11-1996

Involvement of people with psychiatric disabilities in state agencies of vocational rehabilitation: State agency survey

Marsha Langer Ellison
University of Massachusetts Medical School, marsha.ellison@umassmed.edu

Karen Sue Danley
Boston University

Tim Crean
Boston University

See next page for additional authors

Involvement of people with psychiatric disabilities in state agencies of vocational rehabilitation: State agency survey

Authors
Marsha Langer Ellison, Karen Sue Danley, Tim Crean, E. Sally Rogers, and Robin Colodzin

Comments
At the time of publication, Marsha Langer Ellison was not yet affiliated with the University of Massachusetts Medical School.

Involvement of People with Psychiatric Disabilities in State Agencies of Vocational Rehabilitation: State Agency Survey

Marsha Langer Ellison, Ph.D.
Karen Sue Danley, Ph.D.
Tim Crean
E. Sally Rogers, Ph.D.
Robin Colodzin
Boston University

Abstract: *A survey was conducted with the 50 state agencies of Vocational Rehabilitation (and the District of Columbia) on the involvement of people with psychiatric disabilities in their agencies. Such involvement is increasingly mandated for state agencies. It is a complex process that can be understood and practiced along several dimensions. Survey data showed moderate to low consumer involvement in agency system, program, and individual service delivery activities. For the most part, states involve consumers in planning and policy development. Less involvement of consumers was reported in roles related to service provision. Some survey items pertaining to consumer involvement in provision of direct services were correlated with successful rehabilitation outcome. No correlation was found between a composite score of all involvement strategies per state and rehabilitation outcomes. Data on a range of involvement activities and strategies and resulting conclusions are described.*

For several decades, a salient feature of program innovation in the human services has been increased involvement of clients in the services they receive. "Consumer

---

Marsha Langer Ellison, serves as the Project Director and Research Associate for the Center for Psychiatric Rehabilitation at Boston University, Sargent College of Allied Health Professions.

Karen Sue Danley, is the Director of Development for the Center for Psychiatric Rehabilitation at Boston University, Sargent College of Allied Health Professions.

Tim Crean is a Research Assistant at the Center for Psychiatric Rehabilitation, Boston University, Sargent College of Allied Health Professions.

E. Sally Rogers is currently the Director of Research at Boston University, Sargent College of Allied Health Professions.

Robin Colodzin is a Research Assistant at the Center for Psychiatric Rehabilitation, Boston University, Sargent College of Allied Health Professions.

involvement" has meant both greater participation in the operations of the programs and agencies, as well as greater control by individuals over the services they receive. The thrust of consumer involvement can be traced to the efforts of the civil rights and consumer movements of the 1960's which underscored community involvement and minority representation in the large bureaucracies and programs purported to serve them (Browning, Rhoades, & Crosson, 1980; Galvin, 1980). Additionally, the call for consumer involvement in human services echoes innovations in business that acknowledge the benefits of increased participation of workers in managerial domains (Blumberg, 1968; Katan & Prager, 1986).

The federally funded state agencies of vocational rehabilitation (VR) have not been immune to these changes. Increasingly, Congress has mandated and state agencies have advanced initiatives for involving clients in the VR service system and process. These initiatives were codified in the passage of the Rehabilitation Act Amendments of 1992. For example, these amendments specify that: a) vocational rehabilitation clients should have choice over the services and service providers described in their Individualized Written Rehabilitation Program (IWRP); b) clients "must be active participants in their own rehabilitation programs, including making meaningful and informed choices about the selection of their vocational goals, objectives, and services" (Rehabilitation Services Administration [RSA], 1993, p. 7); c) clients must make a statement about their informed choice in these matters in the IWRP; and d) the vocational rehabilitation state plan must establish a consumer controlled advisory council from which the agency will seek advice on policies and implementation of services (RSA, 1993).

