Empowerment and Mental Health in Community: Narratives of Psychiatric Consumer/Survivors

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ABSTRACT

This paper clarifies the concepts of empowerment and mental health and examines their inter-relationships in a qualitative study of psychiatric consumer/survivors participating in three innovative community mental health programmes. Focus group interviews with 59 stakeholders and in-depth stories of six consumer/survivors served as the data base. We defined mental health as the development of choice, control, and community integration and the acquisition of valued resources, and our research identified indicators of each of these qualities. Moreover, we found empowering processes at the micro, meso, and macro levels of analysis that facilitated the recovery of mental health, as well as disempowering processes that impeded mental health. The findings are discussed in the context of the literature on innovative practices and the emergence of an alternative paradigm in community mental health. Copyright © 2001 John Wiley & Sons, Ltd.

Key words: empowerment; mental health; narratives; community; psychiatric consumer/survivors; alternative paradigm

INTRODUCTION

Traditional approaches for people with serious mental health problems have emphasized professional expertise and control, diagnosis of deficits, 'symptom' reduction, and life skills training. The limitations of these professionally-controlled, medicalized, person-centred approaches have been increasingly noted (Nelson *et al.*, 2001). A socio-political analysis suggests that people with serious mental health problems are an oppressed group (Lord and Dufort, 1996) and that innovative approaches are needed to address the lack of power and control, stigma, poverty, unemployment, and poor housing manifest in the con-crete daily living realities that these citizens face.

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With the advent of deinstitutionalization, different types of community support have been implemented. While non-coercive, de-medicalized approaches to community support, such as Soteria House (Mosher and Bola, 2000), have been around for many years, they have been overshadowed by more coercive, medicalized approaches, such as Assertive Community Treatment (ACT) (Gomory, 1999; Spindel, 2000). However, in the 1990s, we have witnessed increased reference to an empowerment philosophy in mental health, emphasizing the values of empowerment, community integration, and social justice (Nelson *et al.*, 2001; Prilleltensky, 1994). Carling (1995) has identified promising practices based on this philosophy, such as self-help, empowerment-oriented support coordination, and supported housing, education, and employment. The empowerment paradigm also sees mental health as a construct that needs to be addressed beyond the mental health system. It is believed that fixing the current system will have limited benefits, and that economic, political, and community changes are also necessary to enhance empowerment and mental health (Fook, 1993; Nelson *et al.*, 2001; Spindel, 2000).

The purpose of this paper is to explore consumer/survivor (for purposes of brevity we will usually refer to consumer/survivors as 'consumers') experiences of empowerment and mental health, and to understand them in terms of the emerging empowerment paradigm. We begin by clarifying these concepts and noting relevant research.

Beginning with the concept of empowerment, there are three common elements to various definitions of empowerment (Prilleltensky, 1994; Rappaport, 1995; Spindel, 2000). First, empowerment includes a personal dimension of both perceived and actual power. Many have argued that vulnerable people often experience 'power over' and domination in their relationships with professionals (Burstow and Weitz, 1988; Constantino and Nelson, 1995; Janeway, 1980), while others have argued that oppression is also embedded in economic and political processes (Foucault, 1965; McCubbin and Cohen, 1996; Starhawk, 1990). Regardless of the source, the reality is that many citizens experiencing mental health problems are conditioned to be compliant and often come to believe they are powerless, even in supportive communities (Lord and Dufort, 1996). Thus, personal empowerment includes both real and perceived powerlessness (Lerner, 1991; Prilleltensky and Gonick, 1996). 'Having choice and control' is a key element in the empowerment process.

Second, empowerment has been conceived of as a process involving 'self in community' (Lord and Hutchison, 1998). Research on the empowerment process has found that with support, consumers can move from a state of powerlessness to having more power (Baxter and Diehl, 1998; Lord and Hutchison, 1993; Young and Ensing, 1999). This process often involves struggling for identity, learning valued social roles, and enhancing participation in community life (Lord and Hutchison, 1993). The process of 'self in community' involves changes in power relations and is enhanced through knowledge and awareness, skill development, relationship building, and supportive community contexts (Lord and Hutchison, 1993; Lucksted, 1997; Staples, 1997). Thus, community integration is a key part of empowerment.

Third, empowerment also includes access to valued resources (Prilleltensky, 1994). Many oppressed groups, like psychiatric consumers, live in poverty and poor quality housing, have high rates of unemployment, and inadequate access to education. Indeed, it is hard to imagine a process of empowerment occurring in the absence of improvement in the material conditions of life of consumers (Prilleltensky, 1994).

Turning to the concept of mental health, professionals have focused more on 'mental illness' than on mental health. Mental health, however, is more than the absence of illness;

it involves the presence of positive qualities. Typically, positive mental health is defined in terms of individual characteristics (e.g. coping ability, problem-solving skills). In a Canadian report, mental health was defined more broadly as:

> ...the capacity of the individual, the group, and the environment to interact with one another in ways that promote subjective well-being, the optimal development and use of mental abilities (cognitive, affective, and relational), the achievement of individual and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality. (Epp, 1988, p. 7)

This definition emphasizes the individual in his/her environment and includes issues of justice and equality. The recent focus on the recovery of mental health by people who have experienced serious mental health problems similarly emphasizes interactions between individuals and their social environments (Anthony, 1993; Baxter and Diehl, 1998; Young and Ensing, 1999). Similarly, we believe that a holistic view of mental health considers positive individual qualities in the context of relationships, community, and society.

