Chapter 17

Transforming Research for Transformative Change in Mental Health:

Towards the Future

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Genuinely transformative change, as discussed in Chapters 1 and 2 of this book, involves not merely the substitution of one dominant ideology for another, but rather a far-reaching social justice-oriented reconfiguration of traditional power hierarchies. It is our contention that increased user/survivor[1] autonomy and control in mental health research have a fundamental contribution to make to the transformation of community mental health *precisely through* such a redistribution of power. Users and survivors of the mental health system, that is, must be allowed to take on leading roles in both the generation and dissemination of scientific knowledge. Transformative change, according to this approach, will thus come from the historical margins, driven by traditionally subjugated knowledges grounded in the lived experience of madness and its social and institutional contexts.

Traditionally, users of mental health services—particularly those classified as "seriously and persistently ill"--have had virtually no control over either the nature of the services they receive or the evidence base that legitimizes these services. Admittedly, the past few decades have witnessed substantive improvements in the overall participation of user/survivors in the

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[1] The term "user/survivor" is used throughout this chapter to connote individuals who may identify rhetorically in various ways with the lived experience of mental health issues and/or the mental health system. Respecting people's chosen language is a hallmark characteristic of the user/survivor/ex-patient movement, as the power of institutional language to marginalize diverse mental states is a central organizing tenet of the movement. However, for the sake of consistency and brevity the term "user/survivor" will be used throughout this chapter with the exception of instances where individuals are directly quoted. It is also important to acknowledge the diversity *within* this community and avoid any attempts to see "user/survivors" as a monolithic category, which erases the intersectionality of oppression experienced by its members.

areas of policy, evaluation and governance as user involvement has been recognized as a key component of person-centered systems of care. In addition, there has been some growth in the adoption of participatory approaches in mental health services research (see, among others, the work of Pat Corrigan, Larry Davidson and others in the US, Geoff Nelson and colleagues in Canada, and José Ornelas in Portugal). Nevertheless *full control* over the research process—including the power to decide what questions are asked, what ideologies are challenged, and what methodologies are used—remains almost wholly outside the hands of service users, survivors, and those who self-identify as "mad."

We suggest that, in addition to embodying a truly emancipatory practice, user/survivor-led research has the potential to generate new user/survivor-focused knowledge that will contribute to the transformation of community mental health at both the individual and systems levels. For decades, community-based user/survivor communities and organizations have led in the creation of innovative alternatives to mainstream mental health services—alternatives grounded in direct experience of both madness and service use. Leadership in the domain of research, as already suggested by work in the UK (see below), promises to bring these same perspectives and innovations to the forefront of research, evaluation and development.

Fulfillment of this potential, of course, clearly depends on the adequate resourcing of training, including access to academia, and community capacity-building, as well as the creation of real and figurative spaces that promote collective meaning making among user/survivors—including conferences, user-run research initiatives, and other communities of practice. Enduring environmental and sociopolitical barriers—barriers that include the devaluation of lived experience *in the context of science and social research*, academic stigma, inadequate

accommodations, and insufficient resourcing of community-owned research—must also be addressed.

Given that our arguments are premised on the importance of a collective re-valuation of lived experience, before outlining our chapter we want to say something about our own positions and experiences. Each of the co-authors of this chapter identifies as a user and/or survivor of the mental health system. Collectively, we have experienced a range of psychiatric issues, services and labels (from depression to psychosis, peer support to involuntary hospitalization). [2] Although we herald from three different universities in three different countries, we have all at various points experienced significant stigma, discrimination and lack of understanding in the context of research and higher education, as well as varying degrees of a perceived disconnect between the values we have been taught (in community psychology and social work) and the actual state of mental health research in our respective disciplines. It is in large part because of these experiences that we are all resolutely committed to challenging the status quo as well as those practical and ideological barriers that continue to stymie meaningful user/survivor involvement in research. Above all, as junior researchers, we hope to see--and help build--a radically different research enterprise informing the future of system transformation within community mental health that prioritizes the experiential knowledge of user/survivors and openly acknowledges and challenges various manifestations of stigma, discrimination and ableism within academia.

In this chapter, we begin with a brief history of user/survivor involvement in research, propose a working definition of power, and use this definition to critically reflect on some of the shortcomings of participatory approaches as currently practiced in the context of mental health

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[2] We want to underscore that given the diversity and heterogeneity among individuals with psychiatric disabilities and intersections with other marginalized identities, we cannot claim to represent all possible perspectives.

and disability. Next we focus on two different ways of simultaneously addressing these shortcomings and affording greater autonomy and control to user/survivors: (a) through the support and development of user/survivor community-based-and-owned approaches that emphasize substantive community control over the research process, and (b) through the targeted training and support of academic user/survivor researchers. We conclude with some reflections specific to community psychology as well as general suggestions for moving toward a more critical and emancipatory model of user/survivor involvement in mental health research.