Simultaneously, the state agencies of VR have responded to pressures to better serve their clients who have psychiatric disabilities. The VR program was first made available to people with mental illness through the Rehabilitation Act Amendments of 1943. The 1954 amendments offered incentives to states to target this population. The 1973 reauthorization acts focused services on those "most severely handicapped" which increasingly included deinstitutionalized people with psychiatric disabilities (Tashjian, Hayward, Stoddard, & Kraus, 1989). Continued interest in enhancing VR services for people with psychiatric disabilities is evident in the funding by the Rehabilitation Services Administration of a study concerning "best practices" for people with severe mental illness (Tashjian et al., 1989). This study bridged these two developments in VR: a) increased involvement of consumers in state agencies and b) addressing the needs

of VR service recipients with psychiatric disabilities. An in-depth exploration was made by surveying the 50 states on these matters.

Purpose of the Study

More specifically, this project sought to explore the "state of the practice" of the involvement of people with psychiatric disabilities in VR agencies through a survey of state agencies. It had the following two goals: a) to describe the state of the practice of consumer involvement in vocational rehabilitation by examining the perceptions of state agency personnel regarding the types and levels of involvement by consumers in the state agencies and b) to test the relationship between specific client outcome data and the types and levels of involvement of consumers in the state agencies. To accomplish this, a mail survey was completed with the 50 state agencies and the District of Columbia. Data were collected during 1993 and 1994.

Method

Explication of the "Involvement" Concept and Survey Design

To construct the survey items, a review of the literature was conducted on the concept of involvement of service recipients in human service programs. In addition, telephone interviews were conducted with several mental health advocates and VR planners knowledgeable about these issues. The review and key informant interviews suggested that involvement is a complex concept that must be understood along several dimensions. First, involvement can occur on four organizational levels of any human service agency, as displayed in Table 1. One is the state or system level.

Many bureaucracies initially address consumer involvement by increasing consumer participation on this level, primarily in planning or advisory committees. Second is the program level. There are opportunities for involving consumers on the program levels, such as through staff training efforts, local evaluation and monitoring, and programmatic administrative review. In the third organizational level, consumers are involved with the individual recipients. They can be so involved by counseling, by advocating for clients, or by more generally providing peer support. Finally, the client or individual service recipient can be conceptualized as having greater or lesser involvement in their own course of service. Clients may be given greater influence over their course of services

