contain transformative potential for exploratory research, or must have the potential to develop theories and understanding for application from the existing body of scientific disaster research on a given topic.

The researcher must then recruit a research team, complete human subject protocols, prepare a budget, make travel arrangements, and find accommodations. Ideally, reconnaissance teams arrive on-site, size up the situation, and make decisions as to which areas are suitable for research. Following these preparations, the team then generally spends at least a week actually engaged in observation, photography, informal interviews, document collection, engineering and geophysical measurements, attending disaster management planning meetings, and other activities. After some preliminary analysis, disaster researchers may return to the site to conduct follow-up visits and interviews and then produce a preliminary report of the team's findings. The work can be physically, intellectually, and emotionally demanding, putting a premium on qualities of patience, stamina, and resourcefulness. In the best cases, the field team has local contacts, but even they are frequently limited in their ability to introduce the team to others. Sometimes the best data emerges in unexpected encounters with agency officials, volunteers, emergent groups, and others operating in the disaster response milieu. Often, the art of blending in becomes key; the art of standing around; skills of conversation and chitchat; the art of talking one's way into places. "You can observe a lot by watching," said Yogi Berra, whose remark applies directly to disaster field research.

As an example of what can be involved, Kendra and Wachtendorf (2003a: 38–39) reported on their work that began within 2 days of the attacks in New York on 9/11:

During that time the field team conducted over 750 collective hours of systematic field observations. These included close observation of key planning meetings at secure facilities, including the EOC, the Federal Emergency Management Agency's (FEMA) Disaster Field Office and incident command posts near the 'Ground Zero' area. The field team spent extensive periods observing operations at Ground Zero; respite centers established for rescue workers; family-assistance centers established for victims' families; and sites for marshaling volunteers, supplies and food. The field team also observed activities at major security checkpoints in lower Manhattan and at other locations that were important in the emergency response. The team wrote voluminous notes that provide a rich description of observations and experiences; it took over 500 photographs; and sketched and collected floor plans of various facilities to chart the spatial and organizational changes over time. We were thus able to track the evolution of the reconstituted EOC, and other facilities, from very early stages... In addition to direct observation in New York City, we collected numerous documents produced by local, state and federal agencies as well as by individuals and organizations with less formal ties to response efforts. These documents included internal and public reports, requests for information or resources, informational handouts, internal memos, schedules, meeting minutes and agendas, maps and internal directives.

While experienced disaster researchers follow well-understood procedures, each disaster is a unique event and requires a creative, improvised approach in carrying out the various elements of a project. Physicist Alvin Weinberg (1985: 60), for example, has said that "Science deals with regularities in our experience; art deals with singularities." Silvio Funtowicz and Jerome Ravetz (1990), a mathematician and philosopher of science, respectively, have argued that much scientific work, especially work outside the controlled environment of a laboratory, entails elements of craftsmanship, experience, and judgment.

The unique circumstances that characterize crisis present the disaster researcher with many considerations that include the moment-to-moment tasks of data gathering and extend to the expectations of the researcher's discipline, their university affiliation, and the affected community. Post-disaster field research necessitates an ability to navigate the academic, political, and legal institutional universe as well as the territory of interpersonal communication and ethical dilemmas. Indeed the art of reconnaissance research design is a creative extension of well-established methodologies blended on a palette of uncertain or unique circumstances, all directed toward theoretical and practical understanding of disaster for the benefit of the field of emergency management as well as disaster science.

Much of what is known about disaster management has been learned in quick response research or in projects that were initiated subsequent to quick response deployments. Auf der Heide (1989: 8-9) has discussed the importance of disaster research and makes a number of arguments for why systematic research by observers other than those who were involved in the event is important:

Many published articles are narratives of a single disaster written from the perspective of one individual. Frequently, the author is one who was actually involved in the incident or was in charge of some aspect of the disaster planning or response. It is never easy for one to impartially evaluate the actions of his own organization. Too often, post-disaster critiques turn out to be defenses or justifications of what was done, rather than objective assessments of problems and mistakes.... In addition, published accounts may delete material that may cause political embarrassment or increase the liability of the response participants. Finally, many disaster critiques are assembled solely for "in-house" use aimed at correcting internal shortcomings and are not meant for others' benefit.

The recounting and evaluation of a disaster by a person involved in the response has another inherent limitation, that is, the narrow perspective available to any single participant (especially if his attention is focused on action rather than observation).

For these reasons, on-site research by disaster scientists offers the best hope for understanding aspects of disaster response. In that sense, there are clear social benefits to quick-response research.

Nevertheless, in spite of the well-established importance of quick-response research, some scholars criticize the approach. These criticisms generally focus on rights of access to the disaster site, the responsibility of researchers to the affected community, and the vulnerability of research participants.

Access to the Disaster Site

Critics such as Gaillard and Gomez (2015) and Citraningtyas et al. (2010) question the propriety of quick response research undertaken without the approval of some sort of local stakeholder or the buy in of local participants. We can approach the matter of travel to disaster-affected areas from several directions. At one level, there is a fundamental right to seek knowledge and to ask questions on any topic (a right held under the First Amendment of the US Constitution as well as under Article 19 of the Universal Declaration of Human Rights, which asserts, “Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.” Thus, we would argue that there is an affirmative right to knowledge about the environment and about changing conditions in it.

