EVALUATING PEER PROVIDERS

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"Nothing about me, without me."
- South African disability movement slogan

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The growing tide of health consumerism, which is rooted in consumer rights protections and total quality management (TQM) with its focus on customer satisfaction, has compelled the healthcare field to grapple with the need to be customer driven. As opposed to the traditional view that "the expert knows best," consumerism is based on the assumption that principles of good healthcare must reflect consumer understandings, values, and desires. In the field of mental health, consumerism also holds that peer providers (i.e., providers who have been labeled with a severe psychiatric illness and have received services), will translate consumer perspectives into services that are more effective for service recipients (i.e., consistent with recipient understandings) (Blanch, 1992).

It is to the issue of evaluating peer providers that we now turn. We define evaluation as activities, grounded in social and behavioral science methods, to measure and track interventions and outcomes and to establish the relationship between the two for the purposes of establishing, maintaining or improving the quality, effectiveness and efficiency of services (Rossi & Freeman, 1993). In this paper, we suggest that future evaluations of peer providers should couple traditional evaluation methods with participatory approaches to evaluation that include peer providers and the consumers they serve in the evaluation process. There has already been substantial interest and involvement of consumer/survivors in evaluation and research and their presence has proven to make evaluations more meaningful, useful for improving service delivery,

¹ We believe the term "peer provider" is the most accurate description and carries little or no stigmatizing effect. It is understood that this term may be used synonymously with "consumer provider", "service recipient provider", and others.

and scientifically convincing (Campbell, Ralph, & Glover, 1993; Tanzman, 1993; Campbell & Schraiber, 1989; Fricks, 1995). Using this approach, we believe, will also result in evaluations that empower peer providers and consumers, and overcome peer provider and consumer resistance to evaluation. The remainder of this chapter is divided into two parts. In the first we discuss a desired research process; combining participatory approaches and evaluation with traditional evaluation methods. In the second, we present a conceptual model of research content for guiding future research on the effectiveness of peer providers. The most successful evaluations use conceptual models to identify important variables to study so that significant influences on program effectiveness are not overlooked (Brekke, 1987). In presenting this model we also discuss the research to date on its variables to suggest useful starting points for original research.

Participatory Approaches to Evaluation

Advocates of peer provided services believe that peer providers and consumers have a "first-hand" or "insider's" understanding of the expectations that recipients have of services and the ways in which traditional providers meet and fail to meet these expectations. Likewise, evaluation research with peer provider participation takes advantage of this unique understanding to increase the meaningfulness and usefulness of investigations. Utilizing a participatory process can reach beyond traditional research and evaluation when it fails to understand the subjective reality of the service recipients or the peer providers because the definitions of the experience of mental illness from the perspective of the consumer are missing from the general culture. For example, much of the existing research in the field of mental health reflects a "blaming the victim" ideology. Problems are defined as person-centered and studies are done to measure

deficits. Consequently, only one version of a set of events has been studied. This alienates consumers by disregarding their experiences and viewing them as the problem rather than suggesting that problems encountered by people with psychiatric diagnoses are social phenomena. Therefore, the perspectives of the mental health consumers and the expertise of mental health consumer/survivor researchers must be proactively sought out rather than ignored or silenced in the conduct of scientific inquiry because the inclusion of their voices enriches and validates the process of evaluation itself (Consumer/Survivor Mental Health Research and Policy Work Group, 1993; Rogers & Palmer-Erbs, 1994).

We also believe that evaluations should empower all mental health stakeholders and that participatory approaches will have this effect for peer providers and consumers. A successful strategy embraced by many traditionally disempowered groups to improve their quality of life and illuminate issues of social science has been the grassroots and scholarly articulation of the value of "native" knowledge and practice. Many disempowered people believe that a more participatory style of research should be adopted where they are consulted at every stage of the process, and assisted and encouraged to carry out research and evaluation themselves. Participatory research supports a coherent and mutually supportive pattern of concepts, values, methods and actions that has wide applications.