While the concepts of empowerment and mental health are quite similar and inter-related, we argue that it is important to distinguish between them. We define empowerment as *opportunities for and conditions that promote* choice and control, community integration, and valued resources. Mental health can be defined as the *development and acquisition* of choice and control, community integration, and valued resources. While empowering conditions set the stage for the development of mental health, we do not believe that a single empowering condition 'produces' mental health in a linear fashion. Rather, we argue that there are transactional processes between individuals and their social environments, so that empowering factors at different ecological levels act in concert with one another to influence mental health.

An ecological analysis of empowerment and mental health highlights multiple levels of analysis, ranging from micro to macro systems. Social support from peers, friends, family, and helpers at the micro level is very important for the mental health of consumers (Hall and Nelson, 1996). At the meso level, Maton and Salem (1995) have identified some of the empowering characteristics of organizations. Mental health and self-help organizations that develop a shared vision, provide opportunities for member participation, and consciously strive to implement the vision in day-to-day practices provide a context conducive to mental health (Ochocka *et al.*, 1999). At the macro level, both the process of mental health policy-making (meaningful consumer participation) and the substance of such policies (funding for consumer self-help organizations, housing, and employment) are important for empowerment and mental health (Church, 1996; McCubbin and Cohen, 1999).

Based on this brief conceptual and empirical overview of empowerment and mental health, we address the following questions in the research we report here:

(1) What changes on different dimensions of mental health do psychiatric consumer/ survivors experience through their participation in community mental health organizations and communities that practice an empowerment philosophy?
(2) What empowering conditions facilitate changes and what disempowering conditions inhibit changes in mental health?
(3) How do these factors contribute to our understanding of the relationship between empowerment and mental health in the emerging paradigm of community mental health?

METHODOLOGY

Context and changes
The research reported in this article is based on a larger study of personal, organizational, and community change in the context of two mainstream community mental health agencies, the Canadian Mental Health Association (CMHA)/Waterloo Region Branch and Waterloo Regional Homes for Mental Health ('WRHomes'), and one self-help organization for psychiatric consumers, Waterloo Region Self Help ('WRSelfHelp') (Nelson *et al.*, 2001). These organizations are located in one urban community in southwestern Ontario, Canada. Beginning in the early 1990s, the two mainstream organizations embarked on a change process, and WRSelfHelp was formed. CMHA provides individualized support coordination; WRHomes provides housing and individualized support; and WRSelfHelp offers self-help groups and peer support. All three organizations serve people with serious mental health issues.

All three organizations began to emphasize the values of empowerment, community integration, and social justice and changed or developed their services and supports to fit this philosophy. We briefly note some of the changes here (for details see Ochocka *et al.*, 1999). CMHA shifted from a traditional case management approach to an empowerment approach to support coordination and started a supported employment programme to help people obtain jobs. WRHomes also moved to a highly individualized, consumer-directed support process. Support staff were no longer attached to specific housing programmes, but were matched with individuals who decided the type and frequency of support they wanted. WRSelfHelp developed self-help groups. More broadly, all three settings emphasized consumer participation in all aspects of organizational life.

At this time, a unique opportunity for these organizational changes existed within the community (Nelson *et al.*, 2001). First, strong leaders with a clear vision and values were within each of the organizations. Second, the medical model of mental illness is not very strong in this community, due to the relatively few psychiatrists and psychiatric beds in the one general hospital. Third, the Ontario government was promoting compatible progressive changes in mental health policy during that period. Finally, the values and approaches taken by the three organizations were consistent and complementary, thus providing a change synergy within the community.

Research approach
Our research approach, based on the values of participatory action research (Nelson *et al.*, 1998) and the assumptions of social constructivism (Lincoln and Guba, 1985), was compatible with the values of the organizations involved in the study. The authors had previous experience with these organizations and were able to develop a research partnership with them.

We developed a Steering Committee, composed of the authors and representatives from each of the three settings, to guide the research; consumers were in the majority, and usually chaired the committee. The committee met almost every month for 2 1/2 years and reviewed, discussed, and approved all decisions regarding the research. To give voice to people's experiences we relied exclusively on qualitative methods (Lord and Hutchison, 1993). Consumer research assistants (one from each setting) were hired and trained to assist us in liaising with the settings and gathering data.

Since we studied changes after the fact, the research emphasized participation more than action. Had we done this study during the change processes, the findings could have been used to guide change. Nevertheless, there were some actions following from the study. Summary bulletins were used as training materials by the agencies for new members and staff, and the Steering Committee submitted a brief on the findings with implications for mental health planning to a government body with a mandate to restructure health services in the region.

Multi-phased methodology

We used a multi-phased research methodology, in which phases were built on the lessons of previous phases. In the first phase, we strove to understand the policy and planning context and the organizational change pathways. In the second phase, we interviewed 59 people, representing managers (4), staff (14), consumers (30), family members (8), and volunteers (3), from each of the three organizations, regarding personal changes experienced by consumers. All senior managers from the three settings were interviewed. Staff members were selected randomly from a master staff list (with no names on the list), but proportionally with respect to the following criteria: gender, length of employment, type of programme, work site, full-time versus part-time status. Consumers and volunteers were selected using gender and type and length of involvement as criteria, and family members were selected by type and length of involvement, relationship to the consumer, and location. Each organization advertised for willing volunteers and family members to attend the interviews. A focus group interview format was used with separate interviews conducted with each stakeholder group at each setting. The vast majority of those who were asked to participate agreed to be interviewed.

In the final phase, we collected in-depth stories of six consumers (two from each organization) through 30 interviews. Six consumers (two from each setting) were purposively selected using the following criteria: a mix of ages, a minimum of 2 years of involvement with the organization (one with shorter, one with longer involvement), gender (one man, one woman), and stage of recovery (one more advanced, one slower). For each story, a consumer was interviewed along with one peer (someone in the community who knows the individual), one friend, one family member, and one support worker. Consumers gave permission for the interviews with the other people in their social support networks.

