Shaping Local HIV/AIDS Services Policy through Activist Research: The Problem of Client Involvement

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This article argues that professional writing researchers can help shape public policy by understanding policy making as a function of institutionalized rhetorical processes and by using an activist research stance to help generate the knowledge necessary to intervene. My goal is to argue for what activist technical writing research might look like, lay out an understanding of institutions that is helpful for influencing public policy, and illustrate the promises and the problems of both positions by using the case of a study focused on local HIV/AIDS policy making. According to this way of thinking, professional writing researchers can impact policy by helping change the processes by which policy gets made.

In response to the HIV/AIDS crisis, Congress enacted the Ryan White Comprehensive AIDS Resources Emergency Act in 1990 (commonly known as the Ryan White C.A.R.E. Act). The emergency legislation was designed to help alleviate the effect of the disease on U.S. cities. When the act was re-authorized the next year, as part of the Health and Human Services Administration’s appropriations for fiscal year 1991, Ryan White legislation took on a quasi-permanent status that continues to this day (because Congress continues to re-authorize it). Originally designed to help ease the burden of the disease on the metropolitan areas most affected by it, the act now funds HIV/AIDS-related services in more than fifty metropolitan areas. The Atlanta area, which was one of the original cities covered by the act, encompasses twenty counties in north Georgia, and in fiscal year 1998, Atlanta received around 30 million dollars in funding from the federal government. The Ryan White Act and the health care systems it made possible are clearly significant and are currently an integral part of HIV/AIDS care in the United States.
The act makes money available to local governments and establishes broad policies and rules. The act requires that there be a local grantee (a local government), and that grantee, in turn, must set up a planning council. At each level, from the federal government to the local planning council, policy is made. My concern, however, is with the local planning council, a powerful policy-making body. The planning council must be composed of individuals who fit a number of categories (everything from health care providers to government officials), but the most significant and progressive aspect of the Ryan White legislation is that at least 25% of the local planning council must be made up of individuals affected by the disease. In addition, the composition of that 25% must match the current demographics of the disease (which has become increasingly female, poor, and of color). The theory here is that those most affected by the disease ought to have a significant say in making policy about their care. However, the democratic promise of the legislation is the source of the problem. Meaningful client involvement isn’t easy.

I have been involved in a process of understanding the problem of client involvement for nearly a year and a half now, and honestly, I’m not sure I understand it yet. In Atlanta, at least, clients are involved at levels required by federal legislation. Still, as I will detail, there are problems with achieving broad and meaningful involvement. The key here is the meaning of the term “involvement.” Involvement means membership on the local planning council and participation in council activities (such as serving on the working committees). But as I will discuss, there are a number of barriers to participation. Simply put, the activities that count as participation self-select those who can participate, thereby limiting the voices influencing public policy. According to a 1994 Division of HIV Services, Health Resources Services Administration report (The Participation of People), there are a number of barriers to fuller and more effective client involvement (7):

- The majority of people living with HIV/AIDS don’t know that planning councils exist or that they can become members.
- Frequently, those affected by the disease on the planning council are affiliated with actual or potential services contractors, setting up a potential conflict of interest.
- The membership process is confusing, the meetings are complicated and intimidating, and the knowledge and literacies required are daunting.
- Burdens of the disease (energy, medications, etc.) and fear of disclosure deter some.
- Feeling that client input is not valued discourages others.

So while clients can, in theory, participate in fundamental ways in making policy related to their own health care, in practice, this is difficult, and many associated with the Atlanta Planning Council are deeply concerned that they hear from only a few active individuals
and communities and not at all from many others. Would policy look different if those most silent were suddenly active? Would policy look different if greater numbers of clients could participate? Probably. This is the problem of client involvement, then: how to improve or change the processes of involvement so that greater numbers and varieties of people can participate in making public policy.

I begin with background on the Ryan White Act because this legislation and the institutions it created provide the context for my discussion of how research in technical and professional communication can influence public policy. My method in this article is to move back and forth between a “story” of policy making—the client involvement case—and an argument for the usefulness and power of activist research in technical communication. My hope is that the case reinforces the research argument and that both demonstrate that writing researchers can influence public policy. Let me begin with my claim: Given that writing researchers should intervene in policy making (and I don't think we should necessarily take this as a given), the most useful and long-lasting interventions will likely be the result of a certain way of understanding policy-making processes and a certain way of doing research. In short, I think researchers can and in some cases should help shape public policy (depending on one’s ethical and political commitments), and they can do so by understanding policy making as a function of institutionalized rhetorical processes and by taking an activist research stance in order to help generate the knowledge necessary to intervene in those processes. According to this way of thinking, professional writing researchers can impact policy by helping to change the processes by which policy gets made.

