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***A WEB BASED PEER REVIEWED PUBLICATION FOR MENTAL HEALTH  
PRACTITIONERS, CONSUMERS & APPLIED RESEARCHERS***

This private *NON-PROFIT* professional publication and associated web-based, information archive service is dedicated to the enhancement of practice, program development, program evaluation and innovations in mental health and substance abuse treatment programs worldwide. Its goal is to provide a public forum for practitioners, consumers and researchers to address the multiple service needs of patients and families and help determine what works, for whom under a variety of circumstances.

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# A Vision and Mission for Peer Support- Stakeholder Perspectives

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**Abstract**

Peer support has been described as a key component to the recovery process of mental illness (Mead & Copeland, 2000); a message that mental health consumer groups have been highlighting since the 1970s (Petr, Holtquist & Martin, 2000). Peer support has been defined as a form of social network therapy in which stigmatized persons interact with each other, feel self-acceptance, and strive to be valued members of a community (Schubert & Borkman, 1991). This paper describes the process that the Canadian Mental Health Association (CMHA)- Metropolitan Branch initiated to decrease social isolation through peer support for consumers within the agency. The process began with a systematic literature review of different models of peer support. It also incorporated interviews with key stakeholders that described a vision, mission, gaps, and future direction for peer support.

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**Introduction**

In 1997, the Canadian Mental Health Association conducted consumer satisfaction surveys that attempted to capture consumers' perspectives on issues that were important in their recovery process and how CMHA was addressing them. One of the primary themes that arose from these surveys was that consumers felt that what was critical to their health was "a job, a home, and a friend". Consumers pointed out that CMHA was providing sufficient resources to acquire the first two, but that opportunities for social interaction through peer support were lacking.

The purpose of this article is to describe the first steps to augment peer support at CMHA. To achieve this, the writers completed a literature review and interviewed consumers who have provided peer support formally or informally as well as professionals who manage and facilitate mutual support services. The results revealed a framework that can facilitate a better understanding of peer support and lead to enhanced opportunities for consumers.

**Background Literature**

The writers began with a literature search that resulted in 48 articles to answer the questions: What is social network therapy?; How is social network therapy helpful, if it is?; How can existing resources (i.e. staff) be used to assist

clients to connect with each other socially to provide peer support?; And how is the effectiveness of social support therapy evaluated?

A systematic review of the articles reveals that peer support is a form of social network therapy where advice and support on "community survival" and advocacy occurs (Carling, 1995). There are three (3) different approaches in which peer support is used for those with severe mental illness: a) mutual support groups- voluntary, informal (often drop-in) groups led by peers for a specific condition or life transition; b) consumer-run services- peers as paid employees of a program that cultivate a consistent and regular interaction with peers; c) employment of consumers as mental health providers within clinical and rehabilitative settings (Davidson, et al, 1999).

Though past research findings are limited due to the lack of rigor in their methodologies, significant gains have been described by participants of groups offering peer support in areas of: self-esteem, better decision-making skills, improved social functioning, decreased psychiatric symptoms (i.e. decreased rates or lengths of hospitalization), lower rates of isolation, larger social networks, increased support seeking, and greater pursuit of educational goals and employment (Davison et al, 1999; Humphreys & Rappaport, 1994; Froland, et al, 2000).

Despite the potential gains of peer support, only a minority of consumers with severe mental illness, that is, up to one third of individuals, participate in activities offering mutual support. In fact, participation appears to be related to "person-environment fit rather than universal appeal" (Davidson, et al, 1999, pg. 168). A significant contributor to this phenomenon includes the attitudes of mental health professionals toward mutual support services. Many are reluctant to refer their clients and even perceive them as potentially detrimental to their overall functioning (Goldman & Lefley, 1991). Clearly, partnerships struck between professional and peer support services are necessary for the peer support role to have a substantial effect on the majority of mental health consumers (Davidson, et al, 1999). Furthermore, due to low utilization and high attrition, it is clear that "mutual support groups alone, and in their current form, do not constitute a sufficient strategy to ensure opportunities for peer support and access to effective role models for person with serious mental illness" (Davidson, et al, 1999, pg. 186).

### **Stakeholder Interviews**

Having completed the literature review, the next step was to interview stakeholders currently delivering or having had experience with peer support services to give further direction to CMHA. A sample of 15 internal and external stakeholders (consumers, consumer groups, and agencies) was interviewed from CMHA- Metropolitan Branch and within Southwestern Ontario. The interviews were conducted in person or by phone and took anywhere between 30 minutes to one hour to complete.

#### **Consumers were asked:**

- 1) What does peer support mean to you?
- 2) What are the benefits and challenges of peer support?
- 3) Given your experience, what models or ways would you like peer support to be occurring at CMHA?

#### **Agencies were asked:**

- 1) Can you describe your model of peer support?
- 2) How do you evaluate your service?
- 3) What are the benefits and challenges you face in your service?
- 4) Given your experience, what would you recommend to CMHA to enhance opportunities for peer support?
- 5) How would you like to see the future of peer support progressing? The responses of the semi-structured interviews were recorded with pen and paper or tape recorded if given permission. All the results were read and discussed by both interviewers to identify themes.

### **Results of Stakeholder Interviews**

The responses clearly demonstrated that there is not one common vision and mission for peer support services. In

addition, results identified a need to empower peer support as a valuable resource alongside more familiar and conventional public mental health services. Responses also reinforced barriers to participation in peer support activities including transportation, lack of childcare, limited time and income.

### **A Vision for Peer Support Services**

Paul Reeve, The Executive Director of Mutual Aid Psychiatric Survivors in Guelph, Ontario, described a vision of peer support that depicts people along a dynamic continuum of wellness and involvement in their community. He stated: "Every person with or without a mental health/ emotional problem is capable and worthy of being a contributing citizen in his/her community. A citizen is someone who can participate in activities that they choose." To understand this vision, one must then evaluate the degree that a peer support service is assisting to "integrate, not segregate, a person within the community. If there is movement towards wellness and community integration, this is the ultimate measure of success." Towards this end, peer support services should not become an "extension of the formal mental health system, but provide 'non-prescriptive' care for anyone to assist in resolving their problems." In the words of Karen Nusbaum of the Mood Disorders Association of Ontario, "peer support does not recommend treatment options or give 'medical advice,' nor does it replace therapy. It complements existing supports and services and can serve as a tool to advocate on behalf of people to enable them to have enhanced quality of life in their community."