Table 1

Examples of Opportunities for Consumer Involvement on Four Organizational Levels

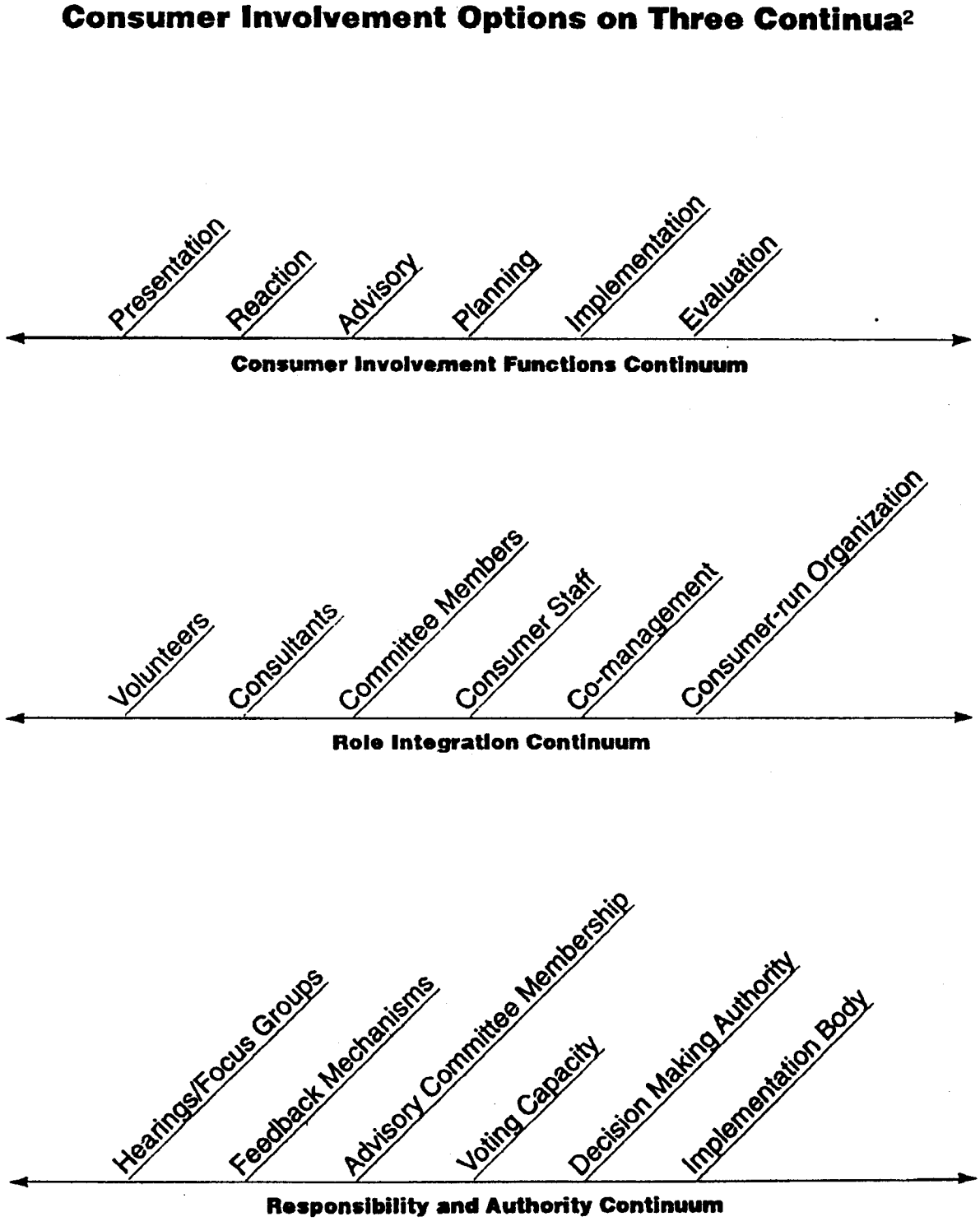
1.	State System Level	Consumer Advisory Council State Plan Committee State Plan Hearings Order of Selection Committee
2.	Program Level	Hearing Officer Counselor Training Service Evaluation Budgeting
3.	Person or Recipient Level	Advocacy for Clients Consumer Counselors Provide Orientation "Peer" Support and Advice
4.	Involvement of Service Recipient in their Course of Service	Influence or Control over Service Plan (Goals & Providers) Influence over Counselor Assigned Knowledge of Rights, Procedures Satisfaction with Services

and/or more choice among available service alternatives, or may have better knowledge about their course of service such as their rights or options.

In addition to these four organizational levels, there are three other dimensions important to understanding the depth and nature of consumer involvement as displayed in Figure 1.

One dimension is the degree to which the consumers' role is integrated into the staffing patterns of the agency. For example, consumers may be involved as volunteers to the agency, or they may act as committee members. These are marginal roles as compared to high levels of role integration when consumers are employed as peer counselors, or they run the agency, as for example, in Centers for Independent Living. In a second continuum, consumers may have any of several functions which have relative degrees of impact on the agency.

Figure 1. Involvement Options on Three Continua.



[2] Copyright, Trustees of Boston University, Center for Psychiatric Rehabilitation, Danley & Ellison (1996). Reprinted with permission from the authors.

For example, they may make presentations, participate in program planning, or be actively involved in implementing program activities. Finally, there is the continuum of degree of consumer responsibility and authority. This can range from a nominal participation in open hearings or satisfaction surveys to serving on committees that have decision-making authority. These involvement "options" illustrated on the three continua are not mutually exclusive. Some can be understood in multiple ways.

These four levels and three dimensions, along with other specific strategies for promoting involvement, served as the framework for constructing survey items. An advisory committee to the project was convened, composed of two state agency Commissioners of Vocational Rehabilitation, two consumer advocates, and several researchers, administrators, and practitioners in vocational rehabilitation. The committee participated in and reviewed the construction of the survey. After several drafts, the survey was submitted to the research committee of the Association of Commissioners of State Agencies of Vocational Rehabilitation. The committee recommended, and eventually approved, a version of the survey that was significantly shortened and reformatted using primarily closed-ended rather than open-ended questions.