In both phases, structured interview guides were used, developed by the researchers and modified based on feedback from Steering Committee members. Interviews were tape-recorded, transcribed, and shared with the people interviewed, providing them an opportunity to edit them. An open coding process (Strauss and Corbin, 1990) was used to analyse the data, whereby the coder reads through the transcripts to develop codes summarizing the data, which are refined in moving back and forth between codes and data (a process of constant comparison). While the broad areas of change (e.g. community integration) were decided on *a priori*, the coding of responses was inductive. The trustworthiness of the codes was determined by having more than one person code the data, and by using 'member checks' with the individuals interviewed and via feedback meetings with organizational members. Participants from the settings believed that the codes reflected their experiences.

FINDINGS

A story of change

We begin this section with one of the six stories of change. While each story is unique, Janice's (a fictitious name) story illustrates many of the themes found in the other stories. Given space limitations, we will present the following story primarily from the consumer's perspective and words.

Janice's story. Since the tragic death of her brother when she was 10 years old, Janice has struggled. Janice has strong memories of the abuse she suffered at the hands of her alcoholic parents, who discouraged her from talking about her problems. She said that she was not an easy child to raise, diagnosed with a learning disability in the early grades and involved with a tough, rebellious crowd in high school. She was often lonely and isolated and began abusing drugs and alcohol. She moved out of her parents' home and lived in boarding houses, spending some nights on the street.

Beginning in high school, Janice was admitted to the hospital many times and spent years in counselling and treatment programmes. Her outlook was bleak:

> I was very needy . . . I needed to be with somebody 24 hours a day . . . I was scared. I was out of control myself. I didn't care about anything, I just wanted to be bad . . . I could never be a normal person. I would always be sick the rest of my life.

In 1991, at the age of 20, Janice moved into a group home with WRHomes and lived there for a year. She believes that otherwise she would have experienced further tragedies:

> My learning disability would show more. I think I would probably be a bum on the street or behind a bottle of alcohol. I would be very self-mutilating . . . I don't think that I would be around . . . They treated me like they were one of my family members and that's what I built my life upon . . . because I really don't have a family as my own. So I felt that in order for me to have a life and to feel that I have a purpose in life, I needed to create a family in a sense, like a secondary family.

When WRHomes created a more flexible support system for people living on their own, Janice, with the aid of a support worker, was able to find her own apartment, where she learned to cook and budget her money. Janice has been active with many committees at WRHomes, and she has recently done part-time paid jobs for the organization and also found other casual work. Janice became active at WRHomes not just to help herself, but also to help others. She repeatedly spoke of 'giving back to others' and 'making a difference' in people's lives.

She talked about 'believing' in herself now. An indication of the change in Janice's self-confidence is the way she has become involved in the broader community. She is active on a sport team and enjoys going to sporting events, social gatherings, and parties. Janice still has hard times:

> It used to be a lot of running away and self-harm. Now periods of high anxiety, sleeplessness, and a feeling of loss of control are still present but not nearly to the degree of frequency that they were.

Janice knows when to admit herself into the hospital, and she has taken advantage of the pager crisis support system and the crisis planning at WRHomes. Hospitalization became less frequent; whereas the hospital was once a 'second home,' Janice now sees it as a 'safe haven' for tough times.

Janice has gradually been able to let down her 'tough' image. From being a withdrawn, cold, and confrontational young adult, Janice now frequently meets with friends:

> . . . things that had helped my changes were becoming involved at WRHomes, being educated [about my mental health issues], having a purpose, caring about myself . . . [and] through the help of other people who cared.

Reflections on Janice's story.   Janice, like many other consumers, experienced long periods of powerlessness. For some time she internalized others' beliefs about her own weaknesses and limitations. Several empowerment principles were utilized by the staff within WRHomes (Lord *et al.*, 1998; Staples, 1997), enabling Janice to have choice (where to live) and self-determination (setting her goals and accessing support to achieve them). Through WRHomes, Janice was able to access individualized support within her own home, although she continued to experience challenges. This kind of support increased her independence and control. As Janice began the process of recovery, her involvements within the organization and the community were also significant. Janice's story reflects the finding that the process of personal empowerment involves both internal motivation and external resources leading to improved mental health (Kieffer, 1984; Lord and Hutchison, 1993).

Changes in mental health

Table 1 presents an overview of changes on three dimensions of mental health, and factors that facilitated or inhibited those changes, as derived from the interviews. Before describing the findings, we make three general observations. First, the vast majority of the comments regarding the three organizations were quite positive. However, there were a few negative comments about each setting. For example, some participants saw the changes in one organization as too ideological, and in another setting, two participants related a conflict between staff and a few members. Second, there was a clear trend across all three settings for the most change to be reported for choice and control and the least change in acquisition of valued resources, with community integration changes somewhere in between. Third, there was considerable consistency between the responses of different stakeholder groups regarding the changes and factors related to those changes.

Choice and control.   Consumers frequently mentioned *improved health and well-being* through support. For example, participants and their network members said that in the past individuals were often hospitalized, but now less often and for shorter periods. As well, consumers reported improved feelings of well-being. Another frequently mentioned change was *increased confidence and self-esteem*. One consumer said: 'I have more confidence now.' A parent made a similar comment: 'I found my [son] more confident . . . His self-esteem has improved.'