Finally, we believe that participatory approaches can foster cooperation with evaluations, particularly those which are externally mandated, by addressing the most common reasons why peer providers and consumers might be reluctant to cooperate. In some cases peer providers and consumers may associate feelings of powerlessness with evaluations if they experienced being treated as "objects" in previous research. Participatory approaches to evaluations should share control of the evaluation process with peer providers and consumers by means of steering

committees and more direct involvement. Peer providers and consumers may disagree with the outcomes being assessed. They may believe, for example, that services should be evaluated in terms of their impact on empowerment when others have elected to measure functional change. Participatory approaches should enable peer providers and consumers to incorporate evaluation measures that reflect their understandings and values. Peer providers and consumers may also fail to see the need for adhering to time consuming and tedious protocols. The reasons for these protocols should be explained and reviewed in participatory process. Finally, peer providers and consumers may feel that evaluations drain scarce resources from direct care. A participatory process should consider how resources allocated to evaluation can be used to improve services. It should be noted that the concerns of peer providers and consumers are often the concerns of other, non-evaluator stakeholders in mental health systems. These concerns may be particularly pronounced among persons in the organizations that employ peer providers, since persons in these organizations, whether traditional mental health agencies, consumer initiatives, self-help programs, or consumer-controlled alternatives, are likely to be particularly sensitive to the alienating aspects of traditional evaluations.

In recommending participatory approaches to evaluation, we believe we are subscribing to a process that has already demonstrated its worth. The last decade has witnessed the blossoming of a vibrant consumer/survivor research and evaluation agenda and the growing belief that consumer involvement in evaluation holds great promise for both system reform and continuous quality improvement of services (Campbell, Ralph, & Glover, 1993). As a result, new questions, methods and ways of interpreting data have emerged in the margins of traditional services research. Consumers are now participating in growing numbers in research and evaluation (Campbell, Ralph, & Glover, 1993) and have led recent efforts to determine needs and

preferences for services and supports (Tanzman, 1993), to define outcome measures (Campbell & Schraiber, 1989; Consumer/Survivor Mental Health Research and Policy Work Group, 1992; Trochim, Dumont, & Campbell, 1993), and to develop and conduct consumer satisfaction assessments (Fricks, 1995).

More specifically, participatory research models have the capacity to critically examine the context in which evaluation occurs to assure that it reflects the processes and outcomes of services as consumers know them. Such research can go beyond statistics that record numbers of service recipients to include the meaningful interactions of those living with a psychiatric diagnosis. It can flesh out thick descriptions of gendered and racial experiences rather than just analyzing variables of sex and race. It can examine not only the differences between peer providers and those professionals without a diagnosis, but can explore what it means to be a person with mental illness working or receiving services within a program or agency.

The role of professional evaluators under a participatory approach is one of educator, consultant, learner and mediator (Rogers & Palmer-Erbs, 1994). It is the function of the professional evaluator to educate the evaluation team about research methods, data collection and data analysis. The professional evaluator, in turn, learns about the "local culture" from other members of the research team. Elden and Levin (1991) describe the role of the evaluator as a "colearner" rather than that of the "expert in charge" and state that it is critical that the evaluator must know how and when to step aside and allow the participatory evaluation team to take charge of its own investigation.

The major hypothesis of participatory research models is that "insiders" have ready access to information that outside professional evaluators can only access with great difficulty if at all.

The involvement of insiders in combination with the overall inclusion of many stakeholder

groups is likely to improve the accuracy of the evaluation's depiction of the organization, the service delivery system, and a broad range of outcomes. Thus, not only does a participatory approach lend a voice to traditionally muted groups, but it provides the means for a more comprehensive, meaningful, and accurate evaluation of peer provided services.

The process of a participatory evaluation is also powerful in its potential to develop collaborative relationships between mental health consumers (including peer providers) and mental health service providers that extend beyond the evaluation effort. The dialogue necessary to cooperatively undertake an evaluation project has the potential to foster relationships between team members and contribute to future success in working together.

