CREATING INCLUSIVE WORKPLACES: EMPLOYING PEOPLE WITH PSYCHIATRIC DISABILITIES IN EVALUATION AND RESEARCH IN COMMUNITY MENTAL HEALTH

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Abstract: People with psychiatric disabilities face barriers to employment both in the larger community and within the mental health system itself. Strategies used to affirmatively employ people with psychiatric disabilities as research personnel in an evaluation of community mental health services are described in this article. Our goal was to address two critical issues in the provision and evaluation of mental health services: the importance of meaningful work and productivity in the lives of people with psychiatric disabilities, and obtaining valid and reliable data regarding the effectiveness of community mental health services. A three-phase methodology for developing affirmative employment opportunities is presented, consisting of three components: affirmative planning, affirmative support, and affirmative rigour and method. The methodology is intended as a guide to assist evaluators and researchers in fulfilling the vision of the Canadian Human Rights Act and the Employment Equity Act.

Résumé: Les personnes ayant des problèmes psychiatriques font face à des obstacles en matière d'emploi tant dans la communauté que dans le système de santé mentale lui-même. On décrit dans cet article les stratégies utilisées pour embaucher des personnes souffrant de problèmes psychiatriques en tant que personnel de recherche dans une évaluation de services communautaires de santé mentale. Notre but était d'aborder deux questions-clés dans la prestation et l'évaluation des services de santé mentale: l'importance, pour les personnes ayant des problèmes psychiatriques, d'occuper un emploi valorisant et d'être productives, et l'obtention de données fidèles et valides concernant l'effica-

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cité des services communautaires de santé mentale. On présente une méthodologie à trois phases pour concevoir des occasions d'emploi, soit la planification, le soutien , la rigueur et la méthode. La méthodologie vise à guider les évaluateurs et les chercheurs à concrétiser la vision de la *Loi canadienne sur les droits de la personne* et de la *Loi sur l'équité en matière d'emploi.*

Everywhere people ask: "What can I actually do?" The answer is as simple as it is disconcerting: we can, each of us, work to put our own house in order. The guidance we need for this cannot be found in science or technology, the value of which utterly depends on the ends they serve; but it can still be found in the traditional wisdom of mankind. (E.F. Shumacher, 1973)

In this article we describe the process and strategies used to affirmatively employ people with psychiatric disabilities as research personnel in an evaluation of community mental health services. Our goal was to address two critical issues in the provision and evaluation of mental health services: the importance of meaningful work/productivity in the lives of people with psychiatric disabilities, and obtaining valid and reliable data regarding the effectiveness of community mental health services. The article describes a three-phase methodology for developing affirmative employment opportunities. It consists of three components: affirmative planning; affirmative support; and affirmative rigour and method. The three-phase methodology is intended as a guide to assist evaluators and researchers in fulfilling their duty to create fair and equitable employment as mandated by the Canadian Human Rights Act and the Employment Equity Act.

Employment and Psychiatric Disability

Employment is an integral part of our lives. Having a job is not only necessary to maintain financial viability; it is also an important aspect of self-worth and is integrally related to citizenship rights (Government of Canada, 1998). For many people with psychiatric disabilities having a job is difficult to achieve. Mental illness may inhibit cognitive and social abilities needed to perform in the world of work (Bell & Bryson, 2001; Lysaker, Bell, Zito, & Bioty, 1995; Peckham & Muller, 1999). Dealing with illness-related issues, particularly during young adulthood, can interfere with the individual's ability to develop a stable work history. In addition, people with

psychiatric disabilities experience stigma and job discrimination that renders them employment disadvantaged (Peckham & Muller; Sayce, 2000). These difficulties result in high rates of unemployment for people with psychiatric disabilities, despite governmental policies regarding employment equity (Government of Canada, 1998) and advances in psycho-social rehabilitation technologies (Tsang, 2003). Even though people with psychiatric disabilities wish to be engaged in work (Donegan & Palmer-Erbs, 1998), rates of employment remain low.