Brief History of User/Survivor Participation in Mental Health Research

As briefly mentioned in our introduction, user/survivors (or those historically labeled as mad, insane, or mentally diseased) have traditionally almost exclusively been the passive subjects of research, including what are now widely considered grossly unethical neurosurgical experiments (e.g., Quality of Health Care in Human Experimentation, 1973). Even today, vastly more user/survivors are involved in mental health research as *subjects* rather than as active researchers, participants, consultants or advisory board members. Because of this history and context, significant reservations and even hostility persist in at least some user/survivor communities with respect to mental health research evidence misappropriated from their lived experience and used to further legitimize practices such as ECT and forced treatment, considered by some to be oppressive while ignoring evidence of alternative conceptualizations of madness and practices for healing distress (these reservations parallel experiences and attitudes in other marginalized and vulnerable populations—see, e.g., Byrd et al., 2011). These factors continue to affect relationships between user/survivors and researchers, as well as community collaboration, issues of identity and perceptions of power.

Although researchers in allied fields such as community development and adult education began to emphasize greater community participation in and control over research with marginalized communities beginning in the 1970s (Fals-Borda, 1987, 2006, 2008; Freire, 1982; Hall, 1992), in the fields of psychiatry and mental health, there has never been real consensus regarding the importance of user/survivor participation. In psychiatric rehabilitation and community mental health in our home countries (Canada, Portugal and the US), small groups of researchers have utilized participatory methods for the last several decades, while other "medical" sub-fields (particularly those concerned with the etiology, epidemiology, nosology and phenomenology of psychiatric disability) rarely include even minimal participatory components. Although there are also certainly individual (disclosed and undisclosed) user/survivor researchers in our countries of origin—researchers whose considerable accomplishments we by no means want to downplay—there are virtually no organized groups of such researchers nor systematic efforts to collectively theorize issues of user/survivor researcher identity or discourse.[3]

Meanwhile, in the UK, more widespread opportunities for participatory involvement emerged during the 1980s and 1990s in the form of service evaluation and policy-oriented participatory research; opportunities which allowed user/survivors to gain substantial research experience (Wallcraft & Nettle, 2009). Early pioneers in the UK such as Jan Wallcraft, Peter Beresford, Diana Rose, Alison Faulkner (and many others), have since worked to develop a robust British user/survivor researcher movement and discourse. In 2009, a group of prominent survivor researchers edited the first full compilation of survivor theory, methodology and

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[3] A recent and promising exception is the Peer Graduate Student Support & Collaboration group started by Laysha Ostrow. See http://www.peersri.org/graduate-students.html.

perspectives as well as first person accounts of research involvement in both academia and the community (Sweeney, Beresford, Faulkner, Nettle & Rose, 2009).

Even more recently, European user/survivors have begun to advocate strongly for user-led or controlled research (Beresford, 2009; Faulkner & Thomas, 2002; Russo, 2012). Beresford and Evans (1999) define such research as both meaningful involvement in and control over every step of the process; user/survivors, that is, should no longer subordinated to passive roles, even in subtle ways. In user/survivor controlled research the initial idea for the investigation comes from user/survivors, and they are also responsible for the design of the research (methodology, type of analyses), are accountable both ethically and financially, and are responsible for the decision-making process related to scientific production and dissemination. In sum, user/survivor controlled research creates a new equilibrium relating to power within the research process intended to explicitly challenge the status quo, and capitalize on the insights of user/survivors.

Although discourse regarding user/survivor controlled research remains strikingly under-developed in most parts of the world, the exigency of reconfiguring power relations that it raises strikes us as fundamental to the transformation of mental health research. Surely an emancipatory system cannot be one in which it is non-user "experts" who, having never experienced the strangeness of psychosis or the dehumanization of certain forms of mental health "treatment," continue to make nearly all crucial research decisions. Nevertheless for such involvement or control to be "real" or "genuine," both the macro- and micro- operations of power as they operate in research and academia, must be critically addressed. Before turning to our own suggestions for research transformation, we thus provide a working definition and discussion of power.

What is Power?

Although power has been theorized in many ways, for example as "the capacity to exert actual influence on decisions" (Kloos, Ornelas, Duarte, & Nelson, this volume), the definition we adopt here is grounded in Foucauldian theory (Foucault, 1972, 1977, 1980; Prilleltensky, 2008; Rose, Thornicroft & Slade, 2006) and holds that power is ubiquitous, diffuse, and fundamentally relational. According to this framework, an individual does not "possess" power, as she would a material good, but rather *exercises* power in the context of a net of social and institutional relations that variably reinforce, challenge, potentiate or otherwise structure her actions. Thus a researcher's decision to do, for example, X or Y, would not be seen as simply "her" decision, but rather an act that (a) has meaning and influence *because of* a variety of contextual social, political and institutional factors and (b) *in its own right* reinforces, challenges or (re)structures social and political discourse. We certainly agree with Kloos et al. (this volume) that power relations often involve control over social and material goods and values, as well as various forms of internalization and subjection, but nevertheless focus on Foucault's power framework in order to call attention to some of the ways in which larger social, institutional or research settings *collectively* shape discourse concerning legitimate or illegitimate knowledge and research practice.