It is important to note that we do not consider participatory approaches as alternatives to existing evaluation methods, but rather as a means of enhancing evaluation methods through the participation of underrepresented individuals. Combining inclusive approaches with experiments, quasi-experiments and qualitative methods (Campbell & Stanley, 1966; Miles & Huberman, 1994) has the potential to result in evaluations that are meaningful and empowering as well as scientifically convincing. Traditional evaluation can be construed as a process in which evaluators educate each other as to theoretical, methodological and utilization options and negotiate the trade-offs required by resource constraints and other practical limitations (e.g., the amount of time persons will set aside for interviews, the time administrators have to "process" evaluation results). In this construction of the evaluation process, participatory approaches highlight the importance of including a wide range of stakeholders in the process and devoting the time and resources necessary to allow for mutual education and negotiation (Rogers & Palmer-Erbs, 1994). It seems to us, that there is nothing inherent in such a more inclusive evaluation process that necessarily compromises the scientific validity of evaluation designs. We

assume that such processes will consider the merits and feasibility of relevant design options. We further assume that design compromises will be made, as they usually must be, because of resource and other practical constraints (Campbell & Stanley, 1966), rather than due solely to stakeholder inclusion.

Obstacles to and Resource Requirements for Evaluations Combining Participatory Approaches and Traditional Evaluation Methods

It should be emphasized that to gain the benefits of participatory approaches coupled with more traditional research methods requires overcoming some professional obstacles as well as investing significant resources. Consumer participation in evaluation, alone, does not necessarily guarantee success. Without constructive ways for dialogue to occur and shared decision-making to take place, participatory research methods can reinforce a kind of turf war over controlling human beings. Legitimate decision-making power and the power to impact the policies and practices of the agencies they evaluate is essential to the success of consumer evaluators.

Important factors such as remuneration and other resource requirements also need to be addressed. Including a variety of stakeholders will almost certainly require additional resources (Rogers & Palmer-Erbs, 1994). Capturing more diverse perspectives can require more data collection and will likely mean more honoraria, consulting fees and travel expenses than might be the case in a more traditional evaluation. Adequate pay and reimbursement of expenses for peer providers and consumers participating in evaluation is essential for trust, cooperation, and sustained commitment. Mowbray, Chamberlain, Jennings, and Reed (1988) conclude that consumer turnover for volunteer work in their peer-support project could be attributed to the fact that they were not paid.

Stigmatizing attitudes of some professionals working in the mental health field present another challenge to consumer participation in evaluation (Reidy, 1993). Professionals are often unwilling to give up power and control they have traditionally possessed, and consumers may hesitate to express their ideas (Curtis, 1993). Lord (1989) observes that the combination of traditional professional power and control, and consumer vulnerability, can stand in the way of true partnership. Other factors that cross-cut the preceding observations arise from the "anynee, menee, mynee, moe" approach by professionals that assumes any and all consumers are the same and will offer the same skills and experiences to evaluation. They consider "the consumer perspective" a homogeneous knowledge set without deference to skills, scholarship, or cultural diversity. This form of tokenism sets consumers up for failure to provide meaningful input at all levels of involvement.

Finally, as in any internal evaluation, the involvement of peer providers and consumers from within an agency poses problems of objectivity, coercion, privacy and confidentiality.

Considerable attention should be given to minimizing bias and coercion and maximizing privacy and confidentiality through careful training. In the consent process, persons being studied should be informed that their peers and/or caregivers will be involved in the conduct of an evaluation.

Threats of bias or violations of confidentiality and privacy are more easily minimized if "outside" data collectors are used. Given this, we recommend that outside persons be used to collect data. The knowledge that insiders have can be incorporated into the data collection instruments and the training of data collectors. If the experience of being a consumer or a peer provider is deemed crucial to the data collection, consumers or peer providers might be recruited from organizations other than the one being evaluated. In those cases where this is not possible, we recommend careful training of internal data collectors that explicitly instructs persons how to avoid

interjecting their biases into the data collection process. We also recommend a validation strategy in which external data collectors obtain data from a random sample of persons seen by inside collectors to estimate the degree and direction of any differences in data obtained by insiders and outsiders. If such differences are found, it may not be clear whether they reflect bias or differential disclosure to the two types of data collectors. However, the differences found can be reported so that evaluation users can take account of these findings in interpreting evaluation results.