The potential to create positive employment outcomes for people with psychiatric disabilities has generated much interest in the field of community mental health. Some of the most successful initiatives have included Supported Employment and Individual, Placement and Support models of service delivery that assertively engage and support people with psychiatric disabilities in real work (Tsang, 2003). Attention has also been focused on developing workplace environments that facilitate employment success (Kirsh, 2000; Ochocka, Roth, & Lord, 1994) and on creating work opportunities by developing alternative businesses (Trainor, Shepherd, Boydell, Leff, & Crawford, 1997).

Another approach, and the focus of this article, is Affirmative Employment. The idea is to develop workplace strategies to increase employment opportunities for people with psychiatric disabilities in a variety of employment situations. Affirmative employment approaches attempt to neutralize the socially determined labour market forces of individualism, competition, and profit that are believed to marginalize people with psychiatric disabilities (Krupa, McCourty, Bonner, von Breisen, & Scott, 1999). As well, affirmative employment has been applied more broadly with a variety of employment disadvantaged people (Neufeldt & Albright, 1998).

Barriers to employment for people with psychiatric disabilities exist within the mental health system itself, even though the system espouses full integration and social participation as primary values. Affirmative employment approaches within the mental health system have yet to be fully explored. To date most affirmative employment efforts in the mental health system have been directed at the creation of peer support positions (Carlson, Rapp, & McDiarmid, 2001; Chinman, Weingarten, Stayner, & Davidson, 2001; Davidson, Chinman, Kloos, Weingarten, Stayner, & Tebes, 1999) and affirmative businesses (Krupa, Lagarde, & Carmichael, 2003; Warner, 1994).

Benefits from Involving Consumers in Evaluation Research

The extent to which the evaluators and researchers of mental health services are sources of disadvantaging is an issue that must be examined. Progress has been made in engaging consumers in paid employment in the context of participatory action research (Ochocka, Janzen, & Nelson, 2002) and in consumer satisfaction surveys (Gill, Pratt, & Librera, 1998). However, employing consumers as research assistants in more traditional research designs has been underreported. This is an important omission, given that the majority of funded evaluation and mental health research continues to be rewarded based on conformity to conventional criteria for scientific merit.

The importance of evaluating the quality and effectiveness of mental health services from a consumer point of view has received increasing support in recent years (Campbell, 1998; Howard, 2000; Lebow, 1982; Sederer, Dickey, & Hermann, 1996). Indeed, there have been concerns raised about the validity of consumer satisfaction research conducted by mental health professionals (Polowczyk, Brutus, Orvieto, Vidal, & Cipriani, 1993). Lebow (1982) suggests that consumers may alter their true perceptions if they feel their responses may jeopardize the services they receive or the careers of their treatment providers. Further, Gill et al. (1998) suggest that consumer responses may be biased because they perceive that staff members have a vested interest in the outcomes of the evaluation. They may respond in ways they perceive to be favourable to their treatment providers.

In order to overcome this bias, several authors have suggested that mental health professionals not collect data from consumers, and even further, that consumers will respond more accurately if they know that the interviewers have had some personal experience in receiving services in the mental health system (Clark, Scott, Boydell, & Goering, 1999; Gill et al., 1998; Lebow, 1982; Polowczyk et al., 1993). However, only one study of evaluation of services was found that employed consumers in the data collection process (Howard & El-Mallakh, 2001). These authors concluded that consumer involvement in the collection of qualitative and quantitative data can improve the accuracy and validity of study findings.

