

Keeping Your Distance: Balancing Political Engagement and Scientific Autonomy with a Psychiatric Consumer/Survivor Group

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Introduction

A key focus of discussion and debate in critical geography has been the contention that ‘traditional’ research is often exploitative. The researcher appropriates knowledge from participants, but may offer little in exchange (Katz 1994). Particularly when projects involve people who are socially oppressed, this raises serious ethical and political questions. What unintended consequences, for example, will research have for the group in question (England 1994)? Should an academic conduct research if (s)he is unable to demonstrate the value of the research to the people involved (Katz 1994)? What constitutes ‘value’? These concerns have elicited attempts to make explicit the power of the researcher over the research process and research outcomes (England 1994). At the same time, efforts have been made to involve research ‘participants’ more fully in study design and implementation. This can help to counter misrepresentation, but also to produce research findings that are of more immediate value to the people involved. These moves have been tied to a broader politicization in which research is explicitly guided by a commitment to social change (Nast 1994; Gottfried 1996; Wilton 2000). Not surprisingly, differing opinions exist as to the appropriate role for the researcher in movements for change (e.g., Routledge 1996; Kitchin 1999). In particular, scholars have drawn attention to the ways in which researchers engaging in critical scholarship need to move between or strategically foreground the intertwined roles/identities of activist, academic, teacher and

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person, recognizing that this movement is: 'fraught with difficulties of a personal and professional nature' (Fuller 1999, 227; also Katz 1994).

In this chapter, I examine critically my collaboration with a psychiatric consumer/survivor group in Hamilton, Ontario in its efforts to improve the material conditions of life for people living in lodging homes. The collaboration, as well as my effort to reflect critically upon it, is informed by two bodies of literature which are outlined below. The first comprises the recent debates in disability studies concerning research on/with people with disabilities by the non-disabled. The second is Pierre Bourdieu's writing on the contours of a reflexive and politically engaged social science. While these literatures are in some ways quite distinct, I suggest that they share a commitment to a social science that is both committed to progressive social change and mindful of the need for a critical distance between researcher and the group with whom (s)he works.

The politics of disability research

Like other oppressed populations, disabled people have come to regard academics, especially non-disabled academics, and academic research with suspicion (Oliver 1992; Shakespeare 1996). Both the burgeoning disability rights movement and psychiatric consumer/survivor organizations have critically interrogated the motivations of researchers, and with good reason given the way in which scholarship has been used to legitimate the social and spatial exclusion of people with physical and psychiatric disabilities. Activists have focused attention on a range of issues including the position of the disabled person in the research relationship, the extent to which 'ableist' assumptions inform what non-disabled academics view as benign research, and the way in which non-disabled academics and professionals speak for and/or on behalf of disabled study participants. Expressions like 'Nothing about us without us' and 'No participation without representation' signal a growing resistance to more traditional research relationships (Shakespeare 1996; Barnes and Mercer 1997; French and Swain 1997).

Recognition of the problematic nature of research relationships has led to a number of responses. Some activists argue that research by non-disabled academics has little or no place within the political project of the disability movement (see Oliver 1996). Others argue not for a complete exclusion of researchers, but for a clear understanding of, and effort to ameliorate, power relations that structure the relationship between researcher and participants (Germon 1996).² As with other marginalized groups, there have been calls for disabled people to be brought into research, not just as well-informed subjects, but as active participants with influence over the type of research that is done, the knowledge produced and the uses to which that knowledge is put (Zarb 1992; Beresford and Wallcraft 1997). French and Swain (1997), for example, contend that three questions need to be answered before disability research can proceed. First, does the research promote disabled people's control over the decision-making processes that shape their lives? Second, does the research address the concerns of the disabled people themselves? Third, does the

² There is also recognition that disabled researchers, while they may be conceived as 'organic intellectuals' in Gramsci's terms, are not exempt from concerns over appropriation and exploitation (Vernon 1997).

research support disabled people in their struggle against oppression and the removal of barriers to equal opportunities and a full participatory democracy for all?

In geography, Kitchin (1999) outlines two approaches to emancipatory research. On the one hand, projects can remain guided by a professional model of research, where the academic is primarily responsible for conducting the research but where participants monitor the process of research and offer feedback. On the other hand, there can be an explicit effort to move away from a professional model toward a participatory model where people are centrally involved in the entire process of research, from coming up with the research topic through the collection and analysis of data, and the preparation of the final report.

These approaches may overcome inequalities characteristic of more traditional research, but there are challenges involved in their implementation. Such challenges include obtaining funding for this kind of work, the constraints under which academics operate (the 'publish or perish' mantra), as well as the negotiation of relationships between participants within the project. There is also a danger of romanticizing participatory research. For example, a move toward increased participation assumes people can and want to be involved in the entire process (Sotelo 1996). Kitchin (2001), for example, found that efforts to involve people in research design and implementation were met with the response that these tasks were the responsibility of the paid researcher. The assumption that people with disabilities can volunteer in research also relies in part on a conception of them as unemployed (also Gleeson 1999). Ideally, people would be paid, but this can be difficult given funding regulations.