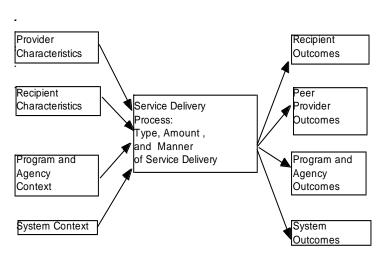
Having discussed a suggested evaluation process, we now turn our attention to the content of evaluations of peer provided services. The development and explication of a conceptual model of peer provided services and the variables which influence process and outcomes should serve as a guide for future evaluation questions. A review of the literature to date will, further, provide a basis for research questions in future studies.

Towards a Conceptual Model for Evaluating Peer Providers

To fully understand and evaluate peer providers, a detailed conceptual model of how peer providers impact on the process of service delivery and outcomes is necessary. This model should describe the different types of outcomes peer providers might affect and the variables that might mediate these impacts. At this time we can present only a very preliminary version of such a model and data from only a small number of evaluations. Future evaluations and additional conceptualization, ideally involving participatory action approaches, will be necessary for model testing and elaboration.

The model we propose is presented in Figure 1. This model postulates that characteristics of providers influence the service delivery process, which in turn, influences outcomes for

recipients, peer providers, organizations/agencies, and systems. It further postulates that the service delivery process is also influenced by program, agency and system variables. Below, we discuss the specific components of the model and review evaluation literature in the extent to which they address these components. While Lovell, Stastny, and Katz (1992) and Kaufmann, Ward-Colasante, and Farmer (1993) used collaborative, consumer oriented approaches reflecting the principles of stakeholder inclusion, the remaining studies reviewed did not appear to involve participatory approaches.



<u>Figure 1:</u> A preliminary conceptual model for evaluating peer providers of mental health services: major categories of variables and hypothesized relationships.

Provider Characteristics. Provider characteristics refer both to whether a provider is a consumer/survivor as well as sociodemographic and clinical characteristics on which providers might vary. We conceptualize these characteristics as independent or mediating variables. The impact of any type of provider might be influenced by other variables such as their age, gender, training, and experience. In the case of peer providers, where an insider's knowledge of mental illness is postulated to be important, the particular diagnoses, treatments, and treatment settings peer providers have experienced may affect their impacts. In the materials we reviewed,

sociodemographic variables explicitly studied included sex, race, employment status, benefits (Sherman & Porter, 1991), age, education, and marital status (Solomon & Draine, 1995).

Clinical variables included in evaluations were DSM III-R diagnosis, physical disability (Sherman & Porter, 1991), and number of psychiatric hospitalizations (Solomon & Draine, 1995).

Recipient Characteristics. Recipient characteristics describe the population being served. Variation in recipient characteristics can have a pronounced influence on how types of providers will affect service delivery and outcomes. Typical measures of recipient characteristics include age, sex, race, psychiatric diagnosis, level of functioning and marital status. The literature reviewed examines a wide range of recipient characteristics including homelessness, living arrangement, drug and alcohol use, attitudes towards medication compliance (Solomon & Draine, 1995), benefits received (SSI and/or Medicaid), duration of disability (Heine, Hasemann, Mangine, Dearborn-Morris, & Royse, 1993), and employment status (Felton, 1992). An example of the utility of recipient characteristic data is provided by Mowbray, Wellwood, and Chamberlain (1988) who used an analysis of recipient demographics and global assessment scores (GAS) to conclude that the population studied was very similar to a population from a psychiatric inpatient unit. This enabled the researchers to infer with some confidence that the peer provided service was effectively preventing hospitalizations in a population at-risk.