A THREE-PHASE METHODOLOGY FOR EMPLOYMENT EQUITY IN MENTAL HEALTH EVALUATION AND RESEARCH

Our efforts to affirmatively employ people with psychiatric disabilities as evaluation research personnel occurred in the context of a four-

year study examining the processes and outcomes of four Assertive Community Treatment (ACT) teams in southeastern Ontario (Krupa, Eastabrook, & Gerber, 1998). ACT teams provide continuous and intensive multi-disciplinary services to promote the adjustment of individuals with severe mental illness directly in their communities. ACT is one of the most widely researched and disseminated models of community-based service delivery (Bond, Drake, Mueser, & Latimer, 2001; Stein & Santos, 1998). This study was one effort to systematically evaluate processes and outcomes associated with provincial investment in Assertive Community Treatment in Ontario.

The development of affirmative employment opportunities was consistent with ACT philosophy, goals, and objectives to promote vocational outcomes as a means to both community employment and improved health and well-being. The development of consumer research positions also occurred in the context of efforts to promote paid peer-support positions on ACT teams in the province. So, while the ACT teams that were the focus of the study had limited experience with the process of creating affirmative employment opportunities for consumers within their services, our efforts to create consumer research positions were relevant to broader changing practice patterns within ACT.

The study was part of the multi-site Community Mental Health Evaluation Initiative (CMHEI). This initiative actively supported the involvement of consumers of mental health services in all aspects of the research process (see <http://www.ontario.cmha.ca/cmhei/>). Although few formal mechanisms were available within CMHEI to support consumers in research employment positions, the multi-site coordinating centre was flexible in adapting its activities to encourage this involvement. For example, consumer researchers were invited to attend multi-site meetings to participate in the presentation of evaluation findings, and project advisory committees were required to demonstrate the meaningful involvement of consumers of mental health services.

Consistent with the ideology of affirmative employment (Krupa et al., 1999), we conceptualized our efforts as attempts to identify and remove those employment elements that systematically disadvantage persons with psychiatric disabilities from gainful employment. We assumed that barriers to the full employment of persons with psychiatric disabilities routinely occur within the evaluation-research enterprise despite the best of intentions. We focused on

neutralizing the forces of individualism, competition, and profit, features of employment that are considered to be primary sources of disadvantage (Krupa et al., 1999). The strategies used to support the affirmative employment of persons with psychiatric disabilities as evaluation research personnel are presented below, organized as a three-phase methodology consisting of affirmative planning, affirmative support, and affirmative rigour and method.

Affirmative Planning

Planning began with the development of a clear description of the duties and responsibilities of these affirmative employment positions. We isolated two specific evaluation research positions to be filled by qualified consumers of mental health services. These included positions as interviewers responsible for administering the study instruments and as data management personnel responsible for data cleaning, data entry, and maintaining the organization of project files. For the interviewers we offered payment based on a completed interview, while we paid by the hour for data-related work. This allowed us to create a "job share" situation, where several consumer researchers could be hired, meeting both the needs of the project to ensure completion of duties and the individual needs of consumer employees with regards to working hours. The pay scale for each of the jobs was consistent with university pay schedules for research-related work.

We developed these positions with a view to eliminating unessential eligibility criteria. For example, by separating interviewing from data-related activities we were able to be flexible with regards to the educational requirements, thus reducing a well-known employment barrier for persons with psychiatric disabilities. We also eliminated any requirements that would tax the already limited financial resources of potential applicants. Interviewing positions in community mental health frequently require access to personal vehicles and submission of receipts for mileage. The study budget was based on the use of public transportation and allowed for cash advances to cover associated transportation costs.

Employers interested in proactively hiring persons with disabilities have expressed difficulties with the process of recruiting eligible applicants, and there have been efforts to establish central databases to access potential employees with disabilities (see, for example, <http://www.mentalhealthworks.ca/employers>). Henry, Nicholson,

Phillips, Stier, and Clayfield (2002) reported on their efforts to recruit research personnel through the development of supported and transitional employment positions in collaboration with local psychosocial rehabilitation centres. Certainly the traditional methods for recruitment used in evaluation research would not have led us to potential consumer research personnel.