At another level, the character of disaster—and therefore who is and is not a relevant stakeholder—can vary widely, inasmuch as disasters have a strong affective dimension. For example, Mitchell (2006) pointed out:

Multiple interpretations of hazard events may be held by a single individual or by different groups or institutions. For example, among others a hurricane like Katrina may be simultaneously regarded as a disaster, a natural experiment, an aesthetic spectacle, a manifestation of divine power, an indicator of anthropogenic climate change, a mechanism of societal differentiation, a test of societal resilience, a device for redistributing economic and political resources, a fortuitous opportunity for mischief making, and an entertaining or cathartic diversion.

Given the view that a disaster can mean many things to many people, or even hold multiple meanings for the same person, there is no one person or even stakeholder group who could give “permission” for entrée. Because a disaster as an object of study is no single thing, any of Mitchell’s interpretations could be a jumping-off point for inquiry.

One official in attendance at the workshop asserted the necessity of contacting the incident commander prior to entering the disaster area. Others forcefully contradicted this assertion. For one thing, experience shows that there are many “incident

commanders,” and that the notion of a single person in charge is largely fiction. Again, such obeisance raises the possibility of the research team being rebuffed or directed toward sources that are not useful or that are restrictive. Certainly, it is wise to be in touch with a helpful incident commander who respects the research function and is comfortable with the presence of researchers, but in order to include and account for the views of other participants researchers cannot allow the research task to be obstructed by the disapproval or trepidation of officials.

Moreover, as Kendra and Wachtendorf (2003b) observed, even identifying a “disaster area” is a challenging task, a point carried further by Aguirre et al. (2005) who argued that future disasters may be characterized by diffusion and ambiguity with regard to causes, borders, and affected populations. Couch and Kroll-Smith (1985) in their discussion of chronic technical disasters, noted that pollution incidents have ambiguous beginnings, endings, and impacts. Peacock and Ragsdale (2000) contend that a disaster is a disruption in a field of social networks linked to one another through an exchange of information, members and resources. There is no real centralized governing body, *per se*. Instead, community functions are coordinated through mutual contingencies, competition, coalitions, and control over resources.

Given these characteristics of certain kinds of disasters, who, then, is a “stakeholder” that might be consulted? And for an event such as Hurricane Katrina, where the whole of the US was involved, or for one such as Hurricane Sandy that affected a highly-populated region, large areas were declared as “disaster areas” owing to their roles in disaster response but where few people were directly affected by the agent-generated or response-generated demands. In such circumstances, no one is able to give permission for *entrée*.

While in some circumstances, permission may be needed for gaining access to places and organizations, and local contacts are nearly always beneficial and indeed to be welcomed as part of building genuine scientific collaborations and exchange of ideas (also, these are virtually mandatory in the international setting where local cultural predilections and language differences can trip up the unwary scholar), it is easy to imagine situations where researchers may need to function in a more insurgent or clandestine way. This is particularly true in situations where there may be forthcoming litigation, as in industrial accidents. Moreover, any deference to local authority may have the effect of hiding from view marginalized, subordinate, or threatened populations—populations that local formal or informal authorities might prefer remain invisible but whose experiences are important to document. In these respects, we would argue that disaster research is not inherently tainted and therefore does not require cleansing through any such purification rituals as seeking permission from authorities or soliciting buy-in from local stakeholders.

Some scholars have asserted that convergence can diminish the potential benefit of the research by adding to the chaos of the situation. In this view, overlapping studies may produce fatigue among interviewees; researchers interviewing the same people asking similar questions may inflame frustrations and consequently strain the willing participation of research participants (Killian 1956). Furthermore, the scarcity of resources and duplicated research efforts prop up the argument for a

more coordinated research effort. Some of the members of the workshop concurred that an awareness of other researchers in the field is needed to bridge research gaps and circumvent issues in the field, such as fatigue among participants. In fact, after the Murrah Federal Building bombing in 1995, the state of Oklahoma adopted an aggressive approach, driven by the University of Oklahoma's Department of Psychiatry and Behavioral Sciences, which "petitioned the governor's office to designate the department and the OUHSC [University of Oklahoma Health Sciences Center] Institutional Review Board (IRB) as the clearinghouse for all mental health research related to the bombing" (American Psychological Association 1997: 53). Again, this was driven by concerns about research fatigue amongst the victims, but mental health research, and again any type of research, could go far beyond the survivors of the Murrah Federal Building and their families. This proposition, however, raises a number of other concerns, such as how this endeavor could be justly coordinated and what entity should properly be responsible for managing the effort.

The Oklahoma restriction, mandated by political officials and driven by state agencies, constituted a serious usurpation of usually-recognized Constitutional guarantees of free speech. At a recent conference on Hurricane Sandy research, where a similar concern was raised about research saturation, one scholar pointed out that even studies that seem similar are rarely exactly duplicative. Scientific advances, especially in the social sciences, may come most reliably from a number of similar studies whose findings might be broadly convergent. And there is a strong craft element to science (Funtowicz and Ravetz 1990), which means that some scholars may be better positioned at one time or another for a particular study.