Another frequently mentioned change was *increased control over daily life*. 'I've seen a few people since they first started definitely taking more control of their lives and venturing out on their own and are extremely proud of it . . .' *Increased independence* was mentioned by many participants, particularly concerning living arrangements. One consumer emphasized, 'You live on your own, you do what you want, and you're free.' Increased independence and its accompanying responsibility was also noticed by several family members. '[He has far more power now] over his own life . . . he also has more responsibility getting meals, cleaning the place and so on.'

Table 1. Changes in three dimensions of mental health and factors which facilitated or inhibited those changes

Mental health changes	Empowering conditions[a]	Disempowering conditions[a]
Choice and control • Improved health and well-being • Increased confidence and self-esteem • Increased control over daily life • Increased independence • Skill development *Community integration* • Better relationships • Increased participation and involvement in the consumer/survivor community, human services, and the larger community *Valued resources* • More people accessing education • A few more people working • People continuing to struggle with poverty • More people accessing housing (1985–1994)	*Personal motivation* • Consumers taking more initiative *Supportive relationships* • More equitable relationships between support workers and consumer/survivors • Natural supports • Peer support and self-help groups *Responsive organizations and communities* • Individualized, community-focused approaches to services and supports • Responsive mental health organizations • Receptiveness of community settings *Social change and social justice* • Advocacy • Other valued resources	*Personal motivation* • Personal issues and personal history • Fear and lack of confidence *Unresponsive or limited organizations and communities* • Lack of control over medical treatment • Limitations of mental health organizations • Continued stigma in the community *Social injustice* • Lack of money • Government cutbacks

[a]The identified facilitating and inhibiting factors do not relate to separate individual changes but reflect people's overall experience related to changes in mental health.

There seemed to be agreement that being active in the organizations and the community enabled people to develop skills. Sometimes the change in *skill development* was remarkable. 'I heard the story of the one woman who came to the depression group and hardly ever opened her mouth. And then she became . . . the leader of the group . . . and it was one of the most successful groups.'

Community integration.   Community integration was the second dimension of mental health that we examined. Many people mentioned that consumers enjoyed better relationships. Consumers described creating more relationships due to their growing involvement in community activities. Others acknowledged the support that they receive from staff and peers. Increased participation and involvement in the community was noted by all stakeholders, who spoke of three different aspects of community: the consumer/survivor community, human services, and the community-at-large. With the emergence of WRSelfHelp in 1991, many participants mentioned their increased participation within the consumer/ survivor community:

> I found with myself, my changes in Waterloo Region Self Help in the beginning, in the early 90s was more to just belong, whereas now I've reached the point where I can work for the organisation and do things that I wouldn't have been able to do earlier . . . Earlier I used to just go out for the groups, now I'm more actively involved. Now I help run the groups.

With the change in direction of the mainstream agencies, consumers also began to participate more in them, becoming more active in policy, advisory, and other volunteer roles, and some have become staff members. Consumer participation is now widespread throughout the three organizations, whereas in the past consumers were more invisible and unheard.

The most change was reported in terms of participation in the community-at-large. Staff spoke of 'helping people to identify what community integration means and how we can achieve that.' Consumers became more involved in leisure activities, churches, and with family and friends. The agencies made a conscious effort to shift away from segregated settings to participation in typical community settings.

Valued resources.   Compared to choice, control, and community integration, the least change was reported in the acquisition of education, employment, income, and housing. There were more positive than negative comments made about change in education and employment; comments about housing were mixed (roughly half were positive and half negative); and there were few comments about positive changes in income.

Overall, participants indicated that *more people are accessing education*. As one person said, 'I see a lot of people are getting access to education where there has been more supportive educational systems.' One consumer said:

> I have gone back to school and found part-time work and am no longer dependent on the government for money. I also volunteer at CMHA along with other consumer/survivors.

Participants identified some improvements in the employment of consumers, noting that some people are getting real jobs, rather than 'segregated jobs'. However, these comments were usually tempered with the recognition that overall there has been only marginal improvement in employment. At the same time, participants noted that more consumers became interested in employment. The following comment was typical. 'So through the supported employment programme offered by another local organisation, we've seen

some changes to employment. But I think we've got a long way to go in terms of employment opportunities.'

Most of the responses to the questions about changes in income indicated that *people are continuing to struggle with poverty.* Many consumers spoke of 'running out of money,' and recent cuts to welfare have impacted on consumers:

> I run out of money usually in the middle of the month, so I'm going by on air, you know. My nutrition is going to affect my mental health. The leisure activities I can afford to get involved in is limited.

Those few people who had obtained employment spoke of having more money than in the past.

Participants noted *improving access to housing* between 1985 and 1994, a period in which a number of supportive housing options were developed in Waterloo Region following government funding initiatives. However, since 1995, with the freeze on low-income housing, few people were seen to obtain decent housing. The lack of affordable housing in the area was frequently mentioned as a problem.

Factors facilitating mental health improvements

Personal motivation.   After being cast in the patient role of compliance and passivity, it is difficult for people to make meaningful changes in their lives. Consumers talked about *taking more initiative* to get out in the community. It was noted that people could begin by taking 'small steps,' but what is important is the personal motivation to change. Of course, personal motivation does not occur in a vacuum, but rather in the context of empowering environmental conditions that we describe next.

Supportive relationships.   With the organizational changes, participants noted *more equitable relationships between support workers and consumers*, and that consumers had become more assertive and directive in expressing their wishes. 'Consumers now direct the type of support that they want. They're – I don't want to say more listened to, it implies that they weren't listened to in the past – but they develop their own path that they want to go on, their own goals.' This shift in power relations signals opportunities for consumers to gain more control and experience self-determination in their lives (Dunst and Trivette, 1989; Lord and Hutchison, 1993).