I became involved with the project to address problems of client involvement through a student’s service learning project in one of my technical writing classes. The project in question was completed with Khurran (Ko) Hassan, an HIV/AIDS educator who works with teens for one of the service providers funded by Ryan White legislation. Ko was concerned with generating and documenting client involvement at his agency (the focus of the student project), but in the course of the student project, he and I began to discuss the larger problem of client involvement that was affecting the planning council’s policy functions. Our conversations eventually evolved into a research project with two interconnected goals: (1) to improve client involvement in policy making by creating with clients procedures that overcame current barriers, and (2) to document client involvement for use in policy discussions and reports of compliance to the government. So I was invited to help address a problem, and this invitation was framed as research, which was important for both the planning council (as will become clear) and for me (for obvious reasons). How this project came about is helpful, I hope, for thinking about how research in professional writing can affect public policy.
Activist Research in Professional Writing

Cynthia Selfe and Richard Selfe note an important tension in conceptualizations of technical communication between private (e.g., the corporation) and public ownership, location, and use (330). For them, this tension raises a question about responsibility, namely whose interests do we serve through research and teaching in technical communication? This question was important to me as I began to think about how to conduct research to help address problems of client involvement (and ultimately to influence public policy by helping to change how it gets made). But this question also lies at the heart of recent debates about research within technical communication. Discussions of research in technical communication have become increasingly critical, self-reflective, and interested in questions of power. I want to extend this trend by thinking about what an explicitly activist research stance in technical communication might look like. Such a stance is not only relevant given recent thinking about research in technical communication, but it is also essential for thinking about how research can influence public policy.

The relatively short history of empirical research in professional writing is marked by a number of general shifts in perspective and methodology. The move toward site-based research that borrows methods from the social sciences was a reflection of social rhetorics and an important addition to text-based methodologies. Once researchers were working within a sociological tradition (e.g., ethnography, case studies), shifts in how research was conceived, conducted, and written mirrored those in other disciplines. Carl Herndl consistently has been most aware of how postmodern theory, critical theory, and rhetoric have impacted research and writing in anthropology and sociology, and in turn, how changes in those disciplines have impacted research on writing (see “Writing Ethnography,” “Teaching Discourse,” and “The Transformation”; see also Doheny-Farina). The impact of the intellectual, political, and ethical positions covered by umbrella concepts like “postmodern theory” cannot be overestimated. Within writing research, shifts in perspective have caused many to reconsider how research is conceived, conducted, and written. People like Nancy Blyler and Herndl have noted, for example, that research in professional writing is typically descriptive and explanatory but rarely critical (Blyler 36). The potential problem with this situation is that descriptive and explanatory research also typically supports, either explicitly or implicitly, the interests of those who sponsor research—either a funding agency or the institution that grants permission or both. While there isn’t necessarily anything wrong with this situation, critics of descriptive and explanatory research argue that it often leaves in place and unquestioned—indeed often unexamined—ideological and cultural practices that are important for more complex (and sometimes contradictory) understandings of discursive practices.
and the institutions that warrant them. While not everyone agrees with the concerns expressed by Herndl, Blyler, and others (see Charney), there is little question that in books and journals at least, research in professional writing has taken a critical turn.

I support this critical turn in technical and professional writing research. With respect to the client involvement project, it has allowed me to consider questions of responsibility and the purpose and use to which my actions as a researcher might be put (not just the results of the research). These moments in the development of research methodologies in professional writing are important in terms of how they affect the purposes and goals of research. Given the arguments of postmodern and critical theorists, it is impossible to construct a neutral researcher stance. Even researchers who intend to conduct descriptive or explanatory studies of writing in the workplace must now consider the fact that their work is always already political and ethical, that it serves the interests of some (and not others), and therefore that they are caught in a relation of power that can both benefit and harm others (and that they can't avoid and so must deal with in some way; see Sullivan and Porter; Blyler). Thus the purposes and goals of research have changed (for some) in an effort to acknowledge that which was always true: we always “take sides” in our research (even in the most mundane ways), so how do we do this in ways which are ethically and politically sound (or at least justifiable)?

This is the question that an activist research stance addresses. For Blyler, the critical perspective is “concerned not with describing and explaining a given aspect of reality, but rather with discovering what that aspect of reality means to social actors . . . ” (36). It means, as well, that the goals of research should be emancipation, empowerment, social change. For Patricia Sullivan and James Porter, critical research practices also aim for social change (20), but not change in the sense of large-scale revolution. Rather, they note that the practices of research change things, that indeed researchers have an effect while conducting their research, that they are actors in the social situations they research. These actions are unavoidable, a form of rhetorical action that takes place both in the time and place of research practices (e.g., data collection and the interactions associated with those activities) and in the time and place of knowledge construction (analysis, writing, and publication). Sullivan and Porter emphasize that their critical research stance, like all research stances, sees the production of knowledge as essential. In their case, they are interested in local, situated knowledge that allows actors to change the situations in which they find themselves.