Foucault's (1977) elaboration of the term power/knowledge is likewise important to our discussion of research settings inasmuch as it emphasizes the *mutual implication* of the exercise of power and the use and generation of knowledge. Knowledge and power, that is, co-constitute one another. Asymmetrical power relations, such as those that exist between psychiatric researchers and service user/survivors—one of whom is the expert, the other most often a relatively passive recipient or beneficiary—fundamentally shape discourse about "mental illness." Diagnostic criteria, disability thresholds, and appropriate treatment are all domains of

knowledge controlled by "experts." However, it is not simply the case that non-user researchers "possess" power in the context of these relations, but rather that they are *able to exercise* power by virtue of the fact that their acts and discourse are supported and legitimized by a network of much larger and more diffuse social relations and forces. These include cultural affirmations of the value of "science" *in general*, norms related to class, and the continued dominance of seemingly "timeless" cultural binaries that pit reason and logic against madness, emotion and "irrationality." Both subjective first person experiences of psychiatric issues and services and peer-designed interventions are thus often devalued relative to the "objective" and expert knowledge held by non-peer clinicians or researchers, not merely because of their conscious efforts to control discourse, but also because of these larger social and cultural forces.

As part of any critical examination of specific *manifestations* of power/knowledge, Foucault (1972) accordingly recommends that we always begin by asking not only *who*, in a particular context, "is speaking" but also who "*is accorded the right to use [a particular] sort of language*? Who is *qualified* to do so?" As well as from where "discourse derive[s] its legitimate [or legitimizing] source and point of application?" (pp. 50-51, our emphases). In the context of research, then, a critical interrogation of power would demand that we ask not only who is doing what, but "what" is allowing them to do and say the things they do and say. What are the processes, for example, whereby an individual is "accorded the right" to determine what questions are asked and what methodologies used in a given type of research project, apply for grants, publish in academic journals, and speak at academic conferences? *What* types of experience, insight, and/or distress are deemed scientifically "legitimate" in these processes of knowledge production and dissemination? What are the institutional and professional norms that provide "training" or grant access to some (again, who?) and deny it to others (who and why?)?

How do various macro and micro structures funnel or constrain possibilities of "subjective" and "objective" representation?

With respect to challenging, and potentially unseating, existing power hierarchies, we contend that even the best-intentioned researchers cannot simply "hand over" power without addressing those macro and micro-structures that support, constrain, potentiate or "impossibilize" user/survivor autonomy, control and influence. Unfortunately, critical awareness of potentially problematic dynamics, as well as those historical and cultural forces that shape and constrain collaboration and inclusion, are only infrequently explicitly addressed in community mental health. As we review in the following section, this can lead to serious problems not just at a theoretical or ideological level, but far more practically.

Mainstream Contemporary Participatory Research

One obvious "solution" to the problem of the imbalance of power between mental health service user/survivors and non-user researchers, as noted in our historical overview, lies in the implementation of various forms of participatory, or "inclusive," research. Although it is not our intention to minimize the importance of such methodologies, we nevertheless remain concerned about the extent to which various participatory approaches *as conventionally practiced* in community psychology and community mental health settings go far enough in equalizing or redistributing power and challenging the status quo. Community psychologists such as Balcazar and colleagues (1997) have proposed a "continuum" of participatory research (PR) ranging from minimal consultation to research leadership. However, mental health PR, albeit with notable exceptions, is often heavily weighted to the more "minimal" side of the spectrum. Thus it is rare to find community participants involved in initial grant-writing, decision-making regarding research design, either statistical or qualitative analysis or manuscript writing. In fact, even in the

broader arena of international participatory research, contemporary critics such as Rahnema (1990) and Leal (2007) have underscored the cooptation and deflection of PR's originally radical commitment to profound social change. As the language of "participation" and "empowerment" has become more and more mainstream, that is, the critical and even revolutionary edge that defined them originally has arguably been mostly lost.

Considering research in community psychology and community mental health, then, we might return to some of our Foucauldian-inspired "critical" questions, and ask whether or not many contemporary participatory projects in fact *either* truly "validate" user/survivor discourse *or* critically challenge those cultural and academic beliefs that may reinforce its invalidation. For instance, what are the implications of a PR project in which the academic publications that result do not include a single user/survivor "co-researcher" as a co-author? Or even that include a merely "token" community co-author (e.g., a "co-author" not actually involved in any way in the conceptualization and writing of the manuscript)? How, that is, might such decisions in fact *reinforce* status quo assumptions about the inability of community members to "speak" to researchers and policy makers, or to directly contribute to the "scientific" literature (i.e., without the scientific "mediation" of sympathetic experts)? Likewise, how common is it for community co-researchers to actually determine the nature of a given research project and not just propose something that fits within the thematic structure the academic researchers in question have already proscribed? Why are issues of chief concern to non-academic activists (e.g., problems associated with labeling, criticisms of drug-centered care, more radical treatment alternatives like Soteria House, and alternative epistemologies of madness and distress) all but absent from the scientific PR literature?

These questions are not merely rhetorical. Undoubtedly no two PR projects are alike, and community co-researchers may be empowered or disempowered in different ways even within the same project. Nevertheless, our concern remains that far too often, co-researchers or community members do *not* in fact have meaningful influence over the production and dissemination of knowledge, not merely because of academic researchers' actions, but because of myriad macro- and micro- cultural and institutional forces that constrain and proscribe those actions. Unless this broader "ecology" of power is critically addressed, and our largely inadequate systems of treatment and conceptualizations of "mental illness" are *explicitly* challenged (as activists have demanded for decades), we believe that the transformative goals of this volume will be impossible to fully realize.