Availability of natural supports.   Support provided by people like families and friends was seen to be another helpful factor in increasing community participation. The role of family was seen as vital for many people:

> So this is where a family can be helpful. If the family says 'This is what he's interested in. You know, this is what he's done in the past' . . . the family can help the worker and the worker can help the individual.

Participants also spoke of encouragement from friends and community members. This finding underscores the importance of natural support networks, rather than professional support, for change (Hall and Nelson, 1996).

Peer support and self-help.   Peer support is informal, through friendships with other consumers, while self-help was viewed as consumer mutual support groups. Participants

noted the benefits of peer support and self-help, for both of which WRSelfHelp provides opportunities. 'And consumers talk to each other a lot and I think that's the biggest morale booster ... So consumers getting together is a huge, huge plus.' 'Once you start developing your leadership skills [through leading groups] and realize that you have something to give, that really adds to people's feelings of empowerment and self-esteem.' One important component of self-help organizations is that the successes of some consumers help to 'pave the way for others'. Seeing other people 'do it' was inspirational and made others believe that they could as well. This study confirms findings of other research of the important role of self-help in facilitating mental health (see Nelson *et al*., 1998).

Responsive organizations and communities. Many participants spoke of the *individualized community-focused approaches to services and supports* offered by the three organizations as a facilitating factor. For example, consumers in both mainstream agencies now make their own crisis plans, which includes outlining 'who they want called, who they don't want called, what they don't want in any circumstances.' This has provided proactive direction to workers in supporting an individual through a crisis. When in the hospital, consumers continue to work closely with their support coordinators from the community agencies and determine 'what's going to be done while they're there.' Although not yet widespread in community mental health, this shift to self-determination and individualized approaches is increasingly seen as fundamentally important in the promotion of well-being for all vulnerable groups (Nelson *et al.*, 2001; Pedlar *et al.*, 1999).

Participants talked about the importance of support workers helping them to set goals and providing 'continual' support and encouragement. Consumers wanting social outings have been encouraged to try non-segregated social events. Support workers made a 'much more conscious effort to make it [community integration] happen' and resources within the organizations were directed to community-focused activities (Ochocka *et al.*, 1999).

Responsive mental health organizations. Some comments about the agencies involved in this study related to enabling people to dream and take risks (Dunst and Trivette, 1989). An individual who had experience with all three organizations described the support he experienced:

> In the case of all three agencies, what has helped is that they have allowed me to dare to dream and try. Very rarely have they put limitations, judgment or stigmatisation on me and made me feel wrong, incompetent or that I just couldn't do something.

Other comments related to the belief the organizations had in people, their strengths, voice, and experience, noting, for example, the organizations' 'recognition that consumers are the ones with the expertise. They have a better handle on mental health issues and what personally they can manage than anybody else does.' The formal agencies in this study both practiced strengths-based approaches, which apply empowerment principles to relationships and support provision (Saleebey, 1992; Staples, 1997).

Receptiveness of community settings. Some consumers talked about how comfortable they feel in settings with which they are involved. Others spoke about being 'accepted as I am,' feeling more 'support,' and not needing to feel 'ashamed' at work, with family or with friends.

Social change and social justice.   Another facilitating factor is *advocacy* to create social change and social justice. Participants mentioned that the advocacy carried out by a number of groups has served to improve the situation for consumers, for example the action of WRSelfHelp's Advocacy Committee over pensions. A housing coalition that operated in the 1980s and early 1990s is another example of advocacy which influenced the growth of supportive and supported housing in the region (Nelson, 1994). More recently, two of the organizations have stood with consumers in opposing community treatment orders and ACT teams, viewing them as coercive and antithetical to an empowerment approach (Gomory, 1999; Spindel, 2000).

Other valued resources.   Since employment, income, and housing are inter-related, improvements in one area help in others. For example, consumers said that having a job makes it easier to obtain better housing. All three organizations recognize the importance of valued resources and have developed new programmes to help consumers access housing and employment.

Factors inhibiting mental health improvements

Personal motivation.   All stakeholder groups mentioned that *personal issues and personal history* hindered improvements in mental health. Participants stated that some individuals have 'self-defeating thinking,' 'fear of failure,' fear of making their 'own decisions,' and 'a very big lack of self-esteem,' all limiting their capacity for change. For example, the feeling of safety and protection people feel when in sheltered housing for long periods makes it difficult to move on to integrated housing. Kieffer (1984) found that internal motivations were critical in the empowerment process; this is especially so in the face of internalized powerlessness or oppression (Lerner, 1991; Prilleltensky and Gonick, 1996). However, motivations take time to change; as one staff person said: 'We've [service-providers] told them for the last 20 years you can never work and now we've changed our mind[s].'

Unresponsive or limited organizations and communities.   Many consumers mentioned that *lack of control over medical treatment* hindered their mental health. One consumer thought that 'some doctors, not all doctors, but some doctors can hinder your progress if they want to keep you doped up.' Several participants talked about consumers being placed in a 'subordinate' position relative to their doctors. One woman related: 'I can remember asking one of my doctors in London if I could see my files and he said "You'll never be in any condition to read your own files".' The imbalance of power relations was very common in the treatment realm (Constantino and Nelson, 1995; McCubbin and Cohen, 1996). Support workers from the agencies assist consumers in confronting these power imbalances through personal advocacy (Fook, 1993).

Limitations of mental health organizations.   In the absence of progressive social policies regarding education, employment, income, and housing, the agencies have limited capacity to assist people in accessing these valued resources.