The critical turn in professional writing research, then, plays out the implications of long-standing methodological issues: the neutrality and objectivity of the researcher, the goals and purposes of research, and the rhetorical nature of research itself. The result is an openly political research stance that incorporates into study design important
issues of power and position. But is critical research activist research? Not necessarily, although I think the two are closely related. Ellen Cushman articulates a clear activist stance for writing researchers, and I think her principles of activist research are useful. Her stance is composed of three general acts: (1) transferring status, (2) reciprocity, and (3) collaborative knowledge construction. For Cushman, transferring status means lending power and position to others in order to achieve a goal. In her study of inner-city residents of Quayville, status was transferred in a number of ways. She gave status to some of her study participants by gaining access to university computing facilities for them, and some of her participants, in turn, gave status to Cushman as a researcher in the community, thereby allowing her access to people and places that would have been inaccessible otherwise. The principle of reciprocity is illustrated throughout the write up of her study (including the disbursement of book royalties), and means, simply and not so simply, that participants must benefit from the processes of research just as the researcher benefits. Essential to the principle of reciprocity is the requirement that outsiders (most researchers) be invited to participate in local problem solving. This is an essential issue of ethics and consistency: participants must invite others to work with them to understand and solve problems, otherwise the “researcher/researched” relation of power is reestablished and local assets and energy will not be utilized (see Kretzmann and McKnight on the importance of local versus “outside” assets for community-based problem solving). Finally, mutual knowledge construction, which is common to much fieldwork in writing research, means that participants have a fundamental opportunity to participate in analysis, reflection, and meaning making. For Cushman, then, “activist research sets for itself the goal of portraying participants in respectful ways while also conveying the texture and complexities of participants’ lived conditions” (36).

Cushman’s activist stance is similar to positions taken by participatory action researchers (PAR) for some time (and PAR is a good model for technical and professional writing because of its long history of work within organizations—see Greenwood and Levin). While there are a number of ways to describe PAR (or action research for some), generally the goals of PAR are to solve problems and/or change local practices with those most affected by them (Holter and Schwartz-Barcott 299). Davydd Greenwood and Morten Levin write that action research is social research carried out by a team encompassing a professional action researcher and members of an organization or community seeking to improve their situation. AR [action research] promotes broad participation in the research process and supports action leading to a more just or satisfying situation for the stakeholders. (4)

Action research demands the co-definition of problems, the cogeneration of knowledge, and collaborative action. Yolanda Wadsworth
argues that participatory action research shouldn’t be seen as an unusual or variant form of social research; it is just social research that is conscious of its commitments, its partiality, and the actions that result. It is self-conscious research, or as Sullivan and Porter argue, research that understands its rhetorical, ethical, and political situatedness and explicitly works through those issues to clearly articulate the purpose of research and those who are to benefit from it.

I go to these lengths to position activist professional writing research because of the status given research. I take it seriously. But more importantly, research can influence public policy; it can change things. In fact, activist research in professional writing must change things. It must take seriously the fact that the very goals and questions that drive research are partial and therefore must question and make explicit whose interests research serves. It must take seriously the fact that researchers, as they design a study, construct relations of power that should benefit participants (reciprocity). It must conduct research in ways that are participatory (e.g., outsiders must be invited to participate and there must be a mutual construction of knowledge). And it must understand that the knowledge produced by research has both disciplinary status and local power that can be used to enact change. Thus far, then, I have used this activist research stance to explain how I began this study of client involvement (I was trying to do this kind of research), but for the most part, I have used this stance as the first part of a larger argument for how professional writing researchers can change public policy. The second part of this argument involves a certain understanding of how policy gets made (as a function of rhetorical institutional processes). To understand how policy gets made, we must understand institutions.

Understanding Institutions

Clearly one key to influencing policy is understanding how it is created. Policy making is a function of rhetorical decision-making processes within institutions. I doubt this statement will elicit much disagreement. It is the implications of such a claim, however, that are important, because if true, then to change policy is to intervene in the process of its making. This requires, I think, an understanding of institutions and institutional change.

We are accustomed to thinking of institutions in the abstract, as things like Government, Law, Religion. In addition, we tend to think of institutions as large, static bureaucracies. The opening to this article outlines such a conceptualization of institutions. The institutions that help shape HIV/AIDS services policy in Atlanta begin with Congress and its legislative power and the Executive branch (e.g., Health and Human Services) and its rule-making and enforcing power. For most, these institutions are overly bureaucratic, and so, slow moving. These institutional sites are certainly locations where
one can influence policy, and they constitute an important part of the total picture for understanding HIV/AIDS services. But while important sites, these institutions provide an incomplete picture. A more complete picture considers local institutions, which are related to larger systems but which are also discrete, somewhat bounded, and therefore powerful and worth understanding. So what, then, are local institutional systems?

