

Empowering and Demedicalized Case Management Practices: Perspectives of Mental Health Consumer Leaders and Professionals

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ABSTRACT. The principles of empowerment and demedicalization have been central to the formulations of rehabilitation and social service practices as well as case management, a core community support service provided to people with psychiatric disabilities. This study describes empowering and demedicalized practices in mental health case management. Semi-structured interviews were conducted with thirty leaders in the mental health consumer movement and five professionals. Twenty-five categories of such practices were developed and are presented. Findings have implications for both the nature of the interaction between

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case manager and client and for program structures, activities, and missions. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2006 by The Haworth Press, Inc. All rights reserved.]

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CASE MANAGEMENT AND SOCIAL WORK IN PSYCHIATRIC DISABILITIES

Case management is one of the core community support services provided to the estimated 4 million adult men and women living in the United States with a psychiatric disability (Manderschied & Henderson, 1998). Growing out of the community support service initiative of the late 1970s (PL99-660; Turner & TenHoor, 1978), case management services became widely implemented and publicly financed as a result of increased awareness of problems related to the organization and delivery of social services. In order to reduce this system fragmentation and increase access to needed community support services, the role of the case manager was conceived. Case managers would have an integral role in deinstitutionalization and post-acute care by helping clients address the overlapping, and difficult to access, array of human services and benefits, while promoting client quality of life and reducing overall social costs (Moxley, 2002; Rapp & Goscha, 2004). A survey of case management providers found that preventing hospitalization is a primary mission for the majority of case management programs and that most focus on assessing client needs, planning, linking, and monitoring client services (Ellison, Rogers, Sciarappa, & Cohen, 1995). Positive outcomes for case management services have been shown, including reduced hospital stays, improvement in housing stability, and moderate improvements in symptom reduction, quality of life, and social functioning (Mueser, Bond, Drake, & Resnick, 1998; Rapp & Goscha, 2004).

Since its inception, case management has been intertwined with the social work profession. For example, models of “social work case management,” in which the two disciplines operate together, have been described in the literature (Moore, 1990; Roberts-DeGennaro, 1987;

Rose, 1992; Vourlekis & Greene, 1992). Further, some authors have argued that case management is the domain of social work (Austin, 1990; Johnson & Rubin, 1983). Although case managers most frequently identify with the social work profession (Ellison et al., 1995), other disciplines such as nursing and rehabilitation counseling have vied for case management leadership and identification (Upton & Beck, 2002; Vourlekis & Greene, 1992).

Empowerment and Demedicalization

Definitions of empowerment abound in the professional literature and there is much discourse across disciplines on the subtleties of empowerment as an internal state, as a guide for program structure, and as a principle of social action (Clark & Krupa, 2002; Houser, Hampton, & Carriker, 2000; Rappaport, 1985; Salzer, 1997; Segal, Silverman, & Temkin, 1995; Zimmerman & Warschausky, 1998). Empowerment is conceptualized as an “individual achievement, a community experience, and a professional aim that orients social interventions, strategies, and tactics” (Rappaport, Swift, & Hess, 1984, p. 5). As an internal state, empowerment is related to experiences of self-esteem and self-efficacy (Rogers, Chamberlin, Ellison, & Crean, 1997; Staples, 1993). A comprehensive definition is offered by Staples (1993) in which empowerment is a process “by which power is developed, facilitated or sanctioned in order that subordinate individuals and groups can increase resources, strengthen self-images, and build capacities to act on their own behalf in psychological, socio-cultural, political, or economic domains” (p. viii).

The concept of empowerment has been central to the mental health consumer movement, whose members perceive themselves as powerless in relation to the larger forces of psychiatry and mental health services generally (Chamberlin, 1990; Kaufmann, 1999; Staples, 1993). People with psychiatric disabilities have defined empowerment as consisting of self-esteem/self-efficacy, optimism, and control over the future (Rogers et al., 1997), as well as having decision-making power, learning skills, understanding people have rights, changing others’ perceptions, and rejecting the role of a passive service recipient (Chamberlin, 1979; Chamberlin, 1990). The empowerment goal derives from consumer’s experiences of how treatment interactions (e.g., forced treatment) result from an imbalance in power relations that inherently place them in a subordinate role (Chamberlin, 1979; Chamberlin, 1990; McLean, 1995).