In line with Rappaport's (1977) observation that "the more solutions there are the better," we devote the remainder of the chapter to discussion of (a) community-based research approaches that explicitly focus on community control and (b) the targeted support and training of doctoral-level user/survivor researchers.

<div style="text-align:center">**Two Strategies for Transformative Research**</div>

Approach One: Community-owned Research

Potential for transformative change. Given our concerns about current participatory research praxis, we focus here on the need for research that is based in, and genuinely controlled and owned by, the community. Following critics like Leal (2007), we do not argue for a new paradigm so much as a *return* to participation as originally conceived by the international founders of participatory action research (PAR). With respect to our own criticisms of much existing participatory research, we argue that truly emancipatory user/survivor involvement must not merely "involve" the community, but should be connected to the broader social

transformation struggles of the user/survivor/ex-patient movement through community ownership. We begin by making a case for the transformative potential and unique contribution of research that emphasizes community control, and then proceed with a brief discussion of current and potential barriers to more widespread implementation.

The liberatory potential of PAR, as articulated by its founders (Fals Borda, 1979, 1987; Freire, 1978; Hall, 1997) is contingent on the relationship between research, education and action; the belief, that is, that research should not be treated as a separate domain of action and knowledge but rather integrated into the development and consciousness-raising activities of the community in its own efforts toward liberation. This requires that community research with liberatory aims be genuinely based in *and owned by* the community.

We raise the issue of ownership specifically given that, as our earlier critique of mainstream PR suggests, most such efforts are in fact "owned" *by the university*; university-based researchers, that is, almost invariably initiate and write grant proposals, choose the research topics and which organization to partner with, who to hire, how much to pay who for what, what sub-projects to fund, and so forth. While buzzwords like empowerment and emancipation are often used in such contexts, critics have argued that PR instead often covertly functions to increase *academic* "power" and influence through the cooptation and dilution of more radical community critiques (Beresford, 2002; Leal, 2007; Rahnema, 1990; Shaw, 2000; Sweeney, 2009). Researchers who undertake PR can also claim greater ecological or construct validity by emphasizing that "their" research now more closely reflects the interests of the population in question, a move which undoubtedly often benefits the researcher more than the community. Incentives inherent in the political economy of the academy further support such practices by forcing even well-intentioned researchers to focus on the exigencies of academic

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publication, individual funding, tenure and so forth rather than acting in line with the objectives of the community (Hall, 1992). Community members and researchers, in contrast, are far more likely to owe primary allegiance to their peer constituencies.

One example of a contemporary alternative to *mainstream* PR, though arguably fully in line with the original goals of international PAR, is community-owned and managed research (COMR). Originally developed by the West End Revitalization Association, a (non mental health related) community-based organization in Mebane, North Carolina, COMR was explicitly conceived to address some of the shortcomings of "university-owned" but nominally "community based" research (Heaney, Wilson & Wilson, 2007). The developers of COMR have explicitly sought to return power to the community by utilizing community-based ethical review boards rather than academic institutional review boards, ensuring that community leaders, via community-based organizations, rather than academic researchers serve as the designated primary investigators on any research grants, and maintaining hiring and firing power over technical consultants. In addition, decisions regarding the dissemination of research findings truly belong to the community organization: they choose what to disseminate, when and how.

Alignment with user/survivor movement. With respect to user/survivor research more generally, we contend that community-owned research closely aligns with the user/survivor movement's foundational emphasis on autonomy, independence and self-determination (e.g., Chamberlin, 1982). Indeed, community-owned user/survivor research might be seen as the replication or mirroring of peer-run and peer-led values, and structures --more commonly found in direct service provision --in the context of research. Although existing barriers should not be underestimated, community-owned user/survivor research holds the potential of facilitating the exploration of, and generation of knowledge about, true alternatives to the mainstream mental

health system as well as alternative conceptualizations of madness. Further, when implemented in the context of an already operational community organization such as a consumer-run organization, the community members involved are far more likely to work as paid team members, rather than temporary contractors (beholden to academic administrators) or even volunteers. Both the practical and symbolic significance of such shifts is worth emphasizing.

Community-owned research thus offers transformative potential to the research enterprise that underpins community mental health inasmuch as it would theoretically result in a far more genuine shift in power relationships between professional researchers and user/survivors. Moreover, it would embed research within the transformative work of the user/survivor community. Community ownership of research further challenges assumptions underlying current research practices as to who can conduct research, and exposes the underlying "ownership" of traditional university-owned community-based research, which is often not made explicit. In addition, community-owned research significantly disturbs the notion that intellectual spaces can only be found within the academy. Although potential resistance on the part of policy makers, academics and even the general public should not be underestimated (see the example below), the potential of community-owned research to challenge these norms and thereby contribute to a more genuine ecological transformation of the mental health service-research complex seems undeniable.