### **The Mission and Values of Peer Support**

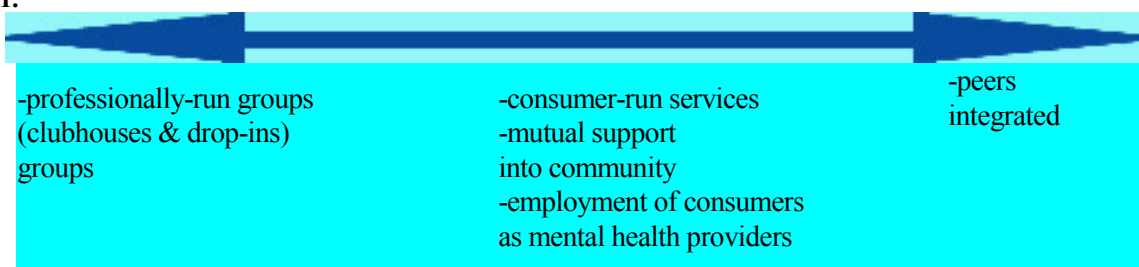
The mission and values of peer support were articulated throughout the dialogues with stakeholders and sometimes formally within pamphlets/ flyers of various agencies. Common themes emerged:

- To foster self-help
- To foster independence amongst peers who enable each other by sharing similar issues and experiences
- To encourage or role model ways to reach personal goals ( i.e. "you can compare your experiences with others and see others doing well")
- To create a physical space that members feel ownership
- To provide a non-threatening, non-judgmental, confidential, safe, and friendly environment where people can come to socialize and overcome the isolation of mental illness ( i.e. "makes you feel like you are not alone," "a place where you can be yourself," "know that somebody cares")
- To be responsible and accountable to other members
- To create a place where members have choice of activities
- To make connections to other people who may become friends, i.e., "can make friends and go outside of group with them"
- To improve consumers' ability to deal with mental illness ( i.e. "helps people become more active and leads to better mental health," "reduces depression," "helps concentration at work knowing you have a place to talk to others after work")
- To encourage leadership roles/ skills amongst members, i.e., "members helps other members learn different skills, like cooking or social skills to get along with others," "to learn to resolve conflicts"
- To strengthen and support people and their families in their role as caregivers
- To provide education and information about resources for people with mental health problems, families, professionals, and the public
- To eliminate discrimination and stigma regarding mental/ emotional illness
- To advocate on behalf of people with mental/ emotional problems and their families

The mission and values of peer support were clearly understood by most of the stakeholders. However, how their mission was enacted varied a great deal. In fact, there was some disagreement as to the effectiveness of certain models, such as the "clubhouse or drop-in models." The writers assert that a wide breadth of services is required to "fit" the complex needs of individuals with mental illness. The role of peer support would be to facilitate the integration of consumers as active and valuable members of their community. Within this process, consumers can potentially move in the direction that meets their needs and where different types of peer support would be ideally

accessible and available.

**Figure 1.**





### **Gaps Identified by Stakeholders**

Three (3) gaps were identified by stakeholders that need to be addressed for future of peer support services: (a) leadership (b) funding, and (c) the ability to address a diversity of needs that include ethno cultural and social factors. Leadership amongst consumers is repeatedly identified as a priority and includes the need for: mentorship for consumers, group facilitation training, peer outreach, greater control over coordination and planning of activities, advocacy, education outreach for consumers, their families, professionals, and the public, and assistance in helping others start peer support services.

Funding is needed to facilitate outreach, training, education, and resources. It is also needed to breakdown some of the barriers to participation that have been described above (i.e. accessibility, limited income, childcare).

The challenge of meeting ethnic and cultural diversity is of paramount importance when Toronto and Greater Toronto is recognized as one of the most diverse cities in all of North America.

### **Future Direction for Peer Support Services**

In accordance with the results of the literature review, the majority of stakeholders concur that there is a need to strike partnerships between professional and peer support services. All stakeholders emphasized to avoid duplication of services, that is, "know your community and develop joint ventures". The involvement of consumers in the planning of services was also highlighted. As Marnie Shepard of the Ontario Peer Initiative stated: "true peer support means there is not an 'expert' and a 'client that define what people are doing." Partnership models suggested between CMHA and other agencies were ones whereby opportunities for peer support could be enhanced by: facilitating training and participation of consumers within leadership roles, seeking and coordinating referrals between different agencies on a regular basis, providing reciprocal consultation, networking, assisting with evaluation of services, outreach, and the development of a central referral service with a web-site for resource information.

All stakeholders supported giving consumers the opportunity and training to serve on committees or within specific jobs as peer workers. Some felt that consumers needed to be remunerated for their training and work to avoid, as one person put it, "the exploitation" of knowledge and experience of consumers.

If there was a partnership between peer support services and CMHA, one organization strongly felt, and literature supports (Wintersteen & Young, 1998), that the facilitative role of CMHA would be temporary. This would promote opportunity and self-actualization for consumers who could divest from the formal sponsoring organization (at a mutually agreed upon time) and ultimately become autonomous.

### **Perspectives from CMHA Consumers**

The internal stakeholders of CMHA (staff and consumers) were the main sources asked to brainstorm ways to enhance peer support. The needs were twofold: to focus on enhancing individual skills to cope with illness and everyday life and to have existing peer support services become more accessible and practical.

#### **Specific suggestions included:**

- train consumers to give telephone support to others peers
- train consumers to lead support groups three to five times a week
- train consumers to give first aid and CPR, craft skills, etc. "anything that would help other consumers to deal with daily life"
- have a health and wellness group that has open topics about disabilities, exercise, nutrition, etc.
- have a business group and space with access to a computer, the internet, a fax machine, a telephone, and assistance to learn how to write resumes or budget their finances
- have a supplementary food bank and clothing depot for consumers of CMHA

#### **To improve existing peer support activities, consumers requested:**

- have professional support and consultation to assist with setting up and running groups

- have recreational activities coordinated and planned by a board of members to give a variety of choice coming from the membership
- encourage responsibility and accountability to other members during group activities, e.g. to use a nominal fee for attendance or to encourage a policy of (apart from illness) "three strikes and you're out"
- encourage social activities outside the walls and boundaries of designated spaces with communication boards or an exchange of telephone numbers to allow informal social activities to occur
- have a comfortable place where one could drop-in during the day and that is wheelchair accessible
- have a mentorship or "buddy" program where trained volunteers give support and encourage social and practical daily living skills to mental health consumers
- expand existing peer support services to have more space and capacity for recreational activities

### **Perspectives from Peer Support Agencies**

Stakeholders voiced similar challenges in facilitating social connections amongst peers. Leadership needs to be flexible amongst consumers. For example, they may have to be relieved of duties if they fall ill, and a roster of trained consumers needs to be readily available on-call. It may be of interest that Cambridge Self-Help (CASH) is a model of mutual support services that has successfully overcome this challenge by hiring four (4) part-time staff to provide consistent and reliable leadership around social and recreational activities.