We developed a brief job advertisement for posting in local community mental health agencies and the disability services department of our university. We also sent the advertisement directly to service providers in the area and asked for their assistance by passing the information along to potential applicants and by providing practical and emotional support for individuals interested in the positions. We also maintained an active recruitment process throughout the project to accommodate changes in personnel over the course of the four-year project.

To encourage individuals to apply, we identified the information and criteria that would assist us with hiring and requested only those supporting documents that would be integral to the hiring process. Assuming that the nature and patterns of the work experiences of people with psychiatric disabilities may not be well represented in traditional curricula vitae, we eliminated this requirement. We limited the application materials to a brief letter of interest and the names of three references who could attest to the applicant's work-related capacities.

To ensure that we hired qualified candidates while maintaining an inclusive hiring process, we organized the formal job interviews to elicit specific desired characteristics. To this end, our interview questions and desired characteristics were as follows:

1. Now that you know about the project, tell us how your skills and experience could benefit this position. (Characteristics — informed about the project, personal characteristics that match the job demands, listening and communication skills.)
2. Describe your present weekly schedule and indicate when you would be available to conduct interviews over this period of time. (Characteristics — availability and flexibility with regards to time.)
3. Describe your views/thoughts on the issue of the support available to people with mental illness living in the community. (Characteristics — neutral outlook on mental health services.)

4. Discuss some experiences that you have had in which you have worked with others as a member of a team. (Characteristics — team player, listening and communication skills.)
5. What previous experience have you had as an interviewer? Did any of these experiences include conducting interviews with consumers of mental health services? (Characteristics — interview experience preferred, listening and communication skills.)

Through this process we were successful in recruiting people with a range of relevant skills. Several applicants had research skills gained through post-secondary education or interviewing skills gained through volunteer positions in the mental health system and consumer initiatives. We focused primarily on hiring interview personnel for the study. In the context of this process we were able to identify people with the educational and background experiences that also qualified them for the data entry position (working with data, computer skills, organizational/clerical skills).

Over the course of four years we hired 12 consumer research assistants for this project that involved administering a set of standardized research instruments to approximately 180 study participants at three points in time. We realized a good degree of employment stability amongst this group of employees. Five of these research assistants were employed across the three data collection periods, while another four were employed for two periods. Reasons for leaving included going on to other employment, going back to school, and personal changes.

Affirmative Support

The independent nature of research work can provide the benefits of relatively individualized work schedules and decrease the social interaction demands associated with structured work settings and shared work space. However, the work can be isolating and impersonal, lacking in connections for social support, including both practical assistance and friendships.

We focused on developing a cohesive group of research assistants. Our goal was to create a positive social network that would encourage ongoing discussion and clarification about the roles and responsibilities of the job, provide collegial relationships, enhance commitment to the study, and encourage an attitude of shared responsibility to

allow individuals to be flexible with their hours of employment, while ensuring that the work of the project was completed.

While training of research assistants is a regular feature of evaluation research and should not be considered a job accommodation, we did focus on how training should be designed to best support these employees on the job. To achieve this outcome we designed training initiatives that required frequent interactions and encouraged contacts outside of training sessions. Training focused on developing the skills to anticipate problems on the job and to develop potential solutions.

The training and supervision of all research assistants was carried out consistently by the project coordinator. This management structure was developed to encourage open communication and facilitate the identification and removal of barriers to employment. For example, the project coordinator developed a system to reduce the out-of-pocket expenses incurred by research assistants while traveling to interviews, and the coordinator worked closely with the ACT teams to manage issues such as confidentiality that could compromise their collaboration in the research process.

As in more structured work environments, we held annual Christmas parties and organized gatherings with invited dignitaries from the university and mental health communities to offer certificates of merit or small gifts to formally recognize the work accomplished. It should be noted that these activities are typical in many workplaces. We have found, however, that they are not always typical of university research environments, perhaps because research assistants drawn from the academic environment are assumed to have a support group on campus and beyond.