An even more appalling instance of the restriction of research occurred in New Zealand after the Christchurch earthquake in 2011. Beaven et al. (2016) described the "social science moratorium" that was implemented by emergency officials. Emergency workers had reported being deluged with requests for visits to impacted areas, and members of local organizations and agencies similarly reported receiving many requests from international researchers seeking contacts or other information. According to Beaven et al., emergency workers and New Zealand scholars felt overwhelmed by the number of inquiries, and emergency officials were worried that researchers would contact and further distress people affected by the earthquake. Thus only research that was construed as directed toward supporting relief efforts was allowed. Beaven et al. further stated that the moratorium was a relief, since it relieved people of the burden of refusing. Nevertheless, the moratorium, and proposed efforts of its kind, are an abridgement of usually-accepted rights to speech and inquiry. To begin with, it singled out a particular kind of speech—social scientific speech—for particular repression. Second, it deprived local residents of their autonomy, either to decline to participate or to choose to tell their stories. It deprived local researchers of the capacity to understand social phenomena in their environs, and it blocked new entrants to the disaster research field. Paradoxically, the case demonstrates something else, too: it can be better for field researchers to eschew contacts with officials, since it was these contacts that officials found burdensome. The case also shows the consequences that can occur when research is regarded as an institutional or professional activity that is decoupled from basic human rights.

Curiously, as Beaven et al. (2016) explain, the moratorium was directed at *all* research not being coordinated through the formal disaster response system, and in fact it was mostly engineers who were requesting access. Nevertheless, according to Beaven et al., the directive was logged in as specifically referring to social science, and thus the label of “social science moratorium” crystallized. It is beyond the scope of this chapter to address this moratorium in full detail, but it must stand out as a noteworthy example of the suppression of research.

Some scholars have argued that the merit of disaster research is compromised by its potential to interfere with disaster management activities, jeopardize the reputation or wellbeing of research participants, or produce unintended consequences without accountability (Kelman 2005). Kelman (2005), for example, flipped the conjecture that disaster operations affect the pursuit of research to consider the impact research might have on disaster operations. Kelman posed questions as to whether or not disaster research interferes with disaster operations and whether or not scholars owe some accountability to decision makers that may have been influenced by the researcher’s findings and taken actions that proved harmful.

While it may be possible to find instances where researchers can get in the way (Kelman 2005), plentiful disaster research shows that actions leading to such concern are easily mitigated. Much quick-response research is observational, involving walking around, taking photographs, chatting informally with officials or residents of the affected area, and other such low-impact activities where the researcher blends into the surroundings and is soon not noticed. Moreover, while the most acute part of the response phase has a surge of considerable activity (almost always before researchers arrive), in a very few days normal human routines begin to reappear, including meals, rest breaks, and so on. In other words, someone always has time to talk and often the enthusiasm to do so. Clearly there is a research skill involved, that might derive from qualities of compassion and empathy that enables a scholar to see who might be able and willing to talk for a few minutes, but there are no grounds to assume the research is distracting or disruptive to operations.

As to Kelman’s other concerns, standard precautions for anonymizing findings and shielding individuals from identification are well-known for protecting human subjects. Whether researchers should be accountable in some way for the recommendations stemming from their work is a large question. Owing to the normative orientation of much disaster work, scholars would surely want their findings to lead to salutary policies. However, this concern would relate to any form of research in any area; while scholars should be concerned about the validity and usefulness of their research, it is a challenge that extends across all of science and is not confined to this one area.

The Responsibility of Researchers to Their Study Participants

Some discussion at the workshop shifted toward what obligation—if any—is owed to affected places. Scholars argued for such an obligation, and some scholars assert that obligation as an affirmative duty (Citraningtyas et al. 2010). Scholars who subscribe to a normative ethos toward science as the basis for disaster risk reduction would consider the value of the work generated as a necessary consideration in research design and implementation. At the quick-response workshop, they suggested that there should be funding for follow-up trips to the affected communities for disseminating results. Many participants desired that some provisions be made for sharing results or findings with the affected community. The view was that such sharing would serve broadly as recompense for the time that participants shared with the researchers. Sharing research findings may ease the ethical dilemma—sensed by some—of data extraction by providing the affected community the opportunity to participate in their recovery through an open system in disaster research. A number of workshop participants asserted that there was an ethical obligation to ensure that research findings should benefit the affected community.

Most disaster scholars identify a normative quality to their work, with knowledge disseminated broadly. In arguing for the development of improved disaster theory, Alexander asserted that:

...I hope that one day there will be a sufficiently large body of theory to permit us to inaugurate a new “interdisciplinary discipline” dedicated to the understanding of disastrous natural phenomena and their effects, and hence to the service of humanity (Alexander: 1993: xvii).

Returning findings to the affected community is part of the normative quality of this work and might be more of a consideration with very long-term projects that involve substantial community contacts. Yet even this suggestion was met with certain cautions: what if the findings of a particular study reflect negatively on local efforts? Citraningtyas et al. (2010) based some of their arguments on the Helsinki Declaration for medical research, and assert that the community should benefit from research. However, social science research is different from medical research. There is always the possibility that findings may call local political systems into question, or highlight deficiencies or injustices that some in the community would prefer remain hidden.