A common challenge is how to get members excited and motivated to attend when often apathy and an internalized stigma are present. However, once consumers participate, there is then the challenge of retention as well as "letting go" towards integration into the community. It was interesting to note that several stakeholders identified a sub-culture of people who work within mental health programs or experience mental illness, that foster the assumption that people with mental illness "can only hang out with other people with mental illness." One consumer, in particular articulated his struggle to "free himself" from this sub-culture and be "around non-judgmental, 'normal' people." As Paul Reeve stated, "the challenge is the degree in which we foster consumers' capability within an enabling role, as opposed to a disabling one".

Finally, the evaluation of peer support initiatives was daunting for all stakeholders without support resources to facilitate this. All agreed that a combination of qualitative and quantitative methods are necessary to establish effectiveness and efficiency of resources.

### **Discussion**

The writers assert the need for a framework for peer support that has a clear vision that is flexible to the needs of the diverse community in which it serves. The challenge for many public mental health agencies will be to negotiate common ground for a vision and mission of peer support that complements their existing beliefs and pedagogy. As traditional mental health staff training does not include the importance of peer support, it may be necessary to include a variety of strategies to allow staff of C CMHA to learn and engage with self-help groups and their philosophy of care. According to literature, experiential learning opportunities need to be expanded to include more direct involvement or linkage with self-help groups and greater preparation for the roles of partner and consultant (Stewart, 1990). It is imperative that administrative leaders and clinical opinion leaders support a common vision and mission that value peer support. With this support, informal leaders or "internal champions" may be encouraged to support consumers to participate on advisory boards. Furthermore, they may encourage colleagues to develop skills to participate in research and continued education regarding the impact of mutual aid and its benefits and challenges.

Despite the lack of rigorous evaluative research about peer support, the writers suggest that the different types of peer support have varied success and individual worth because they are based on people that are just as complex and unique. Therefore, we contend that as much flexibility and opportunities need to be available to allow consumers to make choices about the "best fit" between peer support services and their needs. With collaborative research that evaluates the effectiveness, the questions related to "What makes people join or drop out of groups?" and "How can we make mutual aid therapy more accessible and acceptable to consumers?" will be answered.

## Conclusions

Based on our literature review and the interviews with stakeholders, the writers suggest CMHA embark on partnerships that will work toward a dynamic and comprehensive plan for peer support. Through sharing, coordinating, and complimenting work with other services, CMHA can offer consumers practical and accessible peer support services that contribute to fulfillment and self-actualization.

Finally, the writers would like to acknowledge and thank all the stakeholders interviewed for contributing to this summary with their ideas, education, and personal and professional experiences.

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# Support Needs of People with Mental Illness in Vocational Rehabilitation Programs -The Role of the Social Network

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## **Abstract**

This paper reports on a study of the social networks of people with mental illness who participated in a vocational rehabilitation program to gain employment. The study found that social networks were critical to employment outcomes. Furthermore the study challenged existing assumptions about the social network characteristics of this group, revealing that family networks, despite their limitations, have valuable resources to offer for the success of rehabilitation programs.

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## **Introduction**

The shift in the locus of care from mental institutions to the community in the last three decades has significantly changed the life conditions of people with mental illness. Though many of the needs of people with mental illness have yet to be met by the community mental health system, major innovations have been made in the areas of community treatment and rehabilitation. These programs are aimed at enhancing the skills and supports of people with mental illness and promote their reintegration into community life.

Paid work in open employment settings is now being increasingly viewed as one of the ways of helping people who have recovered from mental illness to participate more fully in community life, improve their standard of living and reduce their dependence on income support. The last few decades have therefore seen a surge in the development and implementation of a variety of vocational rehabilitation approaches to prepare people with mental illness for employment. Research suggests that these approaches have achieved only limited success in

moving people into open employment (Lehman, 1995; Marrone, 1995). The latest approach is Supported Employment (SE) where clients are placed directly in integrated work settings at award wages and provided with training and support. Advocates of SE claim that this approach has been the most effective so far in helping people to progress into open employment (Bond, et al, 1997). Research however shows that even with this approach between 41% and 77% of clients terminate their supported employment positions within 6 months (Gervey et al, 1995; Becker et al, 1996).

Several explanations have been offered for the poor employment outcomes of people with mental illness. While some writers have claimed that people with mental illness are ill prepared for employment by education, work skills and work experience, others have ascribed to myths that symptoms make these individuals too unstable to undertake work (Akabas, 1994; Cohen, 1990; Black, 1988). In keeping with these assumptions most vocational rehabilitation programs have directed their resources largely towards improving the work competence of people with mental illness through various training and placement support activities. This primary focus however has reflected interest away from an important factor that can have a significant role in influencing employment outcomes. This is the mentally ill person's social support network. Though vocational rehabilitation literature has acknowledged the importance of this network for successful employment outcomes (Storey and Certo, 1996; Danley, 1992), there is little information on the social networks of people who have recovered from mental illness and are participating in rehabilitation programs to gain employment.

Over the years a considerable body of literature has accumulated on the social networks of people with mental illness. This data suggests that the networks of people with mental illness are dominated by family members and that the mentally ill individual establishes dependent, non-reciprocal relationships with network members (Rosenfield & Wenzel, 1997). Studies have shown that such networks are positively related to pathology and rehospitalisation among ex psychiatric patients (Holmes-Eber and Riger, 1990). Expressed Emotion studies have suggested that the family's attitudes (hostility, criticism, or emotional overinvolvement) towards their mentally ill relative may lead to relapse and rehospitalisation (Leff and Vaughn, 1985). Family burden studies have highlighted the stress involved in providing ongoing care to the mentally ill relative and that often this care is provided under the most difficult conditions (Hatfield, 1997, Lefley, 1995). While it is clear that social networks, particularly family networks of people with mental illness play a significant role in the course and outcome of their relative's illness, their specific contribution to recovery and rehabilitation programs remains largely unclear.