Data Collection Procedures

The survey was implemented using the Total Design Method advocated by Dillman (Dillman, 1978). The survey was addressed to all state agency Commissioners. The cover letter stated that the survey could be passed to other central office staff who were familiar with practices around the state regarding the involvement of people with psychiatric disabilities. Most offices followed this recommendation.

Directions for the survey stated explicitly that questions pertained to the involvement of individuals with psychiatric disabilities, not to all clients of VR, and asked respondents to limit their answer to VR practices that occurred over the last two years. Unless otherwise requested, respondents were asked not to include practices of vendors or contractors providing services, those parts of their system specifically funded for services to people with visual disabilities, or the activities of Independent Living Centers. Commissioners were informed that a final report presenting a national portrait of VR activities around the involvement of mental health consumers would also be prepared and made available to them.

Table 2

Consumer Involvement in System or Program Aspects: Description, Function, and Perception of Importance[2]

	System Aspects Consumers Are Involved in	Planning	Evaluation	Implementation	Agency Perception of Importance
	% of State agencies reporting consumer involvement in this aspect (n = 51)	% of State agencies reporting consumer involvement in planning of this aspect (n = 51)	% of State agencies reporting consumer involvement in evaluation of this aspect (n = 51)	% of State agencies reporting consumer involvement in implementation of this aspect (n = 51)	% of State agencies that consider this a most important aspect for consumer involvement (n = 51)
State Plan	77	71	41	6	67
Training of VRStaff	59	37	28	53	63
Regulations or Rules	41	37	26	4	49
Independent Living Centers	39	22	16	29	29
Order of Selection Policy	34	29	12	4	24
Budget, Resource Allocation	26	20	14	2	22
Grievance Proced., Hearings, Appeals	22	8	10	6	29
Service Delivery	20	10	18	12	51
Eligibility Determination	12	10	8	0.00	31
Other Aspects	8	6	4	4	6

Note. Consumers may be involved in more that one aspect in any state agency. Therefore, percents do not equal 100.

[2] Copyright, Trustees of Boston University, Center for Psychiatric Rehabilitation, Danley & Ellison (1996). Reprinted with permission from the authors.

There was approximately a 90% return rate from a first and second mailings of the state agency survey. Calls were then made directly to the five non-responders requesting their participation. With the return of these five surveys, the return rate was 100%, including 50 states plus the District of Columbia for a total sample of 51 surveys (the territories were not included in the survey sampling).

The survey items were based entirely on self report, without verification of reported activities. However, it is assumed that there is no outright misrepresentation of involvement opportunities and so replies are used to draw a national portrait of the state of practice of involving consumers in VR agencies.

Results

The results of the survey are presented according to the two goals of the study. The first goal was to describe the state of the practice of consumer involvement, in accordance with the framework for involvement developed for this survey and pictured in Table 1 and Figure 1. First, findings are presented about involvement opportunities on the state and program levels. This includes a presentation on involvement "functions." Next is a presentation on involvement on the individual level. A discussion of involvement "roles" follows. This is followed by findings pertaining to the involvement of the individual recipient in their course of service. Other strategies to enhance involvement and barriers and supports to involvement are described last.

The second goal of the study was to test the relationship between involvement and client rehabilitation outcomes. A discussion of findings for this goal concludes the results section.

Goal 1: Describe the "state of the practice."

Involvement on the state and program levels

VR agency respondents were asked to identify whether consumers with psychiatric disabilities were involved in different aspects of the state VR system. In addition, they were asked to rate which of these aspects was most important for such involvement. Results are displayed in Table 2.

The data suggest that consumers are involved across many aspects of the VR system, and that, by and large, the degree of involvement is consistent with

Table 3

Roles in VR That Consumers Fill

Roles that Consumers Filled in VR Agencies	Percent of Agencies Responding Yes (n = 51)	Agency View of Roles Affording Consumer Greatest Influence, in Percent (n = 51)
Participants in Public Hearings, Forums, Focus Groups, etc.	94.1	86.3
Committee Membership	82.4	92.2
Paid Staff Person	49.0	47.1
Peer Advocate	29.4	43.1
Volunteer Staff Person	27.5	31.4
Paid Consultant to VR	23.5	37.3
Peer Counselor	17.6	45.1
Impartial Hearing Officer	2.0	21.6
Other, Specify	3.9	3.9

Note: Agencies could indicate more that one type of role filled by consumers with psychiatric disabilities in their state. Therefore, percents do not equal 100.

perceived importance of involvement. The striking exception is service delivery and eligibility determination which have low rates of involvement and high ratings of importance.