Benefits to the affected community or population can certainly accrue directly, if the research is converted promptly into practice, but also indirectly. Imagine someone who evacuated to Texas from Hurricane Katrina. What if they were interviewed by researchers, who published their study? That study might then form part of the knowledge base that is taught in emergency management educational programs. When that person evacuates again, they may well be cared for by emergency managers who were trained using the latest Katrina-related research. People in New York City will benefit from research conducted after Hurricane Sandy, and some people will benefit from research conducted elsewhere. Nepal, for example, benefited from experience accumulated in other places. Learning from Kobe was available to people affected by the Tohoku earthquake and tsunami. There is an inevitable pay-it-forward quality to disaster research.

Vulnerability

Although not covered in detail at the workshop, the many concerns that were raised connected with one that Stallings (2007) briefly touched on: that disaster victims are vulnerable. There is a growing body of literature on the mental health of disaster victims. Foa et al.'s (2006) study on the risk factors associated with post-traumatic stress disorder after exposure to a disaster, North et al.'s (2002) study on psychiatric distress after the Oklahoma City bombing, and Norris et al.'s (2006) book, *Methods for Disaster Mental Health Research*, provide some examples of the growing interest in this topic.

There is a concern among some in the academic community that, due to stress induced by the disaster, research participants are vulnerable to harm or exploitation or are not able to give informed consent and, as such, the risks and benefits of conducting disaster research should be carefully weighed before entering the field (Levine 2004). We do not argue that disasters have no psychological impact on people. Norris and Elrod (2006: 27–28) reviewed extensive literature, finding that

The majority of the samples (50%) showed moderate effects, indicative of prolonged stress but little psychopathology. In these samples, depending upon the study's design, there were significant differences between exposed participants and some comparison group, changes between predisaster and postdisaster mental health measures, or significant correlations between exposure measures and mental health measures. The remaining sample showed severe (24%) or very severe (17%) effects, indicative of a high (25–49%) or very high ($\geq 50\%$) prevalence of clinically significant distress (determined on the basis of percentages scoring above established cutoff points on standardized scales of criterion-level psychological disorder (determined on the basis of diagnostic instruments).

However, sometimes writing on the topic is contradictory. For example, Rosenstein (2004) argues that there are no data that traumatic experiences reduce decision-making capacity (DMC). He goes on, though, to argue that people in traumatic situations show responses that call their decision making ability into question: his paper exhibits the overall equivocal character of most writing on the topic, pointing out that though there is no evidence of decision making impairment, the question has never been specifically studied, and thus we can deduce that some people must be impaired or at least vulnerable to being pressured to participate in a study (p. 376). His conclusion reflects this (p. 379):

One of the major conclusions to emerge from a decade of debate regarding research with individuals with mental disorders that may affect DMC was that it is both inaccurate and stigmatizing to conclude that all or most individuals with a psychiatric diagnosis are unable to make decisions for themselves. In considering this question in the context of research in the aftermath of disaster, our main conclusion ought to be the same: that most victims of a disaster would be expected to retain DMC despite expected degrees of extreme upset. Nonetheless, for certain types of studies involving victims of disaster, there may well be compelling reasons to consider the subject population under study as being vulnerable in this regard and therefore in need of additional safeguards.

The key consideration is “certain types of studies”, and the conclusion that there are no grounds to consider *everyone* in a disaster as vulnerable.

In fact, Levine (2004) criticized the expanding ambit of vulnerability. Newman and Kaloupek (2004) reviewed a number of studies of people who had experienced various kinds of trauma, including the 9/11 attacks, domestic violence, and traffic accidents. Some participants in these reported feeling upset, but even those who were upset for the most part did not express regret at participating. Domestic violence studies elicited the most distress, situations very different from the collective stress of a disaster. Moreover, much of the concern about research participation is conceptually anchored in medical research. Rosenstein states (p. 373): “The extent to which victims of a disaster are able to make capacitated and voluntary decisions to enroll in a clinical research study is an important and virtually unexplored question,” but quick-response research is not “clinical research.” His arguments are related to clinical research, interventions, and interventions with a research dimension. Quick response research, especially of the character discussed in this chapter, is in a wholly different realm—as is, in fact, much disaster research, making this entire body of writing unhelpful. Some people in disaster might be vulnerable; some might find answering questions upsetting; some might be impaired—all are possibilities in any research. There are no grounds for singling out “disaster” as a special kind of research. What appears to be happening is a sort of creeping spread of concerns about medical research out into other domains of inquiry. Psychiatric research in a disaster gets called *disaster research*, and then anxieties get grafted onto other kinds of disaster research, but in fact, the entire concept of disaster management rests on an assumption of survivor capacity: that they should be able to take care of themselves for at least 72 h, and phrases such as the “first first responder,” referring to community self-help activities, celebrate local capacities for problem-solving and adaptability.