The second construct studied here, “medicalization,” refers to defining social phenomena into medical terms and concepts and in so doing,

rendering these phenomena to the dominion of medical practice and control (Conrad & Kern, 1986). The following features are found in this medical model: (1) the physician is the technically competent expert, (2) medical care is administered through a chain of authority wherein the physician is the principle decision maker, (3) the patient is expected to assume the sick role (e.g., he/she is exempt from normal social activities and is to seek help and cooperate with the physician), (4) illness is addressed primarily through the use of clinical procedures, and (5) illness is to be treated only by trained practitioners (DeJong, 1979).

Demedicalization, in turn, refers to a process whereby a problem area no longer retains its medical properties and medical terms and interventions are no longer deemed appropriate solutions to problems (Conrad, 1992). In the independent living paradigm advanced by the disability rights movement, the medical model is challenged so that the "problem" is defined as dependence on the professional, the locus of the problem is environmental (e.g., inaccessible architecture), and the solution resides in consumer control and self-help (DeJong, 1979).

Demedicalization has also been central to recent changes in the conceptualization of mental illness. For example, the rehabilitation field has recast mental illness as having components of an impairment, a dysfunction, a disability and a disadvantage (Anthony, 1993). In this model, an educational and rehabilitative approach is offered, with the goal being improved functioning and satisfaction in specific environments, rather than a medical approach of cure, symptom reduction, or development of therapeutic insights (Anthony, Cohen, & Farkas, 1990). Demedicalization principles have also been important to the mental health consumer movement (Benjamin, 1993; Chamberlin, 1979; Garrett & Posey, 1993) and the community support program (Rose & Black, 1985; Stroul, 1986). More recently, the concept of recovery from psychiatric disability has gained momentum. This concept is likewise demedicalized in nature, in that it is comprised of the constructs of personhood, growth, resilience in the face of trauma, and human capacity (Anthony, Cohen, Farkas, & Gagne, 2002; Ralph & Corrigan, 2005).

Empowerment and Demedicalized Practices in Mental Health Case Management

There are growing calls by consumers and professionals in disability services to create opportunities for empowerment and demedicalized practices (Anthony, 1993). Accordingly, several disciplines are investigating how their approaches and practices can be empowering

rather than disempowering to their constituents (Emener, 1991; Holmes, 1993; Kosciulek, 1999; Kruger, 2000; Riggall & Janikowski, 1999; Salzer, 1997; Simon, 1990).

Within mental health case management, empowerment is seen as an explicit or implicit philosophy or orientation by case managers (Ellison et al., 1995) and several models of case management practice espouse principles and activities reflecting both empowerment and demedicalization (Rose & Black, 1985). For example, in the “Personal Strengths” model (Rapp & Chamberlain, 1985; Rapp & Wintersteen, 1989), case managers are instructed to: (1) use a “strengths assessment” rather than the more medical approach of diagnosis of illness, (2) emphasize the long-term potential for growth and change in psychiatric clients, and (3) rely upon natural community-based resources to solve problems, such as networks of neighbors, merchants, and friends. Freddolino and Moxley’s case management model (1993) emphasizes that no specific attempt should be made to coordinate services with mental health providers or to use a treatment plan. Rather, case managers should utilize an assessment that incorporates the person’s own definition of the problem or issue they wish to pursue as a way of detailing the person’s needs.

Researchers are beginning to examine other components of empowering and demedicalized mental health services. One research study on mental health case management presented six key components of empowering practices drawn from the social influence literature and social work strengths perspective (Heaney, Fujishiro, & Burke, 2002). These components were: (1) expressing positive affect and positive regard, (2) encouraging clients to express their feelings and describe their experiences, (3) reflecting client strengths, (4) sharing relevant experiences from their own lives with their clients, (5) supporting client choices, and (6) sharing information and access to resources. A recent assessment of the “active ingredients” of case management describes practices relevant to the concept under study here, such as using natural community resources and promoting client choice (Rapp & Goscha, 2004).

Purposes of This Study

Given the increased emphasis on empowerment and demedicalization within the human services, the current study sought to query both leaders in the mental health consumer movement and academics who have written on case management practices about the meaning of

empowering and demedicalized practices in mental health case management. In doing so, there is an opportunity to add the voice of consumers to the definition of case management using these concepts, which had not been previously done. This approach is also in keeping with an empowerment perspective and the principles of participatory action research (PAR) (Danley & Ellison, 1999; Rogers & Palmer-Erbs, 1994; Whyte, 1991). The results of this study provide a framework to implement empowering and demedicalized practices into existing case management service models.