An important barrier for many of the consumer research assistants is the financial instability they experience when working and collecting disability support income. While the casual and part-time nature of much research assistant work provides the potential for a flexible employment structure, schedules for work assignments and institutional payment schedules can seriously destabilize an individual's income management strategies and weaken investment in employment. The problem of financial overcompensation followed by government disability income clawback has received much attention as a significant employment disincentive (Krupa et al., 2003; Warner & Polak, 1995). We addressed this issue proactively, by ne-

gotiating working hours with employees and by providing consistent payment schedules.

Although these job positions were developed as affirmative employment, they were identified as regular research assistant positions both publicly and in the context of organizational procedures. Employees did indicate to study participants that they had been recipients of mental health services. However, in carrying out their duties, the consumer research assistants also came in contact with a large number of university and service personnel, including other research assistants, faculty, students, and staff. We developed strategies to ensure that any broader disclosure would be a personal decision. For example, individual employment schedules, including hours of employment and payment, were negotiated directly with the employee, and there was no need to discuss the specifics of these arrangements with university human resources or financial services. As well, references to future employers focused on duties and performance, without disclosing that the jobs were created in the context of affirmative employment. These strategies were designed to neutralize the potential for future employers to minimize the performance standards required for the positions.

We kept track of the number of positions and the number of consumers of mental health services hired, but this was primarily to report on the extent to which this CMHEI initiative was able to successfully use the evaluation research process to create employment opportunities.

Affirmative Rigour and Method

Ensuring fidelity to research protocols is integral to all evaluation research. Morse and Field (1995) suggest that "rigor in any research is required to prevent error of either a constant or intermittent nature" (p. 143). A useful framework upon which to examine rigour is the model proposed by Lincoln and Guba (1985). The model addresses four aspects of trustworthiness, which, they suggest, are relevant to both quantitative and qualitative research. These are credibility, consistency, neutrality, and applicability. Applicability has not been addressed here, as it applies to whether the findings can be applied to other settings or with other groups (Morse & Field, 1995) and consequently is beyond the scope of this article . The three remaining criteria provide the framework for our discussion on rigour and method.

The idea of credibility relates to internal validity in empirical research and the recognition that there are multiple realities requiring the researcher to report the perspectives of informants as clearly as possible (Morse & Field, 1995). Patton (2002) suggests that a way to address the credibility criterion is to develop procedures which minimize investigator bias, including rigorous and systematic data collection procedures, for example cross-checking and cross-validating sources during fieldwork. Consistency relates to whether the findings would be consistent if the inquiry was to be replicated with the same subjects or in a similar context. Finally, neutrality or confirmability deals with freedom from bias in the research procedures and results (Morse & Field).

Credibility was established in two ways. First, the consumer research assistants were assumed to have important knowledge of living with mental illness that familiarizes them with the constructs underlying measurement instruments and provides them with the attitudes and experiences to enhance the comfort level of study participants for participation. Without training, however, they were less knowledgeable of standardized research practices. Our training focused on establishing standard conditions in the administration of research instruments to ensure precision in the administration of instruments, and consistency and neutrality among the research assistants. The training included didactic education, manuals, videotaped examples, and practice in administering and scoring each instrument. The consumer research assistants also participated in multi-site training initiatives to ensure standardization across sites. An important focus of training initiatives was establishing inter-rater reliability on research instruments as relevant.

Consistency was also addressed by having both the consumer research assistants and professional clinicians rate tools simultaneously. Measurement tools that explicitly assume administration by clinical professionals to ensure reliability require special training consideration. To ensure that our research assistants could reliably administer these instruments, we had both consumer research assistants and professional clinicians, trained in the administration of the measurement, simultaneously rate a subset of study participants. We then made statistical comparisons to ensure that there were no significant differences in total ratings, and a high degree of agreement and association between ratings.