Moreover, people affected by disaster continue with every facet of their lives. They work, including at responsible jobs. They make purchases. They sign contracts, including for Small Business Administration loans and other post-disaster financial assistance. Some of them are public officials who continue their duties in the fire and law enforcement services or other areas of government. Indeed, the presumption of diminished capacity is especially disturbing given strong research trends over the last quarter-century that have identified the adaptive and resourceful capacities of local populations. Only a strong sense of metaphysics allows one to presume that people can act responsibly in all areas of life *except* when it comes to giving informed consent. We cannot say that an official who can make arrests and carry a sidearm, or a householder who can replace a home and car, is too vulnerable to participate in an informed way in a disaster project, or is incapable of refusing to participate in an interview.

In one study, researchers sought to assess the psychological consequences of participating in disaster research. A cross-sectional study of New Yorkers that lived in the city when the September 11th attacks took place were surveyed to assess if research inquiry posed any psychological stress on research participants.

Altogether, 2,368 people completed the surveys, including a random sample of 1173 respondents who received mental health services after the attacks. Results indicated that 15% of New Yorkers found some of the survey questions stressful, whereas 28% of those

who sought treatment found this to be the case. However, less than 2% reported being upset at survey completion, and among these persons, only four people consented to speak to the study's mental health consultant. (Boscarino et al. 2004:515)

Furthermore, stress arising from participating in a study may stem from many factors, including the nature of the event and characteristics of personal exposure, where "mass violence" usually yields greater stress than other events (Marshall et al. 2003: 86. See Peek and Sutton 2003 for further comparisons of the differences and similarities of event types). While it can be argued that most disasters have human origin, the perception of who is to blame for loss may have an effect on the level of anxiety that study participants feel after their disaster experiences (Marshall et al. 2003). Studies also suggest that psychological issues present before inquiry pose the largest risk. According to Boscarino et al. (2004: 515), "Although the majority of those expressing adverse reactions had sought postdisaster treatment, even among these subjects, only 3% were still upset at survey completion, and 2% wanted more information about counseling services."

In order to avoid risk of imposing stress on these individuals, some have suggested to exclude these people from the interview or include a trained counselor on the research team (Levine 2004; Rosenstein 2004). However, in their study of World Trade Center evacuees, Qureshi et al. (2007: 491) had a psychiatrist for referrals if any of the study participants displayed signs of severe stress from the study. They report: "Of the >1,500 participants in the study, only six participants were identified as potentially requiring referral for follow-up. Of these, only four were known to have directly made contact," a result paralleling Boscarino et al. (2004).

Qureshi et al. (2007: 491–492) were alert to the possibility of psychological distress amongst their research subjects, but they found:

That significant increases in PTSD symptoms did not result from participation; in fact, participation may have been beneficial to some individuals. Participation was viewed as a positive and uplifting experience. Visible signs of improvement could be detected in subjects after participation, as if "a weight had been lifted from their shoulders". Participants felt their input would have an impact on the safety of high-rise buildings and that from their experience, something positive would result. Participants felt their "story" held important facts that could help others, and they welcomed the opportunity to share their experiences. This especially was important before the survivors had organized themselves into a more formal collective group (WTC Survivors' Network). That group now plays an activist role in high-rise safety. The study also provided many participants with an opportunity to channel their rage, anger, disbelief, and helplessness onto a target area, namely high-rise safety, thus providing a focus for these feelings and a sense of control.

As a caveat, the authors noted that (p. 492):

The passage of time (the study began nearly 18 months after the event occurred) may have provided sufficient opportunity to process the experience; many participants reported that they would not have been able to revisit the experience in such detail at an earlier point in time. However, it should be pointed out that these findings are subject to several limitations. Namely, the fact that persons with potentially very high PTSD levels were screened out may have led to a sampling bias.

Nevertheless, the conclusion to be drawn was that participation in the study was not harmful, even with the population that had been exposed to some of the most

direct terror of that day- actually escaping from the burning towers- and when the study was focused exactly on those experiences. It should be noted too, that quick response research does not typically involve gathering the detail assembled in Quereshi et al.'s study or intensive interviews. Rather, the contacts are far more incidental.

The key consideration, in other words, is not whether people are under stress, but whether research is harmful. Fleischman et al. (2006: 85) assert that "Available evidence demonstrates that negative emotions are experienced by at least some individuals during research posttrauma." However, this is not the same as harm. They stated:

Research participation may upset participants, but it does not traumatize them as a disastrous event would (Newman and Kaloupek 2004). Trauma-inducing events involve unpredictable and uncontrollable experience, whereas disaster-focused research should be both predictable and highly controlled. The use of the term *retraumatization* is inappropriate in the disaster-research context and may lead to exaggerating the risk involved in participation.

Out of over 60 formal interviews conducted by the Disaster Research Center approximately 1 year after the World Trade Center attack and in many dozens of informal meetings and conversations in the immediate weeks after the attack (including at Ground Zero in the 1st days), only one person wept and it was sufficient in that instance to express support and condolences, let the person recover, and shift the direction of the discussion. This official provided vital insight on the management of decedent affairs, which was among the most sensitive topics. Moreover, as Paton (2003) has argued with respect to disaster responders, participating in disaster response is often a satisfying, even exhilarating, experience, not a pathological one. In that sense there's no reason to assume that everyone is a victim. Kendra and Wachtendorf (2003a, b, 2007, 2016) have conducted numerous interviews with participants in the waterborne evacuation of Manhattan on 9/11. In nearly 100 interviews, including with people who were very close to the Twin Towers and who were showered with dust and debris, they recalled their role with pride, were glad to share their stories, and—far from being traumatized—clearly considered their participation to be their finest hour (See Linley and Joseph (2004) for discussion of growth following trauma. See Walker et al. (1997: 403) for a study on sexual abuse survivors that found that "the women who participated generally found the experience to be a positive one. Only a small number of women were more upset than they had anticipated, but the vast majority felt they would have completed the survey even if they had known in advance how they would feel").