Moreover, people have expressed concerns about the implications of the contact between academics and marginalized groups, even where the academic may be expressly concerned with advancing the interests of the organizations with which she or he is working. Writing about the psychiatric consumer/survivor movement, Chamberlin (1978) cautions against the invasion of well-meaning professionals into consumer organizations, precisely because professionals tend to influence disproportionately the goals and objectives of the membership, often diverting energy away from a 'liberation agenda' (also Chamberlin 1990; Everett 2000).

Bourdieu and symbolic action

Questions about the relationship between science and politics, and between academics and social movements more specifically, are also a central concern of Pierre Bourdieu's writing on reflexivity in the social sciences. His work offers an outline of a social science that is politically engaged but able to address concerns such as those raised by disability activists.

For Bourdieu, reflexivity implies that social scientists must be actively engaged in an examination of themselves as producers of knowledge, and more broadly of the conditions under which social science is made possible and undertaken (Bourdieu 1989, 1990b).³ While a call for critical self-reflection is not unique, Bourdieu's conception of the three biases against which reflexivity is intended to guard raises important questions about

³ Bourdieu's writing on reflexivity is directed primarily at sociologists, but his argument has a broader relevance for social science and is extended here for thinking about social geography.

theory and practice in the social sciences. The first, and the most obvious, of these biases is a partiality produced by the social location of the social scientist in terms of class, race, gender and other dimensions of social inequality. The second bias concerns the social scientist's location in the academic field, which Bourdieu (1992, 69) conceptualizes as a relatively autonomous field of cultural production. The third and, for Bourdieu, the most important bias is an 'intellectualist' bias which stems from the fact that social scientists necessarily retire from the world in order to study it. While the necessity of retiring from the social world is itself open to critical interrogation (Fuller 1999), Bourdieu's point seems to be that problems arise if we fail to recognize the limitations of the scientist's theoretical gaze. Specifically, we run the risk of conflating the logic of theory with the logic of practice – to 'operate as if the constructions that the scientist must produce to understand practices ... were the main determinants, the actual cause of practices' (1990a, 384; see also 1990b). Avoiding this bias requires an ongoing analysis of our research to make clear the limits of theoretical knowledge. This is not intended as a process of individual introspection, but rather an engagement with the social and intellectual 'unconscious' of the academic field of which one is a part.

Alongside his call for reflexivity, Bourdieu also wrote specifically about the capacity of the intellectual for political action, and on the relationship between the academic field and the field of politics. For Bourdieu, sociology, and we can argue the social sciences more generally, is inherently political because it is: 'concerned with, and enmeshed in, strategies and mechanisms of symbolic domination' (Wacquant 1992, 50; Bourdieu 1989). Symbolic power is intimately linked to and helps to reproduce the material structure of society (Bourdieu 1991).

To achieve symbolic power, dominant groups require a 'sociodicy' – a theoretical justification to explain why it is they who are privileged.⁴ In recent writing, Bourdieu (1998) focused on the sociodicy of neoliberalism – the way in which it has achieved a certain taken-for-grantedness or symbolic domination in the contemporary context. He argued that this sociodicy rests on a certain kind of language that shapes our view of the world:

We absorb it as soon as we open a newspaper, as soon as we turn on the radio, and it is largely made up of euphemisms. ... To announce that a company is sacking 2,000 people, the commentator will refer to 'Alcatel's bold social plan'. Then there is a whole game with the connotations and associations of words like flexibility [and] deregulation, which tends to imply that the neo-liberal message is a universality message of liberation (Bourdieu 1998, 31)

The fact that neoliberalism has been pursued with theoretical sophistication, supported by the work of experts, necessitates a theoretically sophisticated response from its challengers. For Bourdieu, social scientists can contribute to this response both a certain authority and an ability to engage in *symbolic action* – to challenge the polished arguments of experts who: 'dress up simply conservative thought in the guise of pure reason' (1998, 54). Put more bluntly: 'my goal [as a sociologist] is to contribute to

⁴ This is similar to Weber's notion of 'theodicy' and Marx's conception of ideology. Sociodicies – explanations that are accepted both by the dominant and by others – contribute to the reproduction of *doxa* in Bourdieu's terms.

preventing people from being able to utter all kinds of nonsense about the social world' (Bourdieu and Wacquant 1992, 53)

However, for Bourdieu, symbolic action does not entail an active role in social movements striving for change. Academics cannot be 'fellow travelers' precisely because their ability to engage effectively in symbolic action rests on their relative autonomy as 'scientists' (1989).⁵ Although they may appear opposed, Bourdieu argues that scientific autonomy and political engagement can be extended simultaneously; it is the unstable balance of the scientific and political that defines the role of the intellectual in social struggle (Bourdieu and Wacquant 1992).