Additionally, Table 2 displays the types of functions consumers perform (e.g., planning or policy development, evaluation, feedback or monitoring, and implementation or actual delivery of each aspect). The percentages of states reporting consumer involvement with these functions is shown. In general, when people with psychiatric disabilities are involved in service system aspects they tend to be involved in a planning function. To a lesser degree they are involved in evaluating the service system, and to a far lesser degree they are involved in implementing any service system activities. There are three notable exceptions. Consumers tend to be more involved in implementing training of VR staff than

in either planning or evaluating training, in policy implementation for Centers for Independent Living, and in evaluation of service delivery than in its planning or implementation. These results suggest that the involvement of consumers with psychiatric disabilities has been mostly limited to planning functions on the state policy level. An exception to this is the high rate of involvement in training of VR staff and implementation of this training.

Involvement on the individual level

VR agencies were asked if people with psychiatric disabilities who are not VR counselors give assistance to consumers with psychiatric disability who are applying for or receiving VR services. Fifty-three percent of the 51 respondents indicated that such assistance is not available, 43% said a few people (up to 15% of applicants) receive such assistance, and one state indicated that many people (up to 50%) receive such assistance. No states reported that a majority of consumers with psychiatric disability receive such assistance. Service recipients received the following types of help from other consumers: advocacy (27%), orientation (18%), training on how to work with counselors (14%), or help with the assessment process (10%).

Involvement "roles."

VR agencies were asked about the types of staffing roles filled by consumers with psychiatric disabilities in VR, and also which of these roles afford consumers the opportunity for greatest influence. The data (as displayed in Table 3) show that roles that are less integrated with the standard staffing structure are the ones most frequently filled by consumers. There is congruence between the roles filled and the perception of their influence. The exception to this is the peer counselor role which has a low rate of utilization and a much higher perception of influence.

Involvement of the service recipient.

State VR survey respondents were asked several questions concerning their perceptions of service recipient's knowledge about VR operations. When asked how well they feel that the majority (at least 50%) of VR clients with psychiatric disabilities understand overall VR procedures and VR eligibility determination procedures, nearly 70% of the 51 respondents responded "adequately" to both. Approximately 30% of states felt that the majority of their recipients with psychiatric disabilities had minimal knowledge of operations and eligibility determination procedures.

States were asked to indicate the status of state policy on whether VR clients with psychiatric disabilities are offered a choice if they are dissatisfied with their original counselor assignment. The majority of the 51 states reported that such practice is operational, both as policy and practice (27%), as routine practice but not policy (41%), or as practice under unusual situations but not as policy (22%).

Other strategies to promote involvement

One survey question dealt with a number of strategies that state agencies employ which promote involvement opportunities. Many of these strategies were drawn from recommendations made by the "Best Practices" report (Tashjian et al., 1989). Survey results showed that a large majority of the 51 states surveyed reported utilizing these strategies including: a) inter-agency agreements with state Departments of Mental Health (96%), b) designating specialty counselors to serve persons with psychiatric disabilities (90%), c) holding joint training of agency and Department of Mental Health staff (84%), d) conducting outreach at mental health service delivery sites (84%), e) appointing liaisons to the Department of Mental Health (82%), f) providing special training of agency staff in psychiatric disabilities (82%), g) strategic planning for involvement of all consumers (67%), h) addressing attitudinal barriers among VR staff concerning people with psychiatric disabilities (67%), and i) co-locating counselors at mental health service delivery sites (58%).

Less than half of the state agencies reported targeting funds to promote the involvement of persons with disabilities in VR (42%), delegating a staff position for coordination of consumer involvement in VR (31%), or cooperative agreements with mental health consumer groups (15.7%). Arguably, these last three strategies, though used the least, have a high potential for impact because they represent a specific dedication of resources toward involvement or because consumer groups are directly contacted.