While a further review of the literature in this area is beyond the scope of this chapter, these examples suggest that (1) there are particular risk factors for mental health disorders associated with disaster; (2) there is a lack of empirical research on the long-term adverse effects of disasters on mental health; and (3) there is a lack of evidence of re-traumatization among those that participate in disaster studies.

The different aspects of this problem can be divided into two distinct perspectives. On one side of the debate, some researchers consider disaster survivors to be vulnerable, raising the question of what is considered "real harm" and how the risks

of research are weighed against the benefits. Contrasting this view is one grounded in an ethical orientation that celebrates people's capacity to make their own decisions, and that they should be offered the chance to participate in, or to decline to participate in, any study.

There is also the danger of overconcern. Fleischman and Wood (2002: 317–318) state that “at a minimum, those who are injured, their families, those who escaped the disaster, direct observers, first responders, rescue workers, recovery personnel, and others directly affected by the terror should be afforded additional safeguards and protections.” In New York City on 9/11, this could well be millions. In an egregious overreach, Chung et al. (2008) argue that “The individuals and communities affected by declarations of a state of emergency or disaster should be considered “vulnerable subjects” for the purposes of human subjects research and enhanced strategies for protecting their interests and well-being should be designed into any proposed research.” To take but one instance of the impracticality of this guidance, detached from actual disaster principles, all 254 counties in Texas received FEMA disaster declarations for emergency measures after Hurricane Rita, 29 for public assistance, and 22 for Individual Assistance (State of Texas 2007). We cannot stop all research in Texas owing to these declarations. Or what if it is only the governor who declares a disaster? Does that count?

The overall research base, and mental health researchers themselves, are equivocal at best. None will make a blanket statement on vulnerability or diminished capacity to provide informed consent. The unsurprising conclusion one must draw is that disasters are highly stressful and miserable experiences. Some people—we can't be sure how many—will experience some symptoms of PTSD but most will not go on to develop long-term psychopathologies. A small fraction of disaster survivors—we cannot be sure who or how many—*may* be upset at the end of an interview but this is not the same as retraumatization. And being in a disaster does not mean diminished capacity for giving informed consent. Moreover, even among participants exposed to the most acute and dramatic violence, some will find their research participation to be a positive experience.

Human Subjects Review by Institutional Review Boards

Scholars who work in the international arena are calling for increased oversight by ethics review boards, sometimes citing the US process for evaluating the scientific quality and ethical character of a proposed project. Such calls should be treated with great caution, because the record of institutional review in the US is mixed at best, and is replete with oppression and malpractice. On the topic of ethics review, some workshop attendees stated that human subjects review by Institutional Review Boards can delay deployment. While few would argue the need for some institutional guidance with legitimate authority to enforce standards of ethical conduct, others strongly argue that the standards lack consistency and pose potential impediments to deploying to the field. The Federal regulations for the protection of human

subjects, contained in the Code of Federal Regulations (45CFR46), provide the intellectual and institutional foundation for ethical conduct in research involving human subjects. In turn, those regulations are the implementation of the Belmont Report, which emerged from a conference that was convened to consider ways for protecting research participants in the wake of some notorious breaches in ethical conduct, such as the experiments conducted by Nazis and the Tuskegee Syphilis study. The Belmont Report establishes a code for evaluating the ethical propriety of research, that stresses (1) *respect for persons*: that people have autonomy, and protection for those who do not; (2) *beneficence*: the idea that research should emphasize people's well-being; and (3) *justice*: a consideration of how risks and benefits extend from the study and implicate participants and the society at large. While these have become broadly-accepted ethical guidelines, at least as starting points, they are by no means uncontested in their extent, import, and interpretation.

In the US system, adjudication of these principles has fallen to Institutional Review Boards, commissions established in universities, government agencies, hospitals, and other research-oriented organizations under the auspices of 45CFR46 and the US Department of Health and Human Services. The oversight of these entities ensures that research conducted with Federal funding meets the ethical standards of the Belmont Report and regulations deriving from it. Most institutions extend these principles to all research regardless of funding source. In order to proceed with research, scholars must apply to their IRB and explain the nature of the project, the methods to be used, the anticipated study population, and submit evidence of how they will obtain informed consent, which is typically through a written document signed by the participant but can be in other ways as well.