Some literacy scholars, for example, refer to institutions like specific schools or workplaces as definition-sustaining systems, as relations of authority that give specific literate practices shape and significance (Barton; Street). According to this line of thought, when we fail to see and understand institutions, we struggle to understand why certain classrooms look the way they do, why individuals speak and write in certain ways, or why some citizens have difficulty gaining access to the resources and knowledge necessary to better their lives. Institutions are local, concrete spaces that are given life discursively through the writing that makes them possible. As Dorothy Smith sees them, particular institutional formations are a local manifestation of more general social relations, a nodal point in what I would call a rhetorical relationship between general social (if not sociological) processes and local practices. According to this view of institutions, an institution is a well-established, rhetorically constructed design, a bureaucratic and organizational site where people live and work and where they interrelate with others inside and outside the institution. But just as importantly, according to this view, institutions can be changed. Institutions are fundamentally constructed out of the discourses that make them possible (e.g., legislation, grants, business plans, contracts) and the discourses by which they operate (e.g., policies, procedures, regulations, curricula, lesson plans, assessments). As systems of decision making—as rhetorical systems—institutions can be changed by altering (rhetorically) their processes: change the process and one changes the institution.

So how does one do this? Institutional critique is a methodology that I think works (see Porter et al. for a full discussion). Institutional critique is not new. In one sense, it can be traced back to Foucault. And within English studies, disciplinary critiques like those of Vincent Leitch and James Sosnoski constitute a form of institutional critique. In professional writing, Herndl (“Writing Ethnography” and “Teaching Discourse”) makes similar observations about the importance and power of institutional systems. The approach my colleagues and I take, however, is more locally situated, more spatial, and more empirical, and because we are situated within the field of professional writing, we are more accustomed to thinking of material systems like organizations and workplaces as important and useful frames for situating written literacies (again see Porter et al.).

As a methodology, institutional critique focuses on making institutions visible and then looking for spaces within institutional systems where change is possible. In our formulation, institutional
critique works through mechanisms like postmodern mapping, boundary critique, empirical methods (like cases and other fieldwork methods), and economic analyses. Postmodern mapping is used to make visible perspectives, positions, and values, and to do this by charting changes over time. These maps are tentative and always partial, but they are useful in helping to make institutions visible in terms of the discourses and ideologies that make them possible. Boundary interrogation is a similarly important mechanism. Boundary interrogation seeks to locate spaces of difference within the institution that mark places for change. David Sibley calls these places "zones of ambiguity," those spaces in which there is change, difference, or a clash of values and meanings; these zones of difference are places for change because of the instability that difference often brings (33). Boundary critique is a technique I have used in the client involvement project and will be most visible here.

Institutional critique is fundamentally a pragmatic effort to use rhetorical means to improve institutional systems. To carve out a space, to enact institutional change, is not an easy process, and in some institutions, probably impossible. Sibley recognizes this fact, writing "the tendency to reject difference and to value order" is reinforced by institutions with "tight" institutional controls (a common tendency of bureaucracy). Some individuals do have a say, and can, in effect, alter the design of space, change the space and function of institutions. This can happen (1) because institutions are rhetorically constructed, (2) because their construction and operation is a function of processes (design), (3) because key processes (like decision making) can be places of interaction and difference, and (4) because such places are potentially unstable and open to change. Institutional critique seeks to enable institutional change by locating gaps or fissures where resistance and change are possible. The key and unique function of institutional critique is that it provides the means to recognize and construct institutions (its methodological focus), and it insists that institutions can be changed (its action focus).

The Ryan White Planning Council is a powerful, local, and understandable institution. It is a wonderful example of the power of local institutional systems. This council, largely through its working committees, establishes local priorities (e.g., should we fund more housing or subsidize pharmaceuticals at higher levels?), governs its own composition and operation, oversees needs assessments, awards grants to local service providers, and evaluates the effectiveness of each. Powerful stuff. Legislatively, the planning council is headed by the chief elected official in the metro area, but the real head of the organization is the chair of the planning council (appointed by the elected official). The Atlanta council then has two vice chairs (both self-identified as HIV/AIDS positive), 45 voting members, and 60 at-large members (non-voting and can actually be unlimited in number). As an institutional system, the Atlanta Ryan White Planning Council looks something like this (see Figure 1).
Figure 1. Ryan White Planning Council Institutional Structure, Atlanta.