METHOD

This study used semi-structured interviews conducted with thirty identified leaders of the mental health consumer movement and five professional and academic writers in this area.

Participants

Mental health consumer leaders were defined in this study as people who were influential in or had prominent roles in the mental health consumer movement. These individuals were defined as leaders by the nature of their experience and career positions and were considered to be leaders by other individuals with psychiatric disabilities. Only those participants who were described as having an experience in the mental health consumer movement of an organizational nature were contacted (e.g., positions as consumer representatives in state government or departments of mental health, organizers or administrators of consumer self-help groups or clubhouses, case management service providers). All of the consumer leaders interviewed expressed having familiarity with case management programs and had either delivered or received case management services. A total of sixteen men and fourteen women from across the United States completed telephone interviews. Although this sample cannot be called representative, an attempt was made to employ maximum variation and have a diverse sample in terms of geographic dispersion, gender, and experience with case management (Kuzel, 1992). Five academic professionals who had published specifically in empowering or demedicalized case management practices comprised the second group of participants. They were major writers in the area of mental health representing four proposed models of case management collectively.

Procedures and Analysis

A qualitative interview protocol using an open-ended semi-structured format was used for all participants to help assure comparability. Participants were asked to describe how mental health case management could be conducted to employ empowering and demedicalized principles. Interview sessions were audio-taped and then responses were transcribed. The first 15 interviews were reviewed by the first author. Applying content analysis methodology (Patton, 1990), responses that were found to be similar in meaning were grouped. All phrases that described an empowering or demedicalized approach to case management were used to develop the groupings. Following the principles of grounded theory (Glaser & Strauss, 1967), groupings were expanded or revised so that all descriptions were included. Finally, a title was developed to represent an overall concept implied by the phrases.

To ensure that replicable and meaningful categories of practices were developed, an inter-rater reliability test was undertaken. This was conducted by having two independent raters code the same text passage using the developed set of coding categories along with a set of procedures for coding. A percentage of agreement formula was used (Bartko & Carpenter, 1976), which provided a stringent measure of whether both coders evaluated a section of an interview to be a codeable passage and then whether the same one coding category (out of a possible eighteen) was selected to represent the passage. A 71% coding agreement was found for the empowerment categories and these were then used for coding the remainder of the interviews. Seven categories for demedicalized practices were developed in a similar fashion.

RESULTS

The open-ended questions concerned the actual practices necessary for case management to succeed in being empowering and demedicalized. As noted, a key phrase was developed to express the meaning of the contents of the category and it precedes the description of each category as a title. Most of the categories are titled as actions, though some are a feature or characteristic of the program. However, all can be construed as practices and they are labeled as such. Table 1 displays the titles of the categories and percentage of consumers and professionals who referred to this category of practice in their interview. Categories are arranged in descending order according to the total per-

TABLE 1. Percent of Consumers, Professionals, and Combined Total Who Identified Twenty-Five Empowering and Demedicalized Practices in Mental Health Case Management

Category Name and Number	% of Consumer Sample (N = 30)	% of Professional Sample (N = 5)	% of Total Sample (N = 35)
1. Reduce paternalism and professional distance to create a mutual relationship	77	100	80
2. Client driven services	73	80	74
3. Be flexible, variable, and creative and make wider choices available to meet client needs	70	60	69
4. Give clients voice and help them make decisions	67	80	69
5. See client as a person (not as a diagnosis)	50	80	54
6. Increase client self-reliance	50	80	54
7. Rely on generic, community, natural support, and non-medical interventions	43	80	49
8. Assessment and intervention are based on clients strengths, self-worth, and recovery	40	80	46
9. Be a resource in appropriate areas	50	0	43
10. Consumers involved in case management agencies	37	60	40
11. Client is a customer, case management is a service	33	80	40
12. Voluntary, non-contingent service	37	40	37
13. Emphasize self-help and utilize the help of other consumer	37	40	37
14. De-emphasize use of psychiatrists or other medical personnel in case management and improve status of case managers	27	60	31
15. Improve client quality of life	27	40	29
16. Program is independent from medical and mental health sources and settings	27	40	29
17. Stick to limitations of role and be honest about them	23	40	26
18. Increase client independence from mental health or other services	20	0	17
19. De-emphasize medications	13	40	17
20. Use group and team approach	10	60	17
21. Client centered program quality assurance	10	40	14
22. Change terminology/language	17	0	14
23. Records are not means of professional power	10	20	11
24. Utilize clubhouse model	13	0	11
25. Work with client for service system change	7	0	6

cent of both consumers and professionals (N = 35) who described this practice in their interview.