Over the last decade or so, scholars have increasingly criticized the IRB process, noting inconsistencies in interpreting the regulations across institutions, protracted review timeframes, and ever-broadening interpretations of what might constitute risk to a participant (Hamburger 2007; Bledsoe et al. 2007). For example, according to the Illinois White Paper, a report on IRB excesses, "One IRB, for example, told 'a Caucasian Ph.D. student seeking to study career expectations in relation to ethnicity that African-American Ph.D. students could not be interviewed because it might be traumatic for them to be interviewed by the student.'" In another case, reported by Dr. Zachary Schrag (www.institutionalreviewblog.com), a doctoral student was required to get 80 IRB approvals in order to send her survey questionnaire to faculty at 80 universities. At the same time, others have found no evidence that IRB's provide meaningful protection (Hamburger 2007; Bledsoe et al. 2007).

Rigid and inconsistent protocols of a university's Institutional Review Board can create delays in deployment. The process of acquiring IRB approval may take weeks after a proposal is submitted; moreover, international research may require additional steps to acquiring approval to conduct the study. The process of attaining approval has the potential to extend beyond the window of opportunity to conduct the study. Some scholars argue that Institutional Review Boards exaggerate the meaning of "real harm" imposing upon the researcher's freedom to conduct science (Haggerty 2004; Stark 2007). Moreover, the process of obtaining informed consent sometimes arouses anxiety among parties that may not have been concerned other-

wise (Tierney 2002). Some attendees at the workshop suggested that NSF develop a letter or guidance circular that could be presented to IRBs notifying them of the importance of disaster research and its overall lack of harms to participants.

Strong views on ethics were held in all directions at the workshop, and no consensus was reached. It appears that this is likely to be a topic requiring much more consideration. For example, ideas such as the duty of researchers, if any, to the affected community, returning results to the affected area, and other such matters were raised by some participants but strongly contested in their desirability, practicality, or import by others. Indeed, Institutional Review Board processes, in the context of the entire human subjects protection enterprise, have been the subject of much scholarly discussion, far too much to expound upon here. In 2011, the Department of Health and Human Services issued an Advance Notice of Proposed Rulemaking, containing many pages of potential modifications, for consideration by the research community. Implementation is in progress, but there are many shifts and delays as this is written. In January, 2014, the National Research Council issued its own review, containing many recommendations for simplifying procedures and for withdrawing some forms of research from IRB consideration (*Proposed Revisions to the Common Rule for the Protection of Human Subjects in the Behavioral and Social Sciences*. Washington, DC: The National Academies Press, 2014). Many of these changes would enormously facilitate quick response field research—indeed, some quick response research would no longer be within the IRB purview if those recommendations were implemented—and major research stakeholders should consider those recommendations closely, along with ways in which to support them.

Right to Speech

Finally, the view that some local stakeholder should be consulted prior to initiating disaster research appears to be grounded in an exceptionalist view of disaster: that disaster creates conditions wherein previously acceptable behavior or inquiry is now inappropriate or even deviant (Kendra and Wachtendorf 2005). There is no doubt that disaster conditions are stressful, and that disaster research presents scholars with ethical dilemmas. Browne and Peek (2014) have comprehensively documented potential ethical dilemmas, drawing on their post-Katrina research. Nevertheless, all research—and indeed all human interaction—presents potential ethical dilemmas. But in the US political and cultural system, freedom of thought and inquiry are among the most highly valued rights, and are themselves of moral significance. These rights are similarly held under Article 19 of the Universal Declaration of Human Rights, quoted earlier.

In a special issue of the *Northwestern Law Review*, covering human subjects regulations and Institutional Review Boards, Hamburger (2007) argued that human-subjects regulations as contained in 45CFR46 constitute an unconstitutional “prior license” of speech. Opponents, such as Weinstein (2007), contradicted Hamburger’s

ultimate constitutional argument. But, Weinstein too recognized the constitutional difficulties that are inherent in regulating speech-based research. The entire academic enterprise depends on free inquiry, speech, expression, and publication. Somehow, a distaste for journalistic methods and a belief in the rational superiority of science has lulled academics into thinking that the protections afforded in a free society do not apply to them or that they do not need them within their rather restricted circle. This complacency is dangerous.

A rights-based approach to disaster research extends from one of our fundamental concepts of disaster. Disasters are not merely geological or meteorological phenomena, but are also political events. Whether in the jurisdictional or legal sense or in the informal meaning of power generated by the exchange of resources and information, disasters are social. And where there are social phenomena, there are politics. An examination of disaster recovery reveals the influence of social processes that begin before the disaster event and extend throughout long-term recovery (Nigg 1995). The dynamics of family, social class, race and ethnicity, and gender are all shaped by the exchange of resources and flow of power. Politics are conclusively implicated in the preconditions for disasters and in the trajectory of disaster recovery. The sociopolitical ecology model (Peacock and Ragsdale 2000) helps us understand the interactions of people and place, which is the bedrock principle in hazard and disaster research.

Disaster research, published and presented, is political speech. While the right to speech is regarded to include responsibilities, that right is among the most cherished in the US political system, where the right is virtually a social default setting. It is of no less ethical significance than any of the assertions made by the new critics of disaster research. Seeking to limit, or to compel people to self-police, their political speech is itself ethically dubious.