DISCUSSION AND CONCLUSION

This article contributes to the knowledge of employment and psychiatric disability by describing a three-phase methodology to guide affirmative employment in evaluation research in community mental health. The article is consistent with the duty to accommodate statutes that require employers and service providers to proactively establish policy and procedures to eliminate sources of employment disadvantage. It also highlights the opportunities that exist in mental health evaluation and research to positively influence the employment opportunities of those disadvantaged citizens they are ultimately hired to serve.

The inherent danger of this discussion is the possibility of construing these affirmative efforts as a protected work situation and thereby risking the dignity of individuals by drawing unnecessary attention to disability. From this perspective, affirmative employment opportunities that focus on specific groups of employment-disadvantaged people are vulnerable to negative judgements about the relative merit of the employees compared to those who are successful in open job competitions. While this concern was expressed by people with psychiatric disabilities employed in affirmative businesses (Krupa et al., 2003), the attitudes of employers toward affirmative work opportunities have not been systematically studied. Doe (1999) states that how we conceptualize the design of workplaces can perpetuate the employment discrimination of persons with disabilities. She argues that approaching employment equity as a universal workplace design promotes access to jobs by anticipating variations in humans, whereas the concept of accommodation assumes the individual is the source of the employment problem in the context of a fundamentally fair workplace.

The approaches described focused on reducing individualism, competition, and profit, features of competitive community-based employment assumed to be systematic sources of employment disadvantage. They focused on creating an employment situation that organized the strengths of a group of individuals to effectively complete the job. Efforts were made to encourage interactions between individual employees as a source of day-to-day workplace support, as an effective vehicle for education and training, and as a way to enable investment in, and ownership of, the overall goals of the project. Reducing competition was addressed through active recruitment strategies and carefully matching hiring practices to the actual requirements of the job.

Although the concept of profit is not typically associated with evaluation research, financial considerations do enter into the conceptualization and implementation of these initiatives. The strategies outlined are not financially unfeasible, but they do require planning and forethought, specifically to identify aspects of the evaluation research process that may be constructed as a barrier to employment. For example, the costs associated with recruitment, training, and measuring reliability standards need to be considered in the development of research grant proposals. In fact, hiring consumer research assistants challenges many of the assumptions underlying traditional evaluation and research designs and practices and, as such, requires attention to all elements of the research process. For example, consideration needs to be given to creating processes to maintain confidentiality that will meet governing ethics policies. In our experience, we were able to work with our research ethics board to arrive at effective solutions to ethical dilemmas.

There are now good resources available that provide information, suggestions, and guidelines with regards to employer responsibility for the duty to accommodate (see for example, Canadian Human Rights Commission, <http://www.chrc-ccdp.ca/discrimination/summary>). Although much of this information focuses on examples related to disabilities that are physical in nature, there are publications in the psychiatric rehabilitation literature and developed by community mental health associations that are devoted to understanding supportive work environments and workplace accommodations in the context of psychiatric disability (MacDonald-Wilson, Rogers, Massaro, Lyass, & Crean, 2002; Secker, Membrey, Grove, & Seebohm, 2003; Vandergang, 2003).

In this article we have presented a three-phase methodology for developing affirmative employment opportunities in community mental health evaluation and research. We have highlighted the need for careful attention to three components: affirmative planning, affirmative support, and affirmative rigour and method. Although these components have been applied specifically to traditional evaluation research, they may be useful to those individuals conducting participatory research with consumers of mental health services and other vulnerable or marginalized populations. The approaches outlined are intended as a guide to assist evaluators and researchers in fulfilling the vision of the *Canadian Human Rights Act* and the *Employment Equity Act*. As well, by using the strategies outlined in the article, we were able to enjoy a workforce that had first-hand knowledge about the constructs being tested, and who were, for the

most part, consistently enthusiastic and dedicated to the quality of the data of the study.

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