Mental health exemplar. The iterative process of action and research in community-owned user/survivor research is exemplified by the Second Opinion Society (SOS) in the Yukon territory of Canada, a user-run alternative to psychiatry. In response to the group's early activism regarding a planned housing project, the Yukon Ministry of Health supported the SOSs' goal to conduct an independent participatory needs assessment with psychiatric survivors. The results of

this research led to funding from the territorial government to establish a drop-in and resource center (Sartori, 2007). The work was nevertheless not without challenges. In addition to consuming much of the time and energy of the organization, individuals in the social services and medical sectors criticized and opposed the project. The local medical council, for instance, wrote letters to the editor decrying the "danger" of letting psychiatric survivors conduct research, and the local Mental Health Services center refused to participate (Sartori, 1997). In spite of this opposition, the needs assessment was ultimately a substantial success, lending credibility to the then fledgling SOS. Eventually the Canadian Department of Health Promotion recognized the study as one of the best PR projects conducted in Canada (Wallcraft & Nettle, 2009).

Barriers. As our discussion of power has foregrounded, and the example of SOS underscores, in spite of its enormous potential, there remain considerable ideological and structural barriers to actualizing community-based research projects that are truly owned by user/survivors.

First, as emphasized in our discussion of power, policy makers, funders and the general public alike may not view "uncredentialed" community members as "legitimate" purveyors of science (Armstrong, 1980), leading to a political milieu in which user/survivor community research must struggle for acceptance. Further, the internal capacity of a community organization to undertake the research it deems important may be a substantial barrier to the successful implementation of community-owned research. Although a successful community organization may be able to hire trained consultants to carry out particular tasks, such as statistical analysis, if internal members do not have sufficient background to appreciate the implications of various choices or strategies, their technical control over consultants' decisions may not be truly meaningful. At many stages, the potential for relationships between community

owners and hired researchers to replicate the power dynamics of university-owned research remains. Thus, if user/survivor community-owned research is to truly represent a liberating alternative to university research ownership then attention to relationships with external researchers must be coupled with the on-going development of internal research capacity.

A further barrier to community-owned research lies in restrictions attached to various funding sources. Currently, many research-based private and public funding agencies will not allow community researchers without specific credentials and/or affiliations to directly apply for grants. Even when such restrictions are not made explicit, community organizations may not have the "right" connections, credibility, or background knowledge of funding priorities and agendas. Indeed, in many cases, community-owned research initiatives may be perceived as explicitly threatening by traditional program officers and scientific review committee members precisely because they threaten the more exclusive authority of traditional experts.

In addition, it is worth remembering that the resources of research-intensive universities are often considerable. These resources include accounting, technical support, access to journals and software, grant-writing assistance, "free" consulting from other academic departments, and so on. From this perspective the viability of community-owned research may depend in part on a larger public dialogue about access to past research (i.e., "public access"), as well as the responsibility of publicly or governmentally-funded universities to more freely provide certain services to research-oriented community organizations. An alternate possibility would be the government funding of independent community-run technical assistance centers (specifically aimed at supporting community-owned research) such as those already in place in the US directed toward assistance with the development of consumer-run service organizations.

Finally, a more democratic approach to research potentially entails additional relational issues that may need to be explicitly and proactively addressed. These include not only relationships between community members and academic consultants, but also between community members and organizational leaders. In contrast to academia, in which decision-making hierarchies are often relatively clear cut, horizontal (and hence more ambiguous) relationships may be more common in community settings. In addition, the range of educational backgrounds, cognitive disabilities and intersecting, marginalized identities present in many consumer-run organizations, raise important but difficult questions about inclusion, representation and control as they play out across the spectrum of disability, class, race and sexuality.

Approach Two: Supporting Academic User/Survivor Researchers

Where community-owned research holds the potential to recentralize knowledge production in the community, the targeted support and training of doctoral-level researchers capitalizes instead on the potential of transforming academic research from within. As in the last section, we begin by making a case for the value and importance of academic training and then discuss some of the persistent practical barriers that would need to be addressed in order to mainstream such practices.

Transformative potential. It is almost a truism that research in many areas, particularly quantitative research, requires advanced training in statistics, design and methodology. Technical skills, however tricky they are to define and deconstruct in the context of complex power/knowledge relations, remain a practical necessity for most projects. So long as would-be user/survivor researchers do not possess these skills, it seems legitimate to worry that they will be able to exercise very little "real" power, much less be meaningfully involved, in any number

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of decisions and analyses crucial to research design, analysis and interpretation. Given the relative privilege and position of quantitative work in psychology, a weak user/survivor presence in quantitative research may also help reinforce the stereotype that user/survivor research projects are "soft" or "subjective" and arguably detracts from user/survivors' ability to critically examine complicated statistically-based work.