Together, discussions emerging from the disability rights and psychiatric consumer/ survivor movements about research, and the writing of Bourdieu on the nature of a reflexive and politically engaged social science offer a series of distinct, but overlapping, methodological guidelines that have relevance for critical geography. Specifically, both perspectives suggest the researcher be politically engaged, but mindful of the need to keep his/her distance. For disability activists, researchers must be responsive to the concerns of the groups with which they work, but they must keep their distance to avoid undue influence and impact on those groups. For Bourdieu, researchers can be effective politically only if they maintain a critical distance that provides science with the legitimacy needed for symbolic action. In the remainder of the paper, I detail my own experience working with a psychiatric consumer/survivor group on an anti-poverty project and the challenges involved in keeping one's distance.

Poverty and psychiatric consumer/survivors

Psychiatric consumer/survivors face formidable 'structural' barriers to social inclusion, including poverty, public intolerance and social stigma, lack of affordable accommodation, and limited paid work opportunities (Capponi 1992; Carne 1998; Nelson et al. 2001). Chronic poverty, in particular, affects many people. In Canada, for example, 12 percent of non-disabled adults live in poverty, compared with almost 27 percent of adults diagnosed with psychiatric conditions (Fawcett 1996), and the figure is undoubtedly much higher for people with 'serious psychiatric illnesses' such as schizophrenia. While there has been considerable research on the relationship between income and mental health, much of it has dealt with the role of socioeconomic status as a causal factor in the development of mental health problems (Saraceno and Barbui 1997).

By contrast, the role of poverty in consumer/ survivors' daily lives has not received prominence in research. This is due in part to a continuing tendency to see mental health as an exclusively medical issue (Cohen 2000). This trend is all the more disconcerting as recent decades have seen a fundamental restructuring of welfare programs (Evans 2002; Handler and Hasenfeld 1997; Peck 2001). Welfare rates have often been frozen or reduced, and time limits for assistance introduced, with the justification that such

⁵ Bourdieu talks about the need for a 'division of labour' between researchers and activists (see 1998, 52-59). The issue of autonomy is also important in terms of the relative autonomy of academia from political and economic imperatives of the larger society.

strategies provide ‘incentives’ for people to escape ‘welfare dependency.’⁶ While people with disabilities who satisfy specific criteria are often able access additional supports, restructuring has made community survival increasingly difficult for psychiatric consumer/survivors in particular (Rosenheck 1999; also Nelson et al. 2001).

Hamilton’s tenants committee

In Hamilton, Ontario, the context for this project, more than seven hundred psychiatric consumer/survivors live in residential care facilities. These facilities are privately owned, and emerged as a source of accommodation in the mid-1970s with the rise of deinstitutionalization. Facilities range in size from fifteen beds up to fifty or more, and operators are paid by municipal and provincial governments to provide food and shelter, while tenants receive a Personal Needs Allowance (PNA) to pay for toiletries, clothing, shoes and other needs. The facilities provide vital affordable housing, but concerns about the quality of this accommodation are longstanding. Problems include lack of privacy (with up to four people per room), security (nowhere to securely store belongings), and inadequate nutrition.

In 1995, a housing advocacy center in the city received a small grant to establish a facility tenants’ committee. The group consists of a small number of current and former facility tenants, as well as a staff member from the housing center, Alex. While other people, such as a community organizer from a local legal clinic, sometimes attend meetings, the group is first and foremost a tenants’ group. Alex agreed initially to chair the monthly meetings because no one else would, but he was explicit about creating an environment that was in his own words ‘empowering.’ Over time, and with a commitment of ongoing support, he persuaded other members to take on leadership roles, chairing the meetings and representing the group publicly.

Alex’s approach, and the environment he and other members were able to create, is significant given ongoing concerns about the extent to which psychiatric consumer/survivors are truly represented in groups and organizations run by professionals and service providers. While these groups seek to improve consumer/survivors’ quality of life, they often reproduce a professional/ ‘patient’ opposition in meetings where views and opinions of the former dominate, while the presence of clients at the table legitimizes the work of the organization (Everett 2000). In addition, only certain types of consumer/survivors are invited to join such organizations. People who are too angry or ‘disturbing’ are considered unsuitable (Capponi 1991; Everett 2000). By contrast, the tenants’ group is intended to provide a context in which tenants can express views about housing and other issues of significance. While there have been challenges involved in sustaining the group, its size has remained steady, with eight to ten core members (both women and men), and another six occasional members.

The ‘Personal Needs Allowance’ campaign

The initial mandate of the group was to educate people living in facilities about their rights as tenants. However, in 1997, when the group conducted an informal survey of

⁶ Bourdieu’s conception of symbolic domination has considerable utility for analyzing the contemporary language of welfare reform, composed of terms such as ‘dependency’, ‘fraud’, ‘rescue’ and ‘freedom’.