<u>Program and Agency Context.</u> Program and agency context refers to the nature of the programs and agencies in which providers work. As an example, programs may be classified into mental health agencies, consumer initiatives, self help programs, and consumer controlled initiatives. Program type may be conceptualized as a mediating or an independent variable. We assume that provider functions, roles, and effects are influenced by the type of program or agency

in which the provider is employed. For example, it is likely that the roles that peer providers play in agencies may differ with differing types and amounts of training prior to service provision. The effects of peer providers on professional providers should also be different when both types of providers are employed by the same agency. Additional questions can be raised about the differences in peer provider roles and functioning in programs that receive public funds as opposed to ones that are financially independent. Finally, programs and agencies may differ to the degree to which they are stigmatizing and present barriers to peer provider effectiveness, or provide training and other support. The literature we reviewed indicates that peer providers have worked in several types of agencies and organizations. Traditional mental health service agencies like state departments of mental health (Sherman & Porter, 1991), as well as consumercontrolled alternatives such as consumer-run advocacy and service agencies (Solomon, Draine, & Delaney, 1995), self-help groups, drop-in centers (Kaufmann et. al., 1993, Mowbray, Chamberlain, et al., 1988), and consumer owned and operated businesses (Mowbray, Chamberlain, et al., 1988) have employed service recipients as providers of mental health services. Most frequently peer providers have worked through traditional mental health service organizations or through consumer-controlled alternatives in partnership with traditional service organizations, particularly state level public mental health authorities.

System Context. System context refers to the nature of the system in which the particular agency or program exists. For example, a program may be in the public mental health system, the private mental health system, part of a managed care network, or in the more general social service system. We would also expect that peer providers and their programs will function differently and have different impacts depending on wider system characteristics. For example, the roles of peers may vary as a function of the degree to which systems use hospitalization. In

systems that use relatively more hospitalization, peer providers may play more of an advocacy role, whereas in ones that use less, peer providers may engage in more community support activities. The foregoing example involving advocacy highlights how peer providers might have impacts on systems as well as service recipients and programs. System context is largely absent in the literature that was reviewed. However, we believe it remains an important mediating variable to consider when evaluating peer provider service programs.

Program and system variables can be independent variables when the dependent variables are peer provider roles and functioning. They can be mediating variables when the independent variables are peer provider roles and functioning and the dependent variables are service recipient, program related, or system related outcomes. It will be the rare evaluation that can systematically vary program or system context. However, we recommend that in all cases evaluations provide detailed descriptions of program and system contexts so that their impacts can be considered as evaluation studies accumulate.

Service Delivery Process: Type, Amount, Cost and Manner of Service Delivery. By process variables we mean variables related to the types of service delivered, the amounts of service or the manner of service delivery. These variables are most often treated as mediating or dependent variables. Studying these variables may elucidate the most efficacious and efficient way in which peer provided services can translate into positive outcomes. Examples of specific process variables in the literature reviewed include community resources used, units of service provided, face to face versus office based services provided (Solomon & Draine, 1995), particular service activities and percent of time devoted to them (Mowbray, Wellwood, & Chamberlain, 1988), and pounds of food distributed by a consumer-run food bank (Lovell et al., 1992).

Recipient outcomes. Recipient outcomes refer to the impact of service on the service recipients. These are critical measures in the evaluation of peer provider service programs. Recipient outcomes can include a wide range of variables such as level of functioning, quality of life, and empowerment. It should be noted that empowerment may refer to gaining power within the traditional mental health system as well as power to seek alternatives outside of it (McLean, 1995). Recipient outcomes studied in the literature reviewed were quality of life (Felton, 1992; Heine et al., 1993), income, social network size, interpersonal contact, satisfaction with the mental health system (Solomon & Draine, 1995), and working alliance (Solomon et al., 1995). There is evidence to suggest that positive effects were experienced when consumer/survivor were employed as providers in the recipient outcomes studies reviewed. In one of the few true experimental designs in the literature, Solomon and Draine (1995) report the results of a two-year outcome study using a randomized trial to compare a consumer case management team with a non-consumer team. Data from this study indicate that case management services delivered by consumers were as effective as those provided by non-consumers. Several other studies support the association of peer providers in case management roles with positive outcomes. Felton (1992) and Stastny et al. (1992) present both quantitative and qualitative evidence that peer providers acting as "peer specialists" on an intensive case management team were associated with beneficial client outcomes. The outcome measures in this evaluation included quality of life, social networks, self-esteem, mastery, psychiatric symptomatology, optimism about recovery, and program engagement (Felton, 1992). In addition to case management roles, studies indicate that peer providers were associated with positive outcomes in various service provider roles. Heine et al. (1993) report positive recipient outcomes as measured by symptom severity and quality of life when peer providers were part of a crisis response team. Service recipients

also had positive attitudes towards peer counselors in hospitals as measured by a questionnaire assessing attitudes toward the project (McGill & Patterson, 1990). In addition, the use of peer providers in various social support roles was also associated with positive outcomes as measured by client re-hospitalizations (Mowbray, Chamberlain, et al., 1988).