This figure illustrates a few important institutional features. It is designed as both a general organizational chart, a listing of services provided (column along the left), and a listing of the committees that do the real work of the planning council. Council meetings themselves, as I will discuss below, are like most large administrative meetings. Their primary purposes are reporting and voting, and the results of all votes are largely predetermined (votes in doubt would not make it out of committee). The committees, then, are important. All voting members of the planning council are members of some committee (at-large members are welcome to attend meetings), and it is in the committees where the work gets done, the policy gets made. In addition to the committees, task forces are routinely formed to investigate important issues related to services (e.g., housing problems). As figure 1 also illustrates, the client involvement effort began as an ad hoc committee composed of interested clients and service providers (and me). Our location in figure 1 is meant to suggest our position relative to the larger institution, and it is also meant to illustrate the position of client involvement issues in relation to other priorities.
The Problem of Client Involvement

The problem of client involvement was never compliance with the letter of the Ryan White C.A.R.E. Act; just over 30% of Atlanta’s planning council currently is self-identified as HIV/AIDS positive. As I noted earlier, however, the problem, according to most associated with the planning council, is the spirit of compliance—they want fuller and richer client involvement, which means better numbers and more diverse feedback. Thus the goal of our research project was to understand barriers preventing client involvement, then to work toward improving involvement by creating with clients procedures that overcame current barriers, and finally to document client involvement for use in policy discussions and reports of compliance to the government. These goals were not my own; they were established by those interested in solving and documenting solutions to client involvement problems in Atlanta. The goals, then, focused on solving problems as articulated by key stakeholders (clients, service providers, and indeed the planning council) and were not driven by disciplinary concerns or an outside research program; they were driven by the need to solve problems and change practices.

The argument I have been making in my work with the planning council is that the problem of client involvement has been a communications problem, and closely related to this, a problem (perhaps) with the way in which “involvement” is currently defined and practiced. In what follows, I will outline the general problems of client involvement (as articulated by me, others in Atlanta, and in past government reports on this issue), detail how we began to understand these problems (the activist research practices), and report on our progress so far to change the processes of how policy is made.

I have spent most of my time on this project trying to understand client involvement and why so many people see it as deeply problematic, and here is what I think is going on. There are a number of pieces to the communications problem puzzle; they will seem similar to the problems taken from a nationwide study listed earlier in the article:

1. Most people who receive HIV/AIDS services (clients) do not know about the Ryan White Act, the planning council, or the important role they can play in ensuring that their services continue to be provided in ways they find meaningful.
2. The planning council membership process is complicated and obscure, and therefore invisible to many clients.
3. It is unclear to most (and still to me) what kind of client input the planning council actually wants and/or needs.
4. There is no two-way communication between the council and clients, so even many of those who participate in council activities aren’t entirely sure what policies are made or changed because of client input.
In order to address these issues, the ad hoc committee with which I was associated decided we needed to understand them more fully. Granted, there was a government report that detailed many problems of client involvement that were consistent with what people in Atlanta were saying (Health Resources Services Administration). But we wanted to understand the local barriers to participation, and that meant not just in Atlanta but with specific populations of clients (more on this later). In addition, we needed to understand clients’ preferred ways of communicating with the council, understand the information needs of the council committees (where policy gets made), and then pilot a new client involvement and documentation process that might meet our local needs. The context for this inquiry is important for the activist/participatory stance I’m trying to articulate. This committee, a fluid group of clients, interested service providers, and myself, set priorities and collected information. Much of the information we collected was generated through monthly client involvement meetings that took place for one year and moved around the city from provider to provider. At these meetings, clients discussed problems they were having with services, but we also used the meetings to educate them about the planning council and tried to understand what had prevented most of them from participation in planning council activities. In concert with this, I headed the development of three questionnaires—one each for clients, service providers, and committee chairs—in an attempt to collect information on client barriers and preferred ways of communicating, service provider insight into the same issues, and committee chairs’ perceptions of client involvement problems and possible solutions. Here I am only going to discuss client barriers to participation and how they relate to changing public policy processes.

**Barriers**

I see the effort to articulate the barriers to fuller client participation as an effort in boundary critique. To engage in this critique, I focus on one particular practice, “the meeting,” and attempt to articulate the boundaries in place. What counts as client involvement is fundamentally narrow: participation in planning council activities (meeting attendance and committee work) as either a voting or non-voting member. The meetings themselves are not innocent locations and practices. In fact, client involvement as currently articulated is a thoroughly classed, raced, and gendered process.

The planning council is run like most large professional bodies. The meetings are conducted in a large boardroom at the county department of health in downtown Atlanta, usually at 9:00 in the morning. Council meetings move quickly and follow Robert's Rules of Order. Much of the meeting time is composed of reports from each working committee and task force. There is little time for questions
and answers or other discourse initiated from members not on the agenda, and when a vote is taken, it is usually quick and painless. While incomplete, this brief description is a reference point for understanding boundaries.