Continued stigma in the community.   Participants from all stakeholder groups spoke of 'tremendous stigma,' 'misinformation,' 'stereotyping,' 'labelling,' and a 'climate of ignorance' within the community-at-large. One participant emphasized: 'There's still a long

way to go on the part of the general membership in the community accepting and including them as members, if you will, in the community.' Another person said: 'I really think this problem of stigma in the community in general still presents a problem in getting a job.' Stigma and prejudice remain serious challenges to integration of people with mental health challenges into the community (Page and Day, 1990).

Poverty and social injustice. Money was seen by many as a valued resource that could permit greater independence and quality of life. Several comments attested to the damaging impacts of poverty on mental health, for example 'How can you feel empowered when you don't know if you are going to have food next month.' Similarly, 'I don't know how some of [the consumers] survive on what they get. So how do you plan proper meals, proper clothing, proper transportation to go out into the public and be accepted by the public?'

Poverty and lack of income are serious barriers to mental health (Epp, 1988; Nelson *et al.*, 2001). While we found that many consumers were able to make gains in empowerment and mental health despite limited income, others were not. Our research reminds us of the oppression that results from economic marginalization (Prilleltensky and Gonick, 1996).

Government cutbacks also hindered consumers' access to valued resources. Lack of government support was seen in a number of ways: the freeze on the creation of low-income housing, income regulations for those on social assistance creating a 'disincentive' to work, reductions in welfare, earnings limits for those on disability pensions. These reductions in government support have placed many consumers in a financial situation which limits their options (Capponi, 1997).

DISCUSSION

Through our research we have learned that empowerment processes occurring at multiple levels of analysis are critical for recovery of mental health. Judi Chamberlin (1999), a psychiatric survivor activist, asserted that recovery is about becoming a person and a citizen able to access community supports, while empowerment is about being in control and making choices. In our view, significant progress toward empowerment and mental health cannot occur within the traditional paradigm. A paradigm that underscores self-determination, community integration, and social justice offers the best opportunities to enhance mental health.

One contribution of this research is that we have identified a broad range of indicators of mental health. As Epp (1988) asserted, mental health is more than the absence of problems, it is also the presence of strengths. When asked about the types of changes that consumers had experienced, participants described changes related to choice and control, community integration, and acquisition of resources.

Traditionally, research on the effectiveness of community mental health programmes has relied heavily on measures of hospitalization and reduction in 'symptoms' as outcome indicators. These criteria reflect a focus on 'mental illness,' rather than on mental health. One avenue for future research is the development of outcome measures that tap the different dimensions of mental health reported in this study. The indicators we identified for these dimensions provide a rich base for instrument development.

Previous research with consumers has found that recovery of mental health is embedded in a process of empowerment (Baxter and Diehl, 1998; Lord and Hutchison, 1993; Young and Ensing, 1999). In Figure 1, we present a grounded theory (Strauss and Corbin, 1990) of the relationship between empowerment and mental health. Note that the relationship between these two concepts is mediated by different ecological systems.

At the micro level, participants spoke of the importance of supportive and equitable relationships. The two mainstream mental health agencies adopted an empowerment philosophy of support coordination (Dunst and Trivette, 1989). Also, peer support and self-help groups were viewed as an important and empowering resource for mental health. This finding is consistent with a growing body of research attesting to the benefits of self-help for consumers (Nelson *et al.*, 1998). Natural networks of support with families and friends were also found to be important for mental health, as found by Hall and Nelson (1996).

These relationships are embedded within meso-level services and supports that are individualized, flexible, consumer-directed, and community-focused. Most consumers have experienced pressure to comply with medical treatment regimens. In contrast, the services and supports offered by the organizations in this study do not expect compliance, but rather support consumer choice. As Wartenberg (1990) described it, this approach uses 'power as liberation' instead of 'power as dominance.' The three organizations were described as 'responsive,' with consumers stating that they are valued in these organizations.

Moreover, we found that consumers were visible and vocal in these settings, occupying staff positions and prominent positions on committees and boards of directors. We found that the three organizations possess many of the qualities of empowering settings identified in the literature (Maton and Salem, 1995; Salzer, 1997). We also know that these organizations have embarked on organizational change processes involving all stakeholders in the formulation of a new vision, the development of innovative services, and changes in staff attitudes and practices (Lord *et al.*, 1998). Throughout our study we observed that

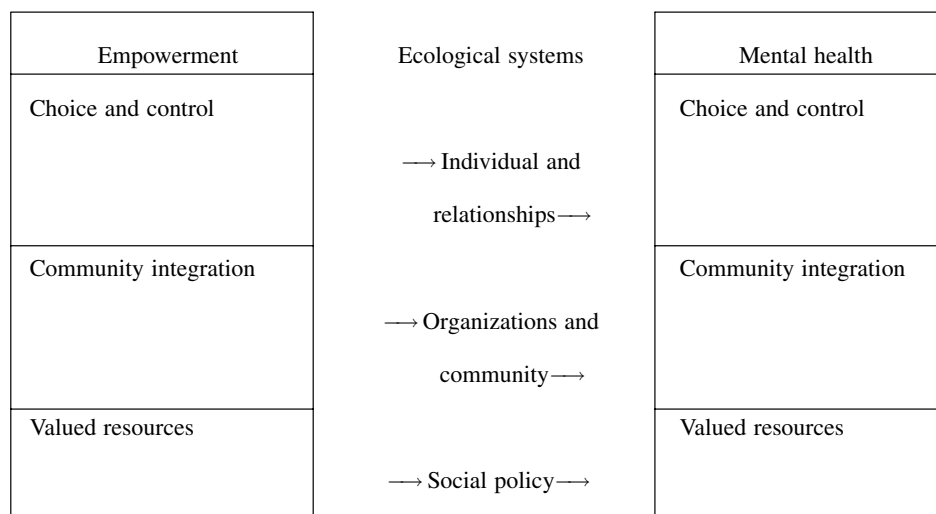| Empowerment	Ecological systems	Mental health
Choice and control		Choice and control
	$\longrightarrow$ Individual and relationships $\longrightarrow$	
Community integration		Community integration
	$\longrightarrow$ Organizations and community $\longrightarrow$	
Valued resources		Valued resources
	$\longrightarrow$ Social policy $\longrightarrow$	