Although some user/survivor researchers in the UK have explicitly criticized the Cochrane hierarchy of evidence and other frameworks that emphasize randomization, control, and quantitative analysis (e.g., Beresford, 2006), mirroring broader social science debates concerning the legitimacy of quantitative vs qualitative methodologies, others have experimented with novel participatory quantitative and mixed methods approaches (Rose, Evans, Sweeney & Wykes, 2011; Tew et al., 2006). Returning to Foucault, we ground our own call for increased quantitative academic training in the belief that the reverse "cooptation" and radical reconfiguration of "the master's tools" can in fact be a highly effective means of navigating and affecting complex power-knowledge relations. Within community psychology, for example, Rapkin, Trickett and colleagues (e.g. Jensen, Hoagwood & Trickett, 1999; Rapkin & Trickett, 2005; Trickett, 2009; see also West et al., 2008) have used an "insider's knowledge" of quantitative evaluation and randomized controlled trials (RCTs) to construct far more progressive and ecologically-sensitive alternatives to the RCT such as the "comprehensive dynamic trial." Rather than viewing the quantitative side of community research as somehow inherently flawed, then, we contend that more traditionally empiricist domains are in fact ripe for creative and radical work.

In addition to the importance of academic training with respect to various technical skills, we also note the common requirement, at least in some regional contexts, that primary

investigators possess doctorates and/or maintain certain types of institutional affiliations. Thus without appropriate training, credentials and affiliations, user/survivors may simply be excluded a priori from entire domains of funding, dissemination and advancement. Further, while community-based organizations may engage in occasional research or evaluation projects, universities and research institutes remain one of the few bases for ongoing intensive research, with supports that are rarely matched outside government and academia.

With respect to the benefit of academic user/survivor researchers within specific institutional settings, we emphasize the potential for such individuals to challenge ableist assumptions among colleagues and the general public, as well as occupy positions in which they may exert considerable control over admissions, training, mentorship and ultimately decisions regarding the tenure and advancement of junior colleagues. The importance of user/survivor academics in such settings--individuals who will presumably attract, support and advocate for user/survivor mentees as well as junior colleagues--should not be underemphasized. In some of our own research (Gutierrez, Jones, Keys & Salzer, in preparation), postsecondary students with psychiatric disabilities queried about their experiences in school bemoan the absence of visible, disclosed user/survivor faculty or mentors and emphasize the difference they think it would make. Given the documented importance of same-group minority mentorship for women and students of color (Bronstein, 1993; Brown, Davis & McClendon, 2010; Padilla, 1994; Society for Research in Child Development, 2006), such wishes are clearly well-founded. Researchers with psychiatric disabilities may be able to provide crucial advice with respect to issues of disclosure, and effective academic accommodations in the context of both research and teaching.

Finally, with respect to the larger user/survivor community, we presume that many academic user/survivor researchers will have greater--and qualitatively different--knowledge of

and access to user/survivors and relevant issues. Qualitative research on community co-researchers in the UK, for example, suggests that user/survivor interviewers may have an easier time establishing rapport with interviewees and be more likely to elicit honest responses (Williamson, Brogden, Jones & Ryan, 2010); that user/survivor data analysts are both better able to identify those themes and findings that are most relevant and sensitive with respect to user/survivors' priorities and more likely to question non-user assumptions (Rose, 2004; Ross et al., 2005); and, that user/survivors often increase the effectiveness of community dissemination as well as community perceptions of trustworthiness (Barnard et al., 2005). Presumably, fully trained and empowered researchers are able to exert even more control in many of these areas--increasing rapport, facilitating other types of PR, and speaking with the credibility of an in-group member to other user/survivors.

Exemplar. As an example of user/survivor research, we chose to highlight the work of the Service User Research Enterprise (SURE) located within the Institute of Psychiatry (IoP) at King's College, London. Launched in 2001, SURE was created as a center for user/survivor academic training and research and currently boasts an impressive list of publications and large-scale research projects (see Rose, 2009). SURE explicitly recruits and trains user/survivor doctoral students, and three users have graduated with PhDs to date (Rose, personal communication, April 28, 2012). Dr. Rose, Co-director of the Enterprise, emphasizes that one of the most important ways in which SURE supports user/survivor researchers is simply through ensuring a "critical mass" of individuals with psychiatric disabilities who can support one another (as well as facilitate the careful mentorship of junior scholars by senior user/survivor researchers such as Dr Rose). Additionally, she notes that the presence of SURE within the IoP has, at least in some cases, helped persuade more traditional colleagues of the value and rigor of

user/survivor research and has opened up the possibility of teaching user/survivor courses or modules to a broad range of students. In her leadership capacity with the Enterprise, Dr. Rose has also been able to serve on a variety of additional academic and policy committees and speak in a variety of academic venues, thereby slowly but surely injecting alternative survivor discourses into the existing research infrastructure.