The first boundary is the formal board and committee meeting itself (as both a practice and a metaphor for involvement). Access to these meetings is difficult to achieve. The most fundamental form of access is attendance. The planning council meets early and downtown, and according to countless conversations with clients (heard through our use of the traveling client involvement committee meetings), this time and location presents problems. First, mothers, particularly single mothers, often cannot make these meetings because they must get their children to school or daycare, and for many, particularly those who are poor and/or sick, the morning rigmarole is prohibitive. Then, of course, there are those who work in jobs that do not allow the autonomy of many professional class positions—the ability to arrange one’s schedule to make a meeting. Second, for those who are sick and/or in active drug therapy, the protocols for the drugs and the side effects from them—let alone the burdens of the disease—often make early morning meetings impossible. One member of the committee, for example, mentioned that he is often in and out of the bathroom for two to three hours in the morning due to these health issues. Third, public transportation is uneven in the Atlanta area. Trains serve only two of the five closest metro counties and users sometimes need hours to make the necessary bus and train transfers. Parking downtown, if people have cars, is never free, and although the council gives vouchers, space is limited. Those who can and do attempt to make meetings have strong support systems, have developed strategies for getting to meetings on time (e.g., waking up at five in the morning for the 9:00 meeting), or are comfortable enough economically to ease or eliminate these fundamental access burdens.

In addition to physical access, the meetings—and here I am grouping together both council and committee meetings—require a significant set of literacies because they are run by professionals who are comfortable with corporate-style board and working committee meetings. Clients must have a working understanding of Robert’s Rules of Order, learn quickly the specialized languages of the various academic and professional disciplines that drive committee work, and possess the reading and writing skills necessary to participate in this discourse. All speaking and writing is geared toward this professional audience, which is why planning council activities are opaque for clients who do not have the education and/or experience to cross the education and experience barriers to involvement.

Even if clients can cross the significant boundaries I have discussed briefly here, they then run into the two-way communication issues mentioned earlier, most importantly the fact that it isn’t clear if or how the planning council uses client input because there is no
communication that details this. We are left, after the weeding due to not knowing about the planning council, not being able to physically attend, and not being able to participate (literacies), with a narrow range of clients who can and do participate. The clients who are active on the planning council say something about the power of the boundaries I have listed: they are largely from a professional class background, largely “healthy” (under care and a manageable drug program if they are actively sick), largely employed or sponsored by an HIV/AIDS service provider (and so paid to attend meetings), and all adults. This is true even though there are extraordinary differences between clients (an issue upon which I don’t have the time to elaborate): the disease is becoming increasingly poor, black, hispanic, female, and young in its epidemiology. So, in short, while the composition of the voting membership is proportionally representative of the disease population in Atlanta (largely in terms of race, gender, and sexual orientation), it may not reflect the population, particularly in terms of class (e.g., there are no homeless representatives on the council), and the practice of the meeting itself tends to reinforce these boundaries. The process, in other words, may prevent more participatory policy.

Changes

The questionnaire we developed was the most important tool for understanding barriers to participation for people not currently associated with the planning council, and the results of this questionnaire became the most important wedge for creating institutional change. I want to underline this from the outset, for while mundane, I think this example of a research practice is an important illustration of how research in professional writing can influence public policy (an intervention that I think is tough, long-term, sometimes boring, and yes, largely mundane).

With the client questionnaire, we focused on where and how clients would feel comfortable sharing feedback and information relevant to planning council activities. The client questionnaire was also written as an information document explaining the council and why clients are important. And our assumption was that attending planning council meetings or becoming a voting member was either not possible or desirable (remember that at this time we were exploring processes other than “the meeting”). We distributed 125 questionnaires at a planning council meeting both to clients who were attending (even though they were not our primary interest, we couldn’t exclude them) and to service providers to distribute to their clients (our main focus). Our response rate was poor, which wasn’t surprising given response rates with this population (see Sengupta and Roe). Our decision to go through service providers was made because we hoped that case managers and nurses, for example, would encourage
response or sit down and go through the questionnaire with clients, and we made follow-up calls to providers to encourage this. Ultimately, we got eighteen responses from three service providers with whom we worked closely to get them. Of those eighteen, thirteen were African-American, one Latino, and one Caucasian (not all responded to this question); six were female and nine male (one was both, which was either a “circling error” or a resistance to our gender categories); and all were positive—seven with no symptoms, five with symptoms, and six with AIDS. In general, we learned that clients were comfortable providing feedback at the doctor’s office (but not with all service providers), they were most comfortable working with others who were positive, and they preferred face-to-face interactions (a preference overwhelmingly confirmed by service providers and which cast doubt on our speculative plans to use forms like comment cards or computer networks to serve as alternate ways to become involved in policy issues). By all social scientific standards, there were significant problems with our questionnaire. I have no confidence in the conclusions in terms of their use in such a reporting context. But we never intended the questionnaire to be used in this way. We saw it as a pilot, a way to generate some initial understanding of the problems in order to plan our next step. And one of these next steps dealt with institutional change.