Figure 1.   A grounded ecological model of the relationship between empowerment and mental health.

there is a coherence in philosophy and values across the three organizations. When individuals move back and forth between these settings, they experience a consistency of approaches, which reinforces a community narrative of empowerment (Rappaport, 1993).

Also, these organizations strive to promote community change and community integration of people with mental health challenges. Mental health and empowerment will be limited if people are segregated in mental health organizations. Both empowerment and recovery involve moving away from the 'mental health bubble,' that invisible barrier that separates consumers from the community (Chamberlin, 1999). Our research underscores the importance of the 'self in community' for mental health and empowerment (Lord and Hutchison, 1993).

We found the most change on the dimension of choice and control and the least change in the acquisition of valued resources, with changes in community integration somewhere between these two. Why this pattern of changes? Meaningfully involving consumers and transforming helping relationships was within the power of the organizations. However, while each organization made partially successful strides to address the issue of valued resources, they were significantly constrained by mental health policy that continues to focus on services rather than housing, employment, and education – areas typically considered to be outside of the domain of mental health policy. Some progress was made on the issue of providing housing when the government provided new funding in initiatives involving health and housing ministry partnerships (Nelson, 1994).

Our analysis and findings suggest that social policy must acknowledge the poverty and unemployment of psychiatric consumers as significant impediments to mental health. Policies which address poverty through the financing of such initiatives as supported employment, consumer-operated businesses, and supported housing can go a long way in overcoming these social injustices (Carling, 1995). With acquisition of valued resources, we would also expect enhanced community integration, as many people develop their social networks through jobs and education.

While the stakeholders of these organizations are working towards empowerment, it needs to be stated that they are also working against the *status quo* of the mental health system and the larger society. Participants identified factors that are endemic to the mental health system and society which stifle mental health. The phenomenology of poor mental health includes years of prolonged dependency, compliance, diminished expectations and hope for recovery and change, and internalized stigma/oppression (Lord and Hutchison, 1993). Also, power imbalances between consumers and medical professionals, and lack of control over treatment, were identified by participants as constraining mental health, as also suggested by a growing literature (Burstow and Weitz, 1988; Constantino and Nelson, 1995; Lord and Dufort, 1996; McCubbin and Cohen, 1996). Finally, community ignorance and stigma remain significant barriers to empowerment for people who have experienced mental health problems (Page and Day, 1990).

Rappaport (1993, 1995) argued for a community narrative of empowerment, whereby psychiatric consumers have a supportive context in which they can reconstruct personal stories that reflect mental health, strengths, and hope, as an alternative to the dominant social narrative of people with mental health problems as dangerous 'psychos.' In qualitative research in other Ontario communities that are saturated with an institutional-medical model as their narrative (Horgan, 2000; Pranger, 1999), the individual stories of consumers participating in community support programmes look quite different than the stories of consumers in our community. These stories from other communities are replete with stigma, powerlessness, and dependency. As we noted, the community context in

which this study was conducted was particularly supportive of the development of a community narrative of empowerment. The extent to which this narrative can be transplanted to other communities that are deeply ensconced in the medical model has yet to be determined.

In summary, this study sheds light on the concepts and inter-relationships of mental health and empowerment. A qualitative study such as this one can suggest pathways that connect empowerment and mental health. Future studies using experimental or quasi-experimental methods are needed to further establish these connections. The findings also point to the importance of the community context for mental health and empowerment. A community narrative of empowerment sets the stage for supportive relationships, empowering organizations, and welcoming communities, all of which are conducive to positive mental health.

ACKNOWLEDGEMENT

REFERENCES

Anthony WA. 1993. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal* **16**: 11–23.

Baxter EA, Diehl S. 1998. Emotional stages: consumers and family members recovering from the trauma of mental illness. *Psychiatric Rehabilitation Journal* **21**: 349–355.

Burstow B, Weitz D. 1988. *Shrink Resistant: The Struggle Against Psychiatry in Canada*. New Star Books: Vancouver.

Capponi P. 1997. *Dispatches from the Poverty Line*. Penguin: Toronto.

Carling PJ. 1995. *Return to Community: Building Support Systems for People with Psychiatric Disabilities*. Guilford: New York.

Chamberlin J. 1999. Keynote Address to the International Association of Psychosocial Rehabilitation Services – Ontario Chapter, Niagara Falls, 21 October.

Church K. 1996. Beyond 'bad manners': the power relations of 'consumer participation' in Ontario's community mental health system. *Canadian Journal of Community Mental Health* **15**(2): 27–44.

Constantino V, Nelson G. 1995. Changing relationships between self-help groups and mental health professionals: shifting ideology and power. *Canadian Journal of Community Mental Health* **14**(2): 55–70.

Dunst CJ, Trivette CM. 1989. An enablement and empowerment perspective of case management. *Topics in Early Childhood Special Education* **8**: 87–102.