Furthermore, research on the social networks of people with mental illness has several limitations. Firstly much of the research evidence is based on the self- report of hospitalised populations of the mentally ill and network assessments taken during hospitalisations are likely be biased due to contamination of assessments by the symptoms and mood experienced by people during these periods. Secondly, the onset of mental illness and subsequent hospitalisation is a crisis for the person and their network members (Hatfield, 1997). This crisis can generate feelings of hostility, fear and embarrassment for network members leading to a decrease in network support during such periods. Thirdly much of the research evidence is based on cross sectional studies that have investigated people (and their networks) only at a single point in time. Assessments taken at a single point in time cannot be generalised across different time periods because people (and their networks) can change during the process of recovery from the illness. Studies that have investigated how people with mental illness function over time suggest that many of them can achieve long term recoveries and that as people recover they can learn to adapt and develop supportive networks (Thornicroft et al, 1995). Lastly a significant limitation of research on social networks is that it has focused on their structural aspects such as size and composition and does not address the quality of network relationships and the kinds of support provided by networks members.

The limitations of research and the lack of information on the social networks of people with mental illness who have recovered and are participating in vocational programs to gain employment, can severely restrict the ability of professionals to access the valuable resources that these networks may be able to provide. It can also limit the ability of professionals to determine the nature, level and combinations of support participants in employment

programs will need to achieve successful employment outcomes. Additionally in the current climate of funding cuts and increasing caseloads of mental health and vocational rehabilitation staff, their capacity to provide the level of ongoing support that may be needed for people with mental illness to be successful in employment is unclear. As pointed out by several writers (Carling, 1995; Lefley, 1993) establishing partnerships with social networks, particularly with significant family members, can only improve the capacity of professionals to provide effective support and improve rehabilitation outcomes.

In the context of the above discussion the purpose of the current study is to examine the network characteristics of people with mental illness participating in employment programs. This study differs from previous studies in the field of vocational rehabilitation in a number of ways. Firstly the current study collected data only from persons with mental illness who had identified open employment as their vocational goal and were participating in a community based vocational rehabilitation program to achieve that goal. Secondly all the participants in this study were residing in the community and their illness had stabilised at the time of their entry into the vocational program.

The specific questions that the study addressed were:

- What are the characteristics of the social networks of people with mental illness in a community based vocational rehabilitation program for open employment?
- Do people with mental illness who gain employment differ in their social support characteristics, from those who do not gain employment?
- Did participants experience changes in their network characteristics as they moved from program intake to program closure?

### **Methods and measures**

The data on which this paper is based was collected as part of a larger study that investigated the work skills, work history, social networks and ongoing health related difficulties of people with a major mental illness who participated in a vocational rehabilitation program for open employment.

Sixty-five clients of the CRS Specialist Services (one of the largest providers of vocational rehabilitation services for people with mental illness in Sydney, Australia) who had been accepted on vocational rehabilitation programs were interviewed at different points during the course of their vocational programs. The treating professionals had certified that these respondents were well enough to participate in the vocational program. The sampling strategy used was purposive sampling, a procedure that is often used in exploratory and field research, and allows the researcher to gather in depth information on specific issues relevant to the study (Neuman, 2000:198). The respondents were first interviewed when they commenced their programs (T1). The purpose of these interviews was to gather information on their social support characteristics, and sociodemographic factors such as age, education and diagnosis. The respondents were again interviewed at the time of program closure (T2).

The purpose of these interviews was to gather information on their experience of their programs and record any changes in their support characteristics. Since most of these interviews were carried out in the respondents' homes it provided the opportunity to record some of the comments of their relatives. Employers who offered work-training placements to respondents were interviewed to obtain information on their work skills and behaviours. In order to address the research questions the respondents were sorted into groups according to the outcome-those who gained employment and those who did not (and those who sustained employment and those who did not).

Information on sociodemographic factors such as age, sex, gender, education and diagnosis was gathered from the files of the respondents. The social support measures used in this study included a social network map, a social support grid and a social support questionnaire. These were adapted from the measures used by Whittaker, Tracy and Marckworth (1989) as part of a Family Support Project. The advantage of the network map was that it



displayed the network and network memberships visually. Thus the total size and the composition of the network with respect to seven domains, namely household (people with whom you live), family and relatives, friends and work colleagues, people from clubs and church, neighbours, and formal services such as doctors, psychiatrist, mental health professionals, were displayed on the map. The map could be employed again at the end of the respondent's program to indicate changes in network size and composition.

Since the map by itself would reveal little information about the relationships in the network, an accompanying support questionnaire and network grid to record responses about the functions of the network, (such as, who provided what types of support), were included. The support questionnaire also included questions related to stability of relationships, frequency of contact with network members, critical relationships, close relationships and reciprocal exchanges with network members.

### *Analysis*

Since quantitative and qualitative data were obtained from respondents the analysis of both kinds of data were used. The first research question was concerned with examining the social support characteristics of the respondents using the information gathered from the questionnaires at T1 and T2. This was carried out by using descriptive statistics particularly means and standard deviation. The size of each respondent's network was determined by adding the network members in all the domains. Adding the network members in each domain and then dividing this by the total number of members in the whole network calculated the proportion of network members in each domain. To examine the support availability for the respondents in each support item the proportion of network members available for providing each item of support was calculated.

The second and third research questions were concerned with comparing the two groups of respondents (those who gained employment and those who did not) on their social network characteristics. For this purpose the analysis of variance (ANOVA) using the 't test' (or f test) for continuous variables was used. In the case of categorical variables, the relationships were examined using contingency tables and the chi square test. Correlation analysis was used to examine the strength of the relationship between the social network characteristics and employment outcome. Since the dependent variable in this study was categorical and dichotomous the point biserial correlation coefficient was used. This is a product moment correlation coefficient and it gives the degree to which the continuous independent variables discriminate between the two categories of the dichotomous dependent variable.