Barriers to and supports provided to facilitate involvement

Survey respondents were also asked to indicate which supports they have used in their state to assist people with psychiatric disabilities to be more involved (other than as a client). The most common supports indicated by the 51 respondents were: travel expenses for involvement are reimbursed (86%), activities scheduled at convenient times (75%), transportation provided (60%), and contact with other people with psychiatric disabilities who were also involved

with vocational rehabilitation (43%). Less frequently used supports were: payment for activities (39%), training provided on duties or expectations of role (39%), other reasonable accommodations (35%), support person or attendant provided (18%), or child care provided (14%).

The 51 agencies responded to a list of barriers that clients in their state frequently encounter in receiving the services they prefer. They responded as follows: counselors think client preferences will not lead to rehabilitation or employment (55%), client preferences for services are not available (31%), counselors do not understand the employment potential of people with psychiatric disabilities (28%), client preferences conflict with agency rules (18%), and counselors do not understand the nature of psychiatric disability (18%).

Goal 2: Client Involvement and Rehabilitation Outcome

One hypothesis of the survey was that the breadth and depth of involvement opportunities for people with psychiatric disabilities would be correlated with better rehabilitation rates. To test this, an "involvement score" was developed for each state. For each survey, a point was added for every indication of an involvement opportunity or involvement role offered, a "best practice" utilized, and for supports for involvement provided. All points were summed. Possible scores ranged from 0 to 76. The actual range of the resulting scores was 19 to 45 ($M = 27.2$, $SD = 6.6$). The narrow range suggests that the states tended to indicate similar depth and breadth of involvement opportunities and that they were all moderate to low. The discrepancy between the highest score achieved (45) and the highest possible score (76), along with the low average score, suggests that there are many more opportunities for involvement than are being used by state agencies.

The involvement scores were then correlated with successful rehabilitation rates reported by the states to the federal Rehabilitation Services Administration for all people diagnosed as having a primary mental illness for FY 1991. No correlation was found between the overall scores and rates of rehabilitation. To shed light on the relationship of involvement to rehabilitation rates all individual survey items were correlated with the rehabilitation rates.[1] The following three

[1] The numerous statistical tests run on the same data set suggest an increased likelihood of making a Type I error. No adjustments were made for this problem, therefore some findings may be spurious (Kleinbaum, Kupper, & Muller, 1988).

items were significantly correlated with successful rehabilitation closures for people with psychiatric disabilities: consumers with psychiatric disabilities help other service recipients with the assessment process ($r = .33, p = .01$); consumers with psychiatric disabilities fulfill roles as peer counselors ($r = .33, p = .01$); and consumers with psychiatric disabilities are involved in the implementation of the order of selection policy ($r = .33$, $p = .01$). Two other items approached significance: peer assistance with the Client Assistance Program ($r = .25$, $p = .08$) and consumer involvement in regulations or rule making ($r = .24, p = .08$).

Discussion

All findings must be weighed in consideration of the self-report survey methodology used. It is likely that respondents would tend to cast their replies toward the more socially desirable responses of greater or more successful involvement opportunities. With this caveat in mind, the survey results portray moderate involvement of people with psychiatric disabilities in state vocational rehabilitation agencies. Agencies report their involvement throughout the system, in a variety of roles, and that they utilize many supports to promote involvement. Agencies tend to involve people in the ways and roles that they think afford people with psychiatric disabilities greatest influence. It is encouraging to note that many of the best practices for serving people with psychiatric disabilities, as specified by Tashjian et. al. (1989), have been adopted by the state agencies.

On closer inspection, however, most attempts at involvement occur on the state or program level (and not the individual level), predominately involve policy and planning functions, and utilize staffing roles that are less integrated into the system. An exception to this is the high rate of involvement in the training of VR counselors. One can characterize the involvement as being peripheral and "top heavy" with fewer opportunity at the service delivery or service recipient level. The roles and functions used also tend to imply lesser degrees of authority and responsibility (the third continuum in Figure 1). Results also show that there are more opportunities for involving consumers than are being accessed by VR agencies.