Perhaps the most important moment in the life of the client involvement project occurred at a December 1998 meeting of the planning council executive committee. A year earlier, the executive committee had given us permission to launch the ad hoc client involvement effort, but their position was simple. They had been wrestling for some time with problems of involvement, had tried a number of solutions, yet the problem still existed. They supported the ad hoc effort, otherwise it wouldn’t have happened (a “moment of ambiguity” in the institution), but they openly expressed weariness with the problem and doubt that we would come up with solutions. At that meeting, Ko and I presented an overview of what we had learned from a year’s worth of client involvement meetings and the questionnaires. We also recommended that we should put some new processes in place and continue with the project (and so begin to focus on piloting and documenting these new processes). The result of this meeting was the establishment of a client involvement task force, an important institutional step forward that happened because the client involvement committee (1) conducted research into the problem and (2) was able to present it coherently. Within a bureaucracy, the move from ad hoc to task force status is significant. Whereas previously our work and recommendations were useful for conversation and consideration, with task force status our work and recommendations must be made part of the public record and acted upon (usually in terms of a vote). We have, in other words, managed to persuade others to give our work more power. There is no question that a more powerful body gave us some of their power, but there is also no question that the
power “given” to us was a function of our ability to persuade others that it was necessary—that the client involvement problem, which everybody recognized (even if they didn’t understand it the same way), might usefully be seen as a communication problem and that we might be able to address it in some way. Understanding the rhetorical processes by which the institution operated, we used them and wrote our way to greater power. The new institutional structure of the planning council now looks like this (see Figure 2).

The first institutional change, then, was to alter the structure of the institution and to insert client involvement efforts into the ongoing processes of decision making. It is a small change, no doubt, but it is significant. The second change concerns what we have done with the client involvement meetings. Where once they were heuristic and much more fluid, as task force meetings they are now focused forums for improving client involvement. As a task force, we are piloting the major recommendation we made to the executive com-
mittee—that a structured mentoring program is necessary to help clients cross the boundaries currently preventing participation (significantly, this was a suggestion made by clients themselves). The meeting changes are subtle moves, yet important. Our meetings, which were always located in a different part of the city and often at variable times, connected those of us who met regularly with a wider spectrum of those affected by HIV/AIDS than were typically present at council meetings. While the task force meetings are more structured than the earlier client involvement meetings, a portion of each meeting will always be devoted to education as well as consideration of policy questions. In this little way, we have changed the processes of client involvement, although we have yet to impact in any significant way how policy is made (i.e., specific policy questions).

Some Difficulties of Activist Research, the Fragility of Institutional Change, and the Place of Technical Communication

My primary goal in this article has been to argue for one way that professional writing researchers can influence public policy. In this respect, the client involvement study is an example—and a problematic one at that—but not the focus of the piece (this is not intended as a write-up of research).

I provide this example not only because it shows that institutional change can happen but also because it makes visible some key issues, particularly the rhetorical processes by which institutions operate and the necessity of making visible and understanding relations of power within institutions. Professional writing researchers are perhaps best suited to uncover and understand problems related to the rhetorical process of institutional decision making and then to design solutions with participants (users) because writing researchers understand better than most that institutions are written. I don’t want to conclude, however, by trying to suture this argument. Instead, I want to problematize it because I think such a move might be even more useful for writing researchers who are interested in developing ways of understanding complex public institutions and addressing issues of public policy.

Given the argument that in order to fundamentally change policy it is necessary to change the processes by which it gets made, the institutional change the client involvement task force created is significant. We are hoping to introduce a greater number and variety of clients into the policy process. But as the project now stands, the meaning of “involvement” has not changed, and the meeting is still the dominant practice. The major recommendation to institute a mentoring program is likely a part of a total solution, but it too works within a narrow process and many of the current boundaries are still
firmly in place. Furthermore, there is no serious effort under way to create educational materials to explain the purpose and function of the planning council, and there is no plan to create better two-way communication. The message that the client involvement problem is a communication problem has not been heard or accepted by everyone, including those on the client involvement task force. And given the fact that I am the champion of this theory (an outsider), it may never be accepted. Our changes are important first steps, but they are not enough.