Qualitative data on the perceptions and experiences of the respondents of their networks and vocational programs was recorded verbatim on their interview schedules. This data was then used to add strength and context to the quantitative data.

## **Results:**

### *Sociodemographic characteristics*

The mean age of the whole sample was 31.5 years (range 18-55) and the majority of the respondents (42) were male. Schizophrenia was the most common diagnosis (37), followed by Major Depression (11), Bipolar Illness (9) and Anxiety Disorders including Obsessive Compulsive disorder (8). Thirty-eight respondents had year 10 qualifications, 18 had HSC level qualifications and 9 had degree qualifications. The majority (46) of the respondents had been unemployed for more than 2 years.

All, except one respondent, had worked in open employment prior to their entry into the vocational program. The majority of the respondents (48) had experienced difficulties maintaining open employment right from the beginning of their working career. These included pressure to meet deadlines and keep up with co-workers, feelings of lack of support from supervisors and co-workers and boredom resulting from repetitive jobs.

### *Assessing network characteristics*

Network size and composition were assessed by asking the respondents to name important people in their lives with whom they had regular contact. The names of these persons were recorded in the appropriate section of the

network map described earlier. The respondents reported a mean network size of 9.89 (sd=2.27) members at intake into the program and 9.21 (sd=2.62) at closure. Most respondents mentioned their immediate family members, friends, and their treating professionals as significant people in their lives.

Family members comprised by far the largest proportion of the respondents' primary networks (46% to 55%), at both time periods. The next largest component comprised treatment professionals (30%) who included primarily treating doctors and mental health casemanagers. This finding provides evidence of the important role played by these professionals in the lives of the respondents during the recovery phase. Friends comprised 15% to 20% of the network at both time periods. Forty-four respondents mentioned at least one friend in their network. The proportion of community members and neighbours in the networks was minimal (0.045 or 4%).

The majority of respondents (41) lived with their families. Of the remaining respondents, all except 3, maintained regular face to face or telephone contact with their family members. A significant finding was that respondents perceived their family members as largely supportive although some members were reported to be critical and hostile at times. The majority of the respondents (60) perceived that they had reciprocal relationships with their family members and friends. Thus respondents perceived themselves to be playing useful roles within their networks rather than always taking on the role of the 'helpee'.

Contact with treating professionals was, on an average, fortnightly to monthly. There was stability in the networks of these respondents. There was a primary core of significant network members who had remained in the network and who had been known for more than three years. This primary core comprised about 70% of the entire network and included members of their immediate family, some long lasting friendships and treating professionals particularly private psychiatrists, general practitioners and casemanagers from mental health services.

The perception of closeness to members of a social network can in itself reduce feelings of isolation and insecurity and enhance feelings of integration and well being. Asking respondents to name people in their networks to whom they felt close assessed the availability of close ties. Except for 2, all the respondents in this study named at least one network member to whom they felt close. The network members most frequently mentioned as close were family members especially partners, mothers, sisters, children and sometimes friends. Some respondents also felt close to their treating

professionals if they were long standing relationships. However close ties though largely supportive would be sometimes critical and exhibit overinvolved and overprotective behaviours from time to time.

*This was illustrated by the following cases:*

Larry had a bipolar illness for several years. He was a qualified tradesman and had worked for many years. He had also suffered several relapses during the course of his working career. He was married and lived with his wife and children. He said, 'I feel close to my wife, she is always there when I am sick. She is comforting and supportive. But she can also be very critical. I can't stand it when she puts me down in front of her brother. Because of this I cannot fully confide in her about everything. There are some things I discuss only with my sister's husband. I feel close to him as well'.

Josefina was 25 years old and lived with her mother and her older sister. She was from a Greek background but Josefina and her sister had been born and brought up in Australia. Josefina had schizophrenia and was on the disability support pension. She reported that she was very close to her sister. Josefina's sister who later joined the interview was very keen to know every aspect of her program. She seemed to be involved in every aspect of Josefina's life. She said, 'Josefina has this illness and is not capable of taking any decisions. She tells me everything and must consult me before doing anything'. During the interview her sister was also very critical of Josefina. She brought up all her failures at work. She also expressed her genuine concern for Josefina's future and wanted her to get a job.

Despite the critical and overinvolved attitudes exhibited by close ties both these respondents perceived that their closeness had not diminished because they still provided supportive resources that were of great value. Both respondents were confident that they could always rely on their close ties when they experienced problems. Thus it appears that supportive resources such as security, stability and feelings of belongingness that these close ties provided (or enhanced) may have compensated for some of their negative characteristics. In fact these perceptions may have maintained the recovered state of these respondents. This is a significant finding because it suggests that social networks that display critical, overinvolved or intrusive behaviours may still be supportive.

*Assessing support availability and comparing the network characteristics and support availability of the employed and unemployed groups.*

Support availability refers to the different kinds of supportive resources that flow through the members in the network. This was broadly classified into 4 main areas, namely, concrete support, instrumental support, emotional support and vocational support. Respondents were firstly asked if the different kinds of support were available to them from their networks. Then they were asked to indicate the extent to which each network member could be relied on to provide each kind of support. Table 1 provides information on the kinds of support that respondents perceived their networks could provide. Respondents said that they could rely on their family members and in some cases friends for concrete support. They perceived that family members, friends and treating professionals could be relied on to provide some forms of emotional support particularly comfort and encouragement. Some respondents, who gained employment expressed that they could rely on their work colleagues and supervisors for work related advice, encouragement and support.

Confidante support is an important aspect of emotional support. Item 4 in table 1 was used to assess the availability of this support. Providers of confidante support were usually partners, close friends and in some cases treating professionals. Parents were frequently perceived as confidantes in the case of younger female respondents.