The failure to link an overall score for involvement activities with rehabilitation rates was surprising. There may be several explanations. One, consumer involvement is still a new phenomena and it may take several more years before the full impact of involving people with psychiatric disabilities is felt and is reflected in rehabilitation outcomes. Also, there is some discrepancy between the time frame of the rehabilitation outcome data (1991) and the data collected

on involvement (1991 through 1994). Another explanation, of course, is that there simply is no relationship between involvement and rehabilitation. Rehabilitation outcomes may well be more directly affected by a host of other factors, such as limited agency resources and counselor mandates to close cases in a certain time frame, that may be incompatible with successfully serving people with psychiatric disabilities. In this case, involvement may be pursued for its intrinsic value rather than because it improves outcome.

However, the analyses point to another and perhaps more potent explanation. As noted, much of the involvement activities has been on the system and planning levels. Yet, two out of the three individual survey items that did correlate with rehabilitation rates for all people with mental illness had to do with involvement on the service delivery level (i.e., consumers being involved as peer counselors, or otherwise providing assistance to service recipients). Perhaps a greater relationship between involvement and outcome would be found were involvement taking place more on the direct service recipient level.

Conclusions and Recommendations

State VR agencies have responded positively to the RSA client involvement mandate, primarily by including individuals with psychiatric disabilities in advisory activities for planning and policy development purposes, activities which they believe to be the most influential. That is, state VR agencies believe they are "doing the right thing" when it comes to involving these individuals. However, if the original intent of the involvement mandate was improved service resulting in increased positive rehabilitation rates, this is not fully evident. It is hopeful, however, that involvement variables which were found to be related to outcome (i.e., peer counseling, assistance with assessment, and peer advocacy) were also viewed by many agency respondents as highly influential, despite the low incidence of these types of involvement. This may indicate an emerging readiness within the agency for more involvement by consumers with psychiatric disabilities at the service delivery level in roles which more directly impact the experience of service recipients. This type and degree of involvement, previously called for by the National Institution on Disability Rehabilitation Research consensus conference on employment of people with long term mental illness (1992) and the leadership of consumer organizations (Fisher, 1994), in turn, may lead to better rehabilitation outcomes.

References

Blumberg, P. (1968). *Industrial democracy.* New York: Shocken Books.

Browning, P., Rhoades, C., & Crosson, P. (1980). The awakening of a social movement. *Advancing your citizenship: Essays on consumer involvement of the handicapped.* Eugene, OR: University of Oregon, Rehabilitation Research and Training Center in Mental Retardation.

Danley, S. & Ellison, M. L. (1996). *Involving people with psychiatric disabilities as consumer advocates in vocational rehabilitation.* Final Report. Boston: Boston University, Center for Psychiatric Rehabilitation.

Dillman, D. (1978). *Mail and telephone surveys: The total design method.* New York: John Wiley & Sons.

Fisher, D. B. (1994). A new vision of healing as constructed by people with psychiatric disabilities working as mental health providers. *Psychosocial Rehabilitation Journal, 17*(3), 67-68.

Galvin, D. (1980). Policy issues in independent living rehabilitation. In K. Miller (Ed.). *Participation of people with disabilities: An international perspective.* Selected Papers from the 1980 World Congress of Rehabilitation International. East Lansing, MI: Michigan State University, Center for International Rehabilitation.

Katan, J., & Prager, E. (1986). Consumer and worker participation in agency-level decision-making: Some consideration of their linkages. *Administration in Social Work, 10*(1), 79-87.

Kleinbaum, D., Kupper, L., & Muller, K. (1988). *Applied regression analysis and other multivariable methods.* Boston: PWS-Kent.

National Institute on Disability and Rehabilitation Research. (1992). *Strategies to secure and maintain employment for people with long term mental illness. Consensus statement.* 1 (3). Washington, DC: U.S. Department of Education.

Rehabilitation Services Administration. (1993). *A synopsis of the rehabilitative act amendments of 1992.* Washington, DC: Author, U.S. Department of Education

Tashjian, M. D., Hayward, B. J., Stoddard, S. & Kraus, L. (1989). *Best practice study of vocational rehabilitation services to severely mentally ill persons.* Washington, DC: Policy Studies Association.

Author's Note: The authors would like to acknowledge the National Institute for Disability and Rehabilitation Research which provided support for this project (Grant #H133A 10019-92). The opinions presented here should be construed as belonging solely to the authors.