The following section enumerates the first 10 categories of empowering and demedicalized practices using paraphrases taken directly from the open-ended responses. These convey the full texture of meanings stated by respondents.

1. *Reduce paternalism and professional distance to create a mutual relationship:*

- Greater equality and mutuality in relationship
- Don't assume case manager knows what's best for clients
- Work with client as a partner, don't "manage a case"
- Don't have a great educational disparity between clients and case managers; there should be similar ethics and values

2. *Client driven services:*

- Turn choices, decisions, and power over to clients
- Goals are not made or presumed by case manager, but are defined by the client
- Client decides how they will participate in the case management process

3. *Be flexible, variable, and creative, and make wider choices available to meet client needs:*

- Provide variable support to clients in accordance with changing needs; "graduated disengagement," not time limited services
- Reduce bureaucratic or procedural rigidities that prevent meeting client needs
- Accompany client when needed, go to where the client is for support (e.g., services don't reside in office)
- Develop flexibility in services provided or available, not tied to existing services only, make wider, "more real" choices available
- 24-hour case manager availability

4. *Give clients voice and help them make decisions:*

- See client as the principle source of knowledge about him/herself

- Provide dialogue and opportunity for the client to explore and articulate his/her own needs and goals
- Teach tools to, and facilitate, client decision-making
- Listen with an open mind, don't judge clients' lives

5. *See client as a person (not as a diagnosis):*

- See client as having the same needs/abilities as everyone else
- Don't use diagnosis as a basis for how services should be provided
- Tolerate clients' differences

6. *Increase client self-reliance:*

- Allow clients responsibilities, allow taking risks and making mistakes
- Give support and opportunities for small steps toward growth and self-confidence
- Transform clients from passive subject to acting object

7. *Rely on generic, community, natural support, and non-medical interventions:*

- Utilize generic (non mental health) community settings (e.g., allow home-based services during crises, access to generic community resources)
- Emphasize holistic approaches or non-traditional healing approaches
- Focus on everyday needs such as housing, work, or friendship
- Utilize natural networks of support (e.g., neighbors, family, friends), link with the family

8. *Assessment and intervention are based on clients' strengths, self-worth, and potential for recovery:*

- Use strengths as a basis for service planning, not medically-based assessments
- Use client language for assessments and goal planning
- Believe in and emphasize recovery
- Service plans point out achievements, make clients feel good about themselves

9. *Be a resource in appropriate areas:*

- Educate about service options, be a mentor, facilitate knowledge
- Provide help without seeing that as “enabling”
- Be authoritative in areas of knowledge

10. *Consumers involved in case management agencies:*

- Case managers should have a disability or like experience
- Consumer participation in program operations (e.g., hiring, grant writing, quality assurance)
- Consumer representation wherever possible or at all levels

DISCUSSION

Results Contrasted with the Literature

The categories described in the current study are consistent with previously published work on empowering and demedicalized practices in mental health case management. The six practices described in the Ohio study (Heaney et al., 2002) are each represented in one or more of the 25 empowering categories of practice developed here. For example, reflecting client strengths is described in the eighth practice (“assessment and intervention are based on clients’ strengths, self-worth, and recovery”), encouraging clients to express their feelings is found in the fourth practice (“give clients voice and help them make decisions”), and sharing information and access to resources is found in the ninth practice (“be a resource in appropriate areas”). The categories developed in this study are also consistent with descriptions of the strengths (Rapp & Chamberlain, 1985; Rapp & Wintersteen, 1989) and advocacy model of case management (Freddolino & Moxley, 1993).