Barriers. The many practical academic barriers currently facing students with significant psychiatric disabilities are equally important to understanding the potential of this method for increasing user/survivor control in research. From an empirical standpoint, stigma at the doctoral and postdoctoral level has not been adequately assessed, but our own experiences and those of our colleagues and contacts, including undisclosed junior faculty, suggest that stigmatizing attitudes remain commonplace in mental health research settings. This is certainly true at the undergraduate level, as multiple qualitative studies suggest (Demery, Thirlaway & Mercer, 2012; Knis-Matthews, Bokara, DeMeo, Lepore, & Mavus, 2007; Megivern, 2001; Megivern, Pellerito & Mowbray, 2003; Salzer, Wick & Rogers, 2008; Weiner & Wiener, 1996). In the context of doctoral admissions, the only published article to have tackled disclosure during the psychology applications process in the US concluded that revealing a psychiatric disorder is widely considered a "kiss of death" by chairs of graduate admissions committees (Appleby & Appleby, 2006). On the flip side, while the British Service User Research Enterprise (SURE) in the UK explicitly recruits and supports user/survivor doctoral students (as described above), we are not aware of any explicit efforts made by particular academic departments or institutions in our countries of origin to seek out promising graduate user/survivor researchers, though the Yale Program for Community Recovery and Health and the Centre for the Study of Gender, Social

Inequities, and Mental Health at Simon Fraser University have made exceptional efforts to include user/survivor postdocs and junior researchers.

Academic accommodation in the context of doctoral work is another area that has unfortunately received little empirical attention. While extensions and flexibility may be common at the undergraduate level, finding "flexibility" in a doctoral program is often extraordinarily challenging, and potentially involves course instructors as well as advisors, research supervisors, practicum supervisors, other graduate students, and community or governmental partners. Some difficulties (e.g., frequent commenting voices or hallucinations, or more pronounced memory problems or medication side effects) may require considerable creativity to work around, and on-going willingness and commitment on the part of faculty and administrators to engage with students. Affected students, further, must constantly agonize over the trade-offs between disclosing and and risking being perceived as "not capable of a competitive research career" or suffering in silence--an often torturous internal process that Goffman (1986) analyzed at length. On the other hand, students may be implicitly or explicitly encouraged to "pass"; ironically the better a given student is at hiding her or his problems, the easier it is for faculty and other department members to simply forget that she or he has a disability at all.

While the presence of mentors or role models (i.e., senior researchers who have navigated these same issues and succeeded in spite of them) would likely be extraordinarily valuable, such individuals, or at least those who are public enough about their disabilities to be identifiable, are few and far between. While many of these challenges have been noted with respect to underrepresented ethnic minority groups, and efforts made on many fronts to promote diversity and inclusion, and provide supplemental diversity-based training and fellowship opportunities

and targeted mentorship (see, e.g., the American Psychological Association's Diversity Fellowship program), such efforts remain extremely rare in the context of "serious mental illness."

A final barrier is the isolation and alienation many user/survivors may experience in doctoral social science training programs. Clinical coursework on psychopathology, for example, may emphasize deficit-based models of "mental disorder," and seminars on prevention may explicitly target "mental illnesses" as phenomena to be eliminated (as, for example, Prilleltensky (2008) recommends). For students who experience madness as a fundamental component of their identity such implicit values may lead to feelings of profound marginalization. These experiences of isolation and alienation may be further compounded by the exclusion of madness, and disability more generally, from both diversity coursework and departmental pro-diversity initiatives.

In summary, the barriers facing user/survivor graduate trainees remain considerable. Although there are notable (disclosed and undisclosed) user/survivor researchers (even outside the UK), who have contributed significantly to the mental health research literature, these individuals mostly remain exceptions that prove the rule. Although the existence of the four of us, as well as this chapter, suggests that things are slowly changing, we all hope that commitments to meaningful inclusion by academic researchers and departments will improve the opportunities and experiences for the next generations and that future user/survivor graduate students will not have to struggle quite as much as we have.

Conclusion

Reflections Specific to Community Psychology

In an effort to speak to as wide an audience as possible, we have thus far limited our reflections to community mental health *in general*. Before concluding, however, we want to make some more pointed comments specific to the sub-field of community psychology (CP).

Although CP, first developed as a response to deinstitutionalization and the need to develop community-based alternatives to institutional care (Anderson, Cooper, Hassol, Klein, Rosenblum & Bennett, 1966; Ornelas, 2008), CP researchers have gradually moved farther and farther away from this early focus on "serious mental illness" and community mental health. Despite CP affirmation of the values of empowerment, inclusion, and social justice (Chapters 1 & 2 of this volume), a critical eye shows that the field has stagnated in a certain type of language and arguably limited vision of what a CP approach to mental health might look like. Thus, in an unpublished critical content analysis of the (primarily North American) CP literature, we found an almost ubiquitous use of the implicitly biomedical language of "serious mental illness" (typically unqualified), little participatory research (overall), no examples of CP user/survivor led research or discourse, and few articles that explicitly challenged mainstream psychiatric etiology, epidemiology, nosology or drug-centered systems of care (Jones, Gutierrez & Keys, unpublished research).

While many factors have undoubtedly contributed to the current state of psychiatric disability research in CP, one key contributing factor is arguably the field's historic turn from intervention to prevention, an approach stemming from CP's commitment to de-emphasizing individual-level interventions (Rappaport, 1981, 1987). A prevention focus, however, risks reifying the pathologization of madness (whether as an individual or social phenomena), as well as moving attention away from the empowerment and self-determination of individuals with *existing* psychiatric disabilities. The European Hearing Voices movement (see Intervoice, n.d.)

provides an illustrative counter-example of an approach simultaneously emphasizing community participation, empowerment and mutual aid *alongside* critical phenomenological, nosological, and epidemiological work (Romme, Escher, Dillon, Corstens & Morris, 2009). In addition, the Hearing Voices movement has contributed to the development of alternative strengths-based *individual* approaches such as the Maastricht Approach to voice-hearing (Corstens, Escher & Romme, 2008).