Those who would restrict research based on the supposed harms to the subjects are therefore cautioned of the ethically dangerous implications of their arguments. In a panel focusing on this subject at the 2009 Natural Hazards Workshop, one of the attendees suggested an embargo on research travel to an affected area. The implications of an embargo are, therefore, worth consideration. At least in the context of the US social, cultural, and political setting and in particular the context of political rights as generally understood, people in the US have the right to go wherever they want, within the scope of US territory. Restrictions are customarily grounded on only the most compelling justification, such as established domains of locational tenure (property rights) or temporary interruptions of passage for life safety, traffic control, etc. Constraining the right to space is, in fact, an attack on liberty (Mitchell 1995, 2003).

One of the most often-articulated arguments in this direction is that journalists operate freely, asking questions and writing articles on whatever they please, unrestricted by Federal regulations (Haggerty 2004). While their excesses may be at times distasteful, most academics would likely resist serious encroachments on the Fourth Estate, certainly encroachments as severe as they themselves tolerate. Press freedoms are recognized as essential to healthy politics and a just society. The practice of *research* seems to be the key distinction. Research is defined in the regulations

as a systematic inquiry designed to produce generalizable knowledge. Are we then to say that speech that is based on data, actual observations, and systematic methods is *unworthy* of protection? Research thus becomes a kind of thought crime: *how* one thinks about one's inquiries is the problem. It's the special kind of thinking that scientists do that makes their speech dangerous, and this is a dangerous proposition.

Schrag (2014, www.institutionalreviewblog.com) makes an explicit connection to freedom. He criticizes the NRC (2014) report for being nearly silent on the matter, and he is bold in his statement: "Freedom is a scholarly enterprise. Freedom is an ethical value. Freedom is a social benefit." He goes on to cite Rena Lederman, who was on the NRC panel that drafted the report: "...those of us working in US colleges, universities, news media, and research institutions have inherited traditions of free inquiry whose continuation is vital to this country's political, economic and social life. It would be deeply ironic if a regulatory system put in place to protect human beings were transformed into a device focused on restricting their power to know the world."

In conclusion, we have the following: a right to research that can be stated in constitutional language, rebuttal of which is equivocal; other rights which need research for their exercise; and a plain-language reading of certain fundamental texts that allow freedom of speech, inquiry, and political participation. We have no evidence of risk from participating in talk-based research of any sort, even in post-disaster mental health research, which might be supposed to be the most likely scenario to lead to harm. There is even evidence that it may be helpful. Therefore, there can be no grounds for restricting speech via any governmental or governmentally constituted body.

The entire human subjects protection enterprise, as relates to the social sciences and humanities and as currently construed in law, regulation, and local IRB interpretation, is now so hopelessly dysfunctional that no patchwork amendment to the regulations will rectify it. Instead, the system needs to be switched off and restarted, from scratch. This rebooting should begin with reconsidering the assumptions underlying the Belmont Report, a document which as scholars such as Hamburger (2007) have argued, uses as its "moral anchor" (2007: 457) the corrupted "research" of Naziism and Tuskegee. Instead, he argued, we might consider guidelines and ethical norms arising from traditions of speech and inquiry.

Concluding Comments

In this chapter, we took seriously the mandate to authors to be provocative and iconoclastic. Our goal was to make a spirited argument for the propriety of disaster research by addressing criticisms that have begun to circulate and to do so in a forthright style. Our approach has been, perhaps, unsparing. Thus, we would like to make plain certain points. First, from our perspective, disaster research should be useful, meaningful, and collaborative to the extent possible, across scales and

locales, and with due regard for local and institutional conditions. Second, there are many nuances to be considered in understanding the ethical character of research. There are many forms of disaster research with varying ethical import. For example, much disaster research is not about the community where it occurs, but focuses on disaster response systems and organizations. Therefore, many recent criticisms do not apply or are less relevant. For this reason, blanket statements about ethical obligations should be regarded with skepticism. Third, with changes to the nature and extent of hazards, ongoing research on hazards and disasters is essential. Most scholars of disaster agree that it is important to collect ephemeral or “perishable” data in the early stages of disaster and to see, as early as practicable, the emergency management challenges that arise and how problems are solved. Much of what is known about disaster has been gathered in early reconnaissance trips; a clear and accurate understanding of disaster phenomena and behavioral and organizational features is necessary to the development of valid science and, therefore, to the development of sound policy that can benefit society by reducing hazards and enabling effective disaster response. Nevertheless, some scholars have emerged to criticize disaster research in general, and quick response research in particular. These criticisms are grounded in many faulty assumptions: that disaster research consumes scarce local resources, that people in a disaster area are too vulnerable to participate in research or to give informed consent, and that there must be local agreement on the nature of the research to be conducted. The comments in this chapter are directed primarily at speech-based research: interviews, focus groups, observation of public behavior, review of documents and publicly-available information. Medical research is in a different register. The notorious harms that impelled the Belmont Report have emerged from medical research—which was really malpractice—torture, and psychological experiments. We must be cautious that medically-oriented models of research oversight do not spill over into the area of speech-based research. The community of disaster scholars, rather than casting yet another entangling net around their research efforts, actually has a unique opportunity to retake some rhetorical ground. In our understanding of disasters as political events, with policy implications running all through our work, we have the strongest possible grounds for making a free speech argument and declaring a freedom to conduct research, in keeping with the US Constitution, the Universal Declaration of Human Rights, and other statements.

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