**Table 1 Support availability for the two groups at T1 (n=65)**

Nature of support	Proportion of network available	
	EMPLOYED	UNEMPLOYED
Drive you to the doctor if needed	0.16 (16%) sd =0.17	0.16 (16%) sd = 0.14
Loan you money if needed	0.14 (14%) sd =0.08	0.16 (16%) sd =0.11
Comfort you if you are upset or feeling down	0.19 (19%) sd =0.11	0.19 (19%) sd = 0.15
Listen to you talk about your problems without being critical	0.21 (26%) ** sd = 0.11	0.14 (14%) ** sd =0.12
Give you appreciation and encouragement	0.22 (22%) sd = 0.12	0.24 (24%) sd = 0.14
Help you cope with the illness or relapse	0.21(21%) sd =0.10	0.20 (20%) sd = 0.12
Help you make a major decision	0.17 (17%) sd = 0.11	0.17 (17%) sd = 0.15
Give you information on job openings	0.12 (12 %) sd = 0.09	0.12 (12%) sd = 0.10
Suggest some actions you should take to help you progress in your career	0.15 (15%) sd = 0.11	0.14 (14%) sd = 0.11
Suggest ways to cope with stressful situations at work	0.21 (21%)* sd = 0.09	0.13 (13%)* sd = 0.11
Liaise with your employer if you are experiencing some difficulties at work	0.12 (12%)* sd = 0.08	0.08 (7.9%)* sd = 0.8
Make job contacts for you	0.12 (11%)* sd = 0.09	0.06 (6.2%)* sd = 0.08

Asterisks indicate significance \*p<0.02; \*\*P<0.001

Table 1 also illustrates the differences between the 2 groups with respect to support availability. Both groups perceived that their networks were capable of providing various kinds of support. However the significantly higher levels of confidante support and vocational support available to the employed group suggests that people in vocational rehabilitation programs whose networks have the capacity to provide these specific kinds of supports may have better employment outcomes.

**Table 2 Network composition at intake (n=65) and at closure (n=62)**

	T1 Employed	Unemployed	T2 Employed	Unemployed
Network size	10.31 0.46 (46%)	9.45 0.47 (47%)	10.06 0.47 (47%)	8.18 0.55* (55%)
Proportion of family members in network				
Proportion of friends in network	0.19 (19%)	0.13* (13%)	0.15 (15%)	0.15 (15%)
Proportion of mental health professionals in network	0.30 (30%)	0.31 (31%)	0.22 (22%)	0.24 (24%)
Proportion of workmates in network	0	0	0.15 (15%)	0
Proportion of others in network	0.03 (3%)	0.06 (6%)	0	0.05 (5%)
Close ties	0.268* (27%)	0.148 (15%)	0.29** (29%)	0.17 (17%)

\*p&lt;0.01, \*\*p&lt;0.001

Table 2 shows the differences in the network characteristics of the employed and unemployed groups. Though the groups did not differ significantly in network size and composition, both at the time of intake and closure of the program, the networks of the employed group had significantly higher proportion of friends ( $p<0.05$ ) and close ties in their networks at both time periods ( $p<0.01$  at T1;  $p<0.001$  at T2). Contrary to expectations the network size of the employed group did not increase significantly at the time of closure of their programs despite the fact that they were now working. This was mainly because friends and mental health professionals had been substituted by work colleagues, supervisors and ongoing employment support providers, who could now be relied on to provide various kinds of support. The family network had remained largely the same. Thus work had provided the opportunity for these respondents to diversify the scope of their network though the overall network size remained the same.

The group that remained unemployed on the other hand experienced a marginal decrease in their network size at the time of program closure. This was mainly due to the exit from their network of some of the shorter term treating professionals. Respondents perceived that these professionals no longer played a significant role in their lives and therefore dropped them from their significant network. Many of these respondents, especially those who had experienced relapse and hospitalisation during the course of their programs, reported more family members in their networks at the time of closure. Thus for this group their dependence on family members had increased. The changes in network composition reflect the temporal nature of networks and network

relationships and suggest that networks and network relationships may change in keeping with the needs of the person and their situation.

**Table 3 Correlations between employment outcome and network structure variables**

Networks characteristics	point biserial correlation coefficient
Network size	0.18
Proportion of family	0.03
Proportion of friends	0.23**
Proportion of mental health professional	0.06
Proportion of close relationships	0.36***

The asterisks indicate that the correlations are significant.

\*\*\* $P < 0.001$

\*\* $P < 0.05$

Table 3 highlights the correlations between network structure variables and employment outcome. The findings suggest that people in vocational rehabilitation programs who have more friends and close relationships in their networks have a greater likelihood of achieving positive employment outcomes. They also suggest that the perceived supportiveness of the network and the kinds of support available to people from the network may be more important than network size in influencing vocational outcomes.

### **Influence of the family on the course of the program**

There is accumulating evidence that the people with whom the individual lives or interacts on a regular basis has a significant influence on their rehabilitation outcomes (Lefley, 1997; Hatfield, 1997). Although most respondents expressed that their families were supportive towards them, the interviews suggested that not all families were as supportive of the individual's goals to return to work. While some family members were able to play a key role in keeping their relative motivated to work, there were others who were clearly overburdened with their caring role or were very anxious that their relative would have a relapse if they returned to work. Many carers had little support, felt very isolated and were possibly exhausted and drained after several years of caring. The anxieties and burden experienced by family carers is illustrated by the following cases:

Linda was thirty years old, had schizoaffective illness and continued to live with her mother. Linda's mother had this to say about Linda :

Linda cannot cope with work. Each time she starts working she becomes sick and has to be hospitalised. I have to then manage Jessie (Linda's daughter) and the house work all on my own. The community centre people only show up when Linda becomes sick and needs to be hospitalised. Work is too stressful for Linda and she has only me to complain to. I am getting old and tired and cannot carry on like this. I wish Linda would stop looking for work and stay home.

Joe, a person from a Croatian background, was 35 years old, had schizophrenia and lived with his elderly parents. Joe's mother said: If going to work will make Joe sick again, we prefer that he stay at home. We have

put in a lot of effort to keep him well and don't want this to be disturbed by you people. Joe also loses his dole when he goes for work. They (Social Security Office) are too much trouble.

There were also family networks that wanted their mentally ill relative to work but had no resources in the form of knowledge or contacts to help them. They were totally reliant on professional support to help the relative find work. Some family networks were apprehensive about their relative's ability to cope with the stress of work. There were also family networks that were keen that their relative should work but wanted them to work only in areas that were in keeping with their family values. This was evident in the case of Peter who had schizophrenia and was placed in a hospital laundry for work training. Peter said after one week of training: I am not used to washing dirty clothes. My parents don't want me to do such jobs. My brother is training to be a doctor. I prefer to work in a laboratory.

Peter subsequently enrolled in a 2-year course in laboratory studies. He had significant difficulties in the areas of attention and concentration and could find it difficult to gain employment as a laboratory technician.