Epp J. 1988. *Mental Health for Canadians: Striking a Balance*. Minister of Supplies and Services: Ottawa.

Fook J. 1993. *Radical Casework: A Theory of Practice*. Allen and Unwin: St Leonards, NSW.

Foucault M. 1965. *Madness and Civilization: A History of Insanity in the Age of Reason*. Vintage: New York.

Gomory T. 1999. Programs of Assertive Community Treatment (PACT): a critical review. *Ethical Human Sciences and Services* **1**: 147–163.

Hall GB, Nelson G. 1996. Social networks, social support, personal empowerment and the adaptation of psychiatric consumers/survivors: path analytic models. *Social Science and Medicine* **43**: 1743–1754.

Horgan S. 2000. The lived experience of people receiving assertive community treatment: a phenomenological study. MA thesis, Wilfrid Laurier University, Waterloo, Ontario.

Janeway E. 1980. *Powers of the Weak*. Knopf: New York.

Kieffer C. 1984. Citizen empowerment: a developmental perspective. *Prevention in Human Services* **3**: 9–36.

Lerner M. 1991. *Surplus Powerlessness*. Humanities Press International: London.

Lincoln YS, Guba EG. 1985. *Naturalistic Inquiry.* Sage: Newbury Park, CA.

Lord J, Dufort F (eds), 1996. Power and oppression in mental health. *Canadian Journal of Community Mental Health* **15**(2): 1–185.

Lord J, Hutchison P. 1993. The process of empowerment: implications for theory and practice. *Canadian Journal of Community Mental Health* **12**(1): 5–22.

Lord J, Hutchison P. 1998. Living with a disability in Canada: toward autonomy and integration. In *Determinants of Health: Settings and Issues*, vol. 3. Editions Multi Mondes: Sainte Foy, Quebec.

Lord J, Ochocka J, Czarny W, MacGillivary H. 1998. Analysis of change within a mental health organization: a participatory process. *Psychiatric Rehabilitation Journal* **21**: 327–339.

Lucksted A. 1997. *Turning Points and Empowerment*. Center for Mental Health Policy and Services Research: Philadelphia, PA.

Maton KI, Salem DA. 1995. Organizational characteristics of empowering community settings: a multiple case study approach. *American Journal of Community Psychology* **23**: 631–656.

McCubbin M, Cohen D. 1996. Extremely unbalanced: interest divergence and power disparities between clients and psychiatry. *International Journal of Law and Psychiatry* **19**: 1–25.

McCubbin M, Cohen D. 1999. A systemic and value-based approach to strategic reform of the mental health system. *Health Care Analysis* **7**: 1–21.

Mosher LR, Bola JR. 2000. The Soteria project: twenty five years of swimming upriver. *Complexity and Change* **9**: 68–74.

Nelson G. 1994. The development of a mental health coalition: a case study. *American Journal of Community Psychology* **22**: 229–255.

Nelson G, Ochocka J, Griffin K, Lord J. 1998. 'Nothing about me, without me': participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. *American Journal of Community Psychology* **26**: 881–912.

Nelson G, Lord J, Ochocka J. 2001. *Shifting the Paradigm in Community Mental Health: Towards Empowerment and Community*. University of Toronto Press: Toronto.

Ochocka J, Nelson G, Lord J. 1999. Organizational change towards the empowerment-community integration paradigm in community mental health. *Canadian Journal of Community Mental Health* **18**(2): 59–72.

Page S, Day D. 1990. Acceptance of the 'mentally ill' in Canadian society: reality and illusion. *Canadian Journal of Community Mental Health* **9**(1): 51–61.

Pedlar A, Haworth L, Hutchison P, Dunn P, Taylor A. 1999. *A Textured Life: Empowerment and People with Developmental Disabilities*. Wilfrid Laurier University Press: Waterloo.

Pranger T. 1999. Mental health consumer involvement in service level decision-making: rhetoric and reality. Doctoral dissertation, Department of Public Health Services, University of Toronto.

Prilleltensky I. 1994. Empowerment in mainstream psychology: legitimacy, obstacles, and opportunities. *Canadian Psychology* **35**: 358–374.

Prilleltensky I, Gonick L. 1996. Polities change, oppression remains: on the psychology and politics of oppression. *Journal of Political Psychology* **17**: 127–148.

Rappaport J. 1993. Narrative studies: personal stories and identity transformation in the mutual help context. *Journal of Applied Behavioral Science* **29**: 239–256.

Rappaport J. 1995. Empowerment meets narrative: listening to stories and creating settings. *American Journal of Community Psychology* **23**: 795–807.

Saleebey D (ed.). 1992. *The Strengths Perspective in Social Work Practice*. Longman: New York.

Salzer MS. 1997. Consumer empowerment in mental health organizations: concept, benefits, and impediments. *Administration and Policy in Mental Health* **24**: 425–434.

Spindel P. 2000. Polar opposites: empowerment philosophy and Assertive Community Treatment (ACT). *Ethical Human Sciences and Services* **2**: 93–100.

Staples L. 1997. Developing, facilitating, and sanctioning mental health consumer empowerment: roles for organized consumers, provider professionals, and the mental health bureaucracy. Paper

presented at the Empowerment Practice in Social Work conference, University of Toronto, September.

Starhawk. 1990. *Truth or Dare: Encounters with Power, Authority, and Mystery.* Harper: San Francisco, CA.

Strauss AL, Corbin J. 1990. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques.* Sage: Newbury Park, CA.

Wartenberg T. 1990. *The Forms of Power: From Domination to Transformation.* Temple University Press: Philadelphia, PA.

Young SL, Ensing DS. 1999. Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal* **22**: 219–231.