It is interesting to compare the described practices with the “active ingredients” of case management described by Rapp and Goscha (2004). Of the ten active ingredients described by these authors, eight are directly reflected in these findings on empowering and demedicalized practices. These include, in part: client should have choices; case managers should be paraprofessionals; services should be time unlimited; clients need 24 × 7 availability; natural community resources are the primary partners; and team case management works. This suggests that empowering and demedicalized practices are not only valued and

articulated goals for case management structures, but they are also the aspects that may best produce positive outcomes.

Several practices described here expand and add greater dimension to the case management literature. In this study, consumer leaders articulated the importance of flexibility and creativity for case managers so they break the “menu” of services by individualizing and tailoring solutions to clients’ needs with the use of generic supports. Consumer leaders expressed the need for voluntary services that have no behavioral “strings attached,” as case management is often a mandatory service tied to hospital release. Further, while case managers’ help was needed for information and referral, consumer leaders were also vocal about having case managers stick to their roles and not overstep boundaries.

Results and Contemporary Case Management

The range of case management practices described in the current study incorporates many themes, some pertaining to the nature of the relationship between the case manager and client, while others are more related to program structure and policies. For example, respondents identified consumer involvement in all aspects of agency structure, particularly with respect to quality assurance mechanisms. They suggested clubhouses as alternative structures to typical case management agencies. They are similarly interested in groups rather than individual practice and they articulated the disempowering use of case records.

It is also important to acknowledge that participants identified several practices that are contrary to the nature of case management services. Case management may be understood to be “system driven” (Anthony, Cohen, Farkas, & Cohen, 1988; Moxley, 2002) or to have latent societal functions such as that of gatekeeper to other services. Case managers, like many social workers, often have ambiguous roles, such as an enforcer of societal norms and someone charged with helping the individual. It is likely that some empowering practices suggested here, such as providing non-coercive and non-contingent services, cannot be adopted into case management agencies without a real restructuring of case management roles and functions.

Contrasting Consumer and Professional Responses

In comparing the consumer and professional responses, we find a great deal of congruence between the two groups. Among the top nine practices described by consumers, eight are similarly most frequently

mentioned by professionals. Further, there is a similar decrease in the frequency with which themes were mentioned by consumers and professionals among all of the 25 practices. We can construe from this that there is substantial agreement among consumer leaders and professionals on the most salient aspects of empowering practices in mental health case management. It is likely that these two groups mutually influence each other, which would result in their providing similar responses. We point out that the “professionals” interviewed here were academics and writers in mental health case management and were not state policy makers or local providers of services.

There were some discrepancies, however, between the groups. For example, while 60% of the professional group thought it was important to “de-emphasize use of psychiatrists and improve the status of case managers,” only 27% of the consumer sample expressed this view. Similarly, while 80% of the professional sample mentioned “rely on generic, community, natural support, and non-medical interventions,” only 43% of the consumer sample made reference to this category. Further, while eighty percent of the professionals referred to “seeing the client as a customer,” only 33% of consumers articulated this view. Although it seems likely that these areas are also important to consumers, it appears that their primary interests lie in the top three categories.

Contrasting the responses of consumer leaders to professionals, we also found some interesting differences. For example, consumers stressed that case managers should “be a resource in appropriate areas,” although this category was completely absent among the professionals. A possible explanation for this discrepancy is that professionals consider being a resource to be a “taken for granted” function of case management. Consumer leaders, however, are finding this practice absent in lived case management experiences. Consumer leaders also mentioned a number of other categories that were missed by professionals such as, “increase client independence from mental health service,” “change case management terminology,” “utilize the clubhouse model,” and “work with client for service system change.” We do not think professionals would disagree with these categories, but think these discrepancies may reflect sampling error or the sample size, rather than any large differences in the outlook of these two groups.

CONCLUSION

The twenty-five categories developed in this study provide a picture of potentially empowering and demedicalized practices in case man-

agement as defined through participatory action research and qualitative methods. The themes of client self-determination and personhood emerge clearly from these data. By considering the top four practices most frequently mentioned across both consumer leaders and professionals, an agenda can be developed for designing case management missions, interactions, and practices that are in keeping with client defined empowering and demedicalized practices. These include creating a mutual relationship, having client driven services, increasing flexibility and creativity to meet client needs, and giving clients a voice to help them make decisions.

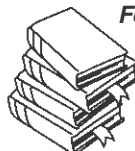
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