### **Discussion**

This study set out to examine the social network characteristics and the role of the network in shaping employment outcomes of people with mental illness participating in a vocational rehabilitation program to gain employment. So far there is little information on the network characteristics of these individuals. The available literature that is largely based on hospitalised populations and data collected at a single point in time has assumed that the networks are small, family dominated and lacking in support. The family network in particular is portrayed as a source of stress for the person. The results of this study clearly demonstrate that this is not the case. They suggest that family dominated networks can be supportive and provide valuable resources that can enhance rehabilitation outcomes.

Current findings that the networks of the respondents in this study were larger than some previous studies (Holmes-Eber and Riger 1990), had a degree of stability and that respondents perceived themselves as playing useful roles within their network suggest that these characteristics may be due to the recovered state of the respondents. It is likely that during the process of recovery from mental illness and as people experience fewer and shorter hospital stays they are able to expand their network, assume significant roles within their networks and give them a degree of stability.

In keeping with previous research family members dominated the network and most respondents lived with their families. However the finding that the family network was supportive and not hostile or stress provoking as indicated by previous studies could be attributed to the recovered state of the respondents. Though the experience of mental illness is traumatic for both the individual and their relatives and can invoke fear, hostility, and distress on both sides, these feelings may subside during the course of recovery and as both sides learn to accept, cope and adjust to the illness. These findings also suggest that networks and network relationships of people with mental illness are not fixed, and can change, depending on the stage of the illness and the needs of the individual at that point in time. Thus assumptions about networks of people with mental illness may be more valid if they are based on longitudinal rather than cross sectional research.

The literature has also assumed that the size of the network is an indication of its support availability. Contrary to previous findings, network size in this study was neither related to support availability nor rehabilitation outcome. These findings are significant because they suggest that the functional characteristics of networks such as the quality of network relationships may be more important than its structural characteristics such as network size in shaping rehabilitation outcomes. The implication of these findings is that network interventions by professionals may be more effective if they are directed towards enhancing the quality of network relations rather than increasing network size.

Present findings provide strong evidence that the closely-knit, family dominated networks of people with mental illness need not necessarily predispose the individual to relapse as indicated by previous research. Since the

majority of the respondents in this study were staying with their families and were also maintaining their recovered state it is likely that their highly interconnected family dominated networks in fact helped to maintain their recovered state. As argued by Wortley (1989), highly interconnected kin dominated networks have their advantages because they may foster an intense social support system, thereby reducing feelings of isolation and decreasing the risk of relapse.

The various kinds of support that the family network provided and the close ties that respondents had established with some of their family members highlight the valuable resources that the family can offer towards achieving rehabilitation goals. The findings also suggest that families were however not always completely effective in providing support. There was evidence of stress, anxiety, carer burden and lack of resources in some networks to provide certain kinds of supports. Some family members, particularly carers, were in need of support and respite. There were others who were supportive of their relative's vocational goals and even encouraged them to participate in the program. However when they had to take independent decisions these families exhibited overprotective attitudes. That the respondents in this study maintained their stable state and valued the support provided by these network members despite their critical and intrusive comments suggests that such attitudes may not always be signs of pathology that lead to relapse and hospitalisation as suggested by previous studies. Instead the intrusive and overprotective attitudes of family members may more likely be a reaction to their anxieties for the well being of their relative, fears of relapse and the associated trauma for the whole family.

The implication of these findings for rehabilitation and mental health service providers is that families play a key role in the recovery process by providing valuable resources and therefore must be involved as partners in the rehabilitation program. The findings also suggest that families experience anxiety and burden even during the recovery stage of their relative's illness, especially when recovery involves milestones such as taking up employment. Hence support to families must be ongoing and cannot stop once the crisis of mental illness has passed. This study provides some evidence of the kinds of on going support that families may need when their relative has recovered and wants to pursue goals such as work. These include periodic respite from the burden of care, education about their relative's capacity for work, alleviation of anxieties regarding relapse and loss of income support benefits if their relative starts working. Supportive family members may also need to be educated on ways to provide some forms of ongoing employment support. They may need advice on areas such as what to say to employers when their relative is sick, recognizing (or being alert to) signs of stress and relapse, and contacting the employment support worker or treatment professional early enough to prevent job loss. Since many people who have recovered from mental illness live with their families (or are dependent on them for various kinds of support) it is likely that providing timely advice and support to significant family members can enhance employment outcomes.

While the family network played a significant role in shaping vocational outcomes, current findings show that mental health treatment providers such as general practitioners, psychiatrists and mental health case managers, who constituted the second largest proportion of the network, were also perceived as serving important emotional and instrumental functions. These findings indicate that for people with mental illness dependence on their treatment professionals may continue even after they have recovered from the illness. Therefore employment outcomes can be enhanced if there is close cooperation between rehabilitation or employment support providers and treatment professionals. Furthermore, the finding that employed respondents included their co-workers and supervisors as part of their significant network suggests that these people also have important resources to offer. However, like family members, they will need ongoing professional support and practical advice on matters such as how to provide workplace support, supervision and reasonable accommodations for the worker with mental illness. The provision of this support however, will depend on whether the worker has disclosed their illness to the employer and the level of professional intervention they want at the workplace.

The findings of the study show that resources flowing through the network are in the form of different kinds of support and that network relationships may acquire significance depending on the kinds of support they provide



to the individual. While different kinds of support are needed by individuals depending on their circumstances and their stage of recovery from mental illness, several studies have shown that the availability of emotional support, particularly, confidante support, can reduce stress and increase psychological well being (Brown and Harris, 1994; Wills, 1985). Thus individuals who have confidante support may be better able to withstand the stress associated gaining and maintaining employment.

The current finding of a significant association between emotional support, particularly confidante support and employment outcome suggests that the availability of this support may have helped in going through the stress of getting and maintaining employment. That emotional support from significant others can significantly influence employment outcomes is supported by a recent study by Rogers et al (1997). Here the authors state "clearly what was needed for people with mental illness in vocational programs was emotional support". The finding that emotional support and vocational support were significantly (though moderately) correlated with employment outcome suggests that the availability of these supports can positively influence employment outcomes. These findings are significant because they suggest the kinds of network support that must be mobilized if people with mental illness have to cope with the demands of open employment.