In addition, although Rappaport (1987) emphasized the exigency of examining implicit ideological assumptions and developing rigorous theory rather than uncritically borrowing ideas from other fields and disciplines, little new theory specific to madness has developed within CP. With the exception of some of Morrison's critical work in the late 70s and early 80s (Morrison, 1976; Morrison & Becker, 1975; Nevid & Morrison, 1980), as well as contemporary efforts by select critical community psychologists (mostly outside the US), community psychologists have largely failed to generate alternative epistemologies of disability and madness or to directly challenge status quo systems of drug-centered care. Discussions of the more far-reaching implications of the recovery movement, or the pitfalls of the continued biomedicalization and clinicalization of psychiatric issues are noticeably absent from CP discourse.

We thus urge community psychologists to more critically reflect on some of the pronounced shortcomings of CP research on "serious mental illness," the continued lack of inclusion of doctoral-level user/survivor researchers in the field, and the disconnect from promising developments associated with critical psychology and the user/survivor researcher movement. We also hope that we as a field can collectively recover the sense of urgency that Rappaport (1977, 1981, 1987) repeatedly referred to as the fuel of radical social change.

Questions and Suggestions

Although the major goal of this chapter has been to emphasize the exigency of increased user/survivor-controlled research in both the academy and the community, we want to conclude with some suggestions and reflections regarding the role and responsibilities of non-user researchers. Clearly enough, our belief is that the current under-representation of user/survivor university and community-based research initiatives is deeply problematic. At the same time, we readily acknowledge that non-user researchers can be valuable allies and partners as well as effective and innovative independent mental health investigators. Nevertheless, we remain committed to a critical position that holds that all too often, community mental health researchers are not making the efforts that they might to more fully include and support user/survivors and challenge the status quo. We thus recommend that researchers consider the following guiding questions in evaluating their field, their own work and their relationships with user/survivors:

(1) First and foremost, are critical questions being asked in the context of mental health research projects and publications with respect to the use of potentially pathologizing language, consideration of academic *and non-academic* user/survivor perspectives, the inclusion or exclusion of ideological perspectives that either challenge or reinforce the status quo (including biomedical models of and approaches to mental health), and consideration of the consequences of various linguistic, methodological and practical choices? Similarly, are the implications of research decisions regarding co-authorship, control and level of involvement being explicitly thought through?

(2) To what extent does [one's own] current research involve or encourage user/survivor *capacity-building*, both internally (i.e. in graduate programs) and externally (in the community)? What is, or could, one be doing to help facilitate the development of the skills and expertise necessary to carry out various types of rigorous research *by* user/survivors?

(3) To what extent does one's own doctoral or postdoctoral training program *explicitly* target and provide support for user/survivor doctoral students and junior researchers? Are barriers such as inadequate accommodations, institutional discrimination, and departmental stigma openly acknowledged and challenged? Are proactive policy measures (such as protected disability or medical leave) in place that would help students with psychiatric disabilities flourish?

(4) To what extent is one invested in promoting independent community-owned research in addition to university-based projects in which one serves as a primary investigator? Is one willing to take a "back-seat" and let community members decide what questions to ask and what methodologies to utilize? If not, *why* not--what might make it so difficult to actually give up control? What forces, for instance--cultural beliefs, public attitudes—might be making it so difficult to suspend the default assumption that "the expert knows best"?

To briefly return to our discussion of power, then, the fundamentally relational nature of the latter means that the renegotiation of hierarchies must always involve multiple stakeholders. User/survivors can only speak with authority if traditional researchers, policy makers and members of the general public come to agree that systems change must be guided both by the lived experience of disability and recovery and through the ongoing critical questioning of often unspoken assumptions about power, truth, and science. Thus, it is not a matter of simply promoting *any* research led by *any* individuals with a psychiatric diagnosis, but rather of critically engaging with the complexity of user/survivors' experiences, as well as ideological tensions and contradictions within the user/survivor movement. If we look at discourse circulating in user/survivor communities right now, for example, we find a literature rich with transformative ideas—from the Hearing Voices movement's claims that voice hearing is simply a valuable "human variation" to user/survivor led articulations of the causal role of trauma and a

range of peer support groups that treat "symptoms" as meaningful human experiences. These ideas can at times contradict one another, but they all speak to a very different understanding of "mental illness" from that currently dominant in the academic literature.

Cooptation, undoubtedly, is not only inevitable, but has accompanied efforts aimed at more radical change from the early days of the user/survivor movement (see, for example, Chamberlin's (1982) introduction to the British re-issue of *On Our Own*). Likewise, not every user/survivor is interested in participating in radical or revolutionary knowledge production; nor will transformative change be instigated by the presence of a few token user/survivor researchers. What we advocate instead is a *system-wide* effort to open academic and research discourse up to the full range of user/survivor perspectives and embrace the challenge of competing conceptualizations and epistemologies of madness. Taken seriously, we believe, such practices *will* transform the status quo.

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