Peer provider outcomes. Peer provider outcomes refer to the impact that taking on the role of service provider has on peer providers themselves. Peer provider outcome variables may include empowerment, employment success, job satisfaction, level of functioning and role strain (Zander, Cohen, & Statland, 1957). The literature reviewed reports evidence for positive peer provider outcomes. McGill and Patterson (1990) report that consumer/survivors who served as peer counselors for hospitalized persons identified increased self-confidence, heightened empathy, and feelings of usefulness and responsibility after serving in the program. In a study of persons with mental illness serving as case management aides, Sherman and Porter (1991) report that a majority of peer providers successfully completed training and reported positive employment experiences. The study also suggests that peer provider roles may have a direct ameliorative effect on peer providers' mental health. The fifteen peer providers who were continuously employed as case management aides required only a combined two bed-days of psychiatric hospitalization over the course of more than two years.

Program and Agency Outcomes. Program and agency outcomes refer to the changes which may take place in a program or agency during the course of a peer provided service. Programs may grow, downsize or change form in some other way. These outcomes are one way to measure the impact of a particular service delivery program. Ways of measuring program and agency outcomes found in the literature include tracking number of clients served (Mowbray, Wellwood, & Chamberlain, 1988), number of peer providers employed or volunteering (Lovell et

al., 1992), and continuation of public funding (Mowbray, Chamberlain, et al., 1988) The literature reviewed indicate that program and agency outcomes tend to support peer provider programs. A number of studies examined temporary or pilot peer provider programs, which, due to their success were extended and/or expanded by the sponsoring organizations (Sherman & Porter, 1991, Mowbray, Chamberlain, et al., 1988). There is also qualitative evidence which suggests that programs employing peer provider programs have become more respected in the mental health community or accepted as viable alternatives to traditional mental health service provision (Nikkel, Smith, & Edwards, 1992; Sherman & Porter, 1991; McGill & Patterson, 1990). In one dissenting report, McLean (1995) documents the failure of a peer provider project which she attributes to an organizational focus on advocacy and neglect of direct support.

System Outcomes. System outcomes refer to the effects which peer provider service delivery have on the system in which the agency or program functions. These types of measures may include a shift towards partnership between professionals and peer providers on case management teams, expansion of public funding for self-help groups and independently operated support groups, and greater emphasis on community based programs. The literature reviewed for the most part lacks data on system outcomes. There are some qualitative reports of an increasing acceptance of peer providers in the traditional mental health system. (Sherman & Porter, 1991). Peer provider programs may have far-reaching effects and so system outcomes should not be neglected in future evaluations.

Summary and Conclusions

In this chapter, we recommend that evaluations of peer providers employ a strategy combining participatory action research with traditional evaluation methods. We believe this

will overcome obstacles to evaluation and will make evaluations more meaningful and empowering. However, partnership with consumers and consumer organizations is only a first step. Participatory research which begins to involve peers in meaningful roles is a prerequisite for more empowering research and service provision relationships in the sense that traditional mental health professionals can learn from consumers and vice-versa. Simply increasing participation and involvement will never by itself empower consumer/survivor evaluators or peer providers unless and until peers themselves control some services and evaluations. French (1992) writes, "Disabled people are now being empowered by the disability movement; the question is, can research become part of that empowerment?" (p. 186) It is our hope that additional evaluation research using participatory approaches will help clarify the preliminary conceptual model presented in this chapter and will help make the goals of scientific knowledge, improved services, and consumer empowerment realities.