There are also challenges for activist research in the client involvement example. I’ve deliberately painted a picture of activist research in broad strokes, but my attempt to enact this stance through the client involvement project is more pedestrian and problematic, and therefore, perhaps, more useful. Participatory action researchers like to talk about the co-definition of problems and research questions and the collaborative nature of research processes, but there are few articles that discuss the problems of doing research in this way. In my case, I was never “in charge” of this project (and I’m still not). We didn’t conduct ourselves as “researchers” in ways I would have always chosen, and the pace of the project had all the fits and starts, dead times and manic phases of inquiry by committee. I wanted to be much more aggressive in the pursuit of alternative ways to become involved, and I wanted to move quickly, collect more data, implement and evaluate multiple solutions. Conducting research in this way was particularly difficult, and our field certainly needs more examples, models, and reflection on activist research practice. Still, we collected good information, and without question, we understand issues of client involvement in Atlanta much more fully than we did before the project, and this level of understanding would not have been possible without the participation of clients and committed service providers.

The strength of an activist stance is the ability to produce local understandings of complicated problems and develop with those most affected new or changed practices to address those problems. More significant for an activist stance, however, is the fact that researchers cannot continue to do research in traditional ways if their methodology changes (and by “methodology,” I mean a researcher’s ideological, ethical, and political positions; see Sullivan and Porter). I don’t want to put too much stock in my experience, which was limited, frustrating, and at the same time fascinating, but activist methodologies change the rhythms, practices, and production of research and knowledge. The question will be whether or not the larger discipline of professional writing will accept an activist research report, which may produce limited “knowledge” but powerful situated understandings and perhaps change.

While I think activist research practices were important for the client involvement project, the fact that I come from a technical communication background was important as well. Previous researchers interested in problems of client involvement typically came from
backgrounds in public health administration, sociology, and medicine. The work they have done and continue to do is important (and I rely on it in this article). In fact, teams of researchers trained in such disciplines conduct the planning council’s needs assessment (based on a surveying methodology), and this assessment is one of the most important tools used in council planning activities. If I brought anything unique to the client involvement project, it was an understanding of organizations as written, an understanding of how documents circulate, both orally and in writing, within organizations and effect change (e.g., the importance of the executive committee presentation), and an understanding of the importance of users to any client involvement solution. Given such a perspective, our focus on the client involvement problem as a communication problem and our use of bottom-up, user-based research methods provided a perspective other researchers had not provided. I think this is the type of specialized knowledge that technical communication researchers can bring to complex public policy situations such as this (and any number of civic, institutional decision-making situations). And this type of user-focused role is why an activist research stance can be so appropriate and useful in technical and professional writing: it acknowledges the situatedness of all research projects in a way that allows us to embrace, if we choose, an activist stance that has long been a part of the technical communicator ethos as user advocate.

The importance of technical communication in this project was not limited to issues of research, however. I noted in passing that the project began with an undergraduate service learning project that I picked up where the student left off. For two years now, service learning projects with community-based organizations and non-profits have been part of both my technical and business writing classes, and slowly we are making service learning an integral part of our undergraduate curriculum in technical and professional writing. We do this for two reasons: (1) it is a good way to learn business and technical writing because of the complex writing problems and situations in which we can situate students, and (2) it is consistent with the ethos of our urban university to become involved in the communities in which we are situated. But the relationships I have established have also been a rich resource for research projects and ideas beyond the client involvement project. Most importantly, however, my work with community-based organizations has made visible writing practices, situations, and users that are clearly within the scope of what we do as technical and professional communicators yet are often invisible in our scholarship and our classrooms. This certainly includes issues related to public policy. So as we are thinking about changes to the graduate and undergraduate curriculum at Georgia State, we are considering the ways in which technical and professional communication intersect with the world in ways we hadn’t previously considered, and therefore, preparing our students for opportunities we didn’t know existed.
Finally, there is the issue of the status of this example as a “professional writing” project. Some colleagues wonder about this issue (as I sometimes do) because of the fact that I did not study writers or even the discursive production of an organization. Furthermore, at this point, we have not produced any new documentation of client involvement. And while this is where we currently are with the project, we may never complete this phase if the task force and executive committee decide to go in a different direction. Yet documentation should not be seen narrowly as a textual practice; if seen as the act of designing processes, this project is all about documentation, about writing. We are searching for a way to involve clients who currently are silent and invisible, and we are looking for ways to do this with their participation. This new involvement will result in new processes, a change in practice for the planning council. Documenting client involvement, by which we hope to influence specific policies by making visible new perspectives, depends on these processes. One cannot be separated from the other. Can professional writing researchers affect public policy? I think so, but the most fundamental change will result from research practices that are activist and participatory and that examine and change the local institutional systems that make policy. Policy written from the bottom up will look and act much differently than policy written from a distance. And our greatest influence will be at the bottom: at local institutions in our communities and with others to whose well being we are committed.

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Works Cited


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