### **Conclusion**

This study is exploratory and is limited by a small non random sample of 65 clients who were specifically selected to participate in a vocational rehabilitation program for open employment. However the majority of the clients had a major mental illness and had experienced significant difficulties in gaining and sustaining open employment. The findings of this study are important in the light of the current emphasis on preparing people who have recovered from mental illness to gain employment. The results demonstrate the important role that social networks play in shaping rehabilitation outcomes and lend strong support to the argument that if employment is to become a reality for people with mental illness a more holistic approach to rehabilitation of these individuals is needed.

Job training and placement support activities which currently comprise the major part vocational rehabilitation programs for the recovered mentally ill must be complemented by the cultivation of a supportive environment at different levels that can sustain their skills and accommodate their disabilities. Since the family forms the largest part of the network and has several resources to offer, the first level for professional intervention should be directed towards supporting and involving this network. Reluctance on the part of professionals to work with this network due to preconceived notions that families cause or exacerbate mental illness may be one of the reasons for the failure of vocational rehabilitation programs.

From this broader perspective successful employment outcomes for people with mental illness will depend not only on the individual who is seeking employment but also equally on the coordinated efforts of professionals, family members, employers, work colleagues and several organisations.

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# Psychotherapy and Education in Prison with Two Native American Youths

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## Abstract

Educational and psychotherapy experiences are presented for two Native American youths incarcerated in a California Youth Authority prison treatment program. Although both were Native American and were both 16-years old, their personalities were very different, with one being very aggressive and dangerous, and the other being passive, and mostly a threat to himself. Both had educational problems, which were helped somewhat at the ungraded prison school.

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## INTRODUCTION

What do you think of when you think of Native Americans, or of American Indians? Do you have a particular stereotype in mind? This article should help you avoid that, and think of them as individuals, each different from one another, despite also possibly having similar cultural backgrounds. Stereotypes are an integral part of prejudice (Allport, 1954; Lefton & Brannon, 2003), thus we need to learn to avoid or overcome them. Native Americans have many problems in American society, and we need to look at them as individuals and not stereotype them (or any other group), in order best to be able to help them to succeed in life, and assist them with their various problems (Bryant, 1998; Capper, 1990; Deyhle, 1995; Green & Tonnesen, 1991; Hasse & Soldier, 1993; Napier, 1995; Ness, 2002; Ryan & Shanley, 1993; Scott, 1996; Simms, 2000; Tierney & Jun, 2001; Warner, 1991).

For almost two years I worked in a California Youth Authority prison treatment program, working with youthful offenders. Two of these were Native Americans, one I will call Jesse, and the other Ron, both 16-years old. The state requires education for all youths, even those in prison. We had a prison school, where students attended ungraded schools, and teachers worked with them on their individual scholastic problems. Most youths had major deficiencies in educational matters. Most found sitting still in school and following instruction to be very difficult. This was either because they had some kind of neurological problems that made paying attention a major problem, or perhaps due to their anti-social nature, wherein they did not want to do what others told them (especially when it was not fun and exciting). Also, we did psychotherapy with all the youths in the prison treatment program. As Senior Clinical Psychologist, I, along with a full-time psychiatrist, was largely in charge of that, and

helped supervise the therapy as well as have a large psychotherapy caseload of my own. Jesse and Ron presented very different kinds of problems, showing that though they were both American Indians, they were also unique individuals.

## JESSE

Jesse was highly anti-social and violent. During group psychotherapy he would sometimes give me the finger when he thought I was not watching, or throw a ball at the wall or window, almost breaking the window. One of his many offenses was firing a gun at an official who took a dog away from his reservation. When I questioned him about his over-reaction to the dog being taken away, he said, "Animals are sacred to the Indian." I never knew when Jesse might attack me. He seemed totally wrapped up in himself and his needs, and had little or no regard for others. Once, he asked for a book on photography from the prison library. I went and got the book for him. But, I was a little afraid to open the door to his room (our prisoners were in small rooms, not cells), because I thought he might hit me, or try to escape. Also, I was a little reluctant to give him the book, because I feared he might tear it up.

I handled the situation by going to Jesse's room, and explaining, through the glass window, that I was going to open the door to give him the book he wanted, but that he should appreciate I was doing him a favor, and not attack me or try to run outside. Also, I said that he should not tear up the book, as that would result in both him and others not receiving this kind of favor any more. He said, "OK," but I did not know if I could believe him. Fortunately, nothing bad occurred. He went back into his room with the book, and I locked his room back up. Later, the book was returned to the library in good shape.

Like most of our other prisoners, Jesse was difficult to teach at the prison school. I regularly consulted with the teachers there, and found that he--like the others--did not seem to be able to concentrate on anything for any length of time. Thus, learning had to be done in small increments. However, using this individualized approach, Jesse seemed to make some progress in basic areas such as reading and mathematics. These are very important skills to have, to get along in American society. Probably, through individual and group psychotherapy, and through the prison school, some progress was made in getting Jesse to have a little less impulsivity and to learn some basic skills. However, before much could be achieved, or before we could see him as a failure who would not achieve much in our program, he was transferred to another prison, a nontreatment facility. Apparently, someone thought that a brief time in a treatment program would help him. My thought is that he needed much more treatment, and not just being in a regular prison setting, where his anti-social ways will get reinforced by the other prisoners.

## RON

As aggressive as Jesse was, Ron was passive. He said little, and related little to the other prisoners. He mostly spent time with a rather intelligent 16-year old child molester, who was despised by the other prisoners because of his offense. On psychological tests, Ron showed signs of schizophrenia. He had committed many burglaries, which caused him to be committed to the California Youth Authority prison system. He said he wanted to go to prison to get away from his mother. His mother would constantly seduce his male friends and have sexual intercourse with them. Perhaps she, too, was schizophrenic. Anyway, in a desperate attempt to flee that situation, he decided that the only thing he knew how to do was get himself arrested and sent to prison. There should have been interventions earlier with him, to show him other options in his life.

Ron caused no trouble in psychotherapy or in school. However, like Jesse, he was not a fast learner. Perhaps his mental illness got in the way of learning. Ron tried harder than Jesse, though, and also

made progress in improving his reading and mathematics skills. In psychotherapy, he would often sit silent, but would try to answer questions posed to him. He did not actively resist therapy the way Jesse did, but he was not a great therapy client, either. From my experiences, people with severe mental illness--such as schizophrenia or bipolar disorder (manic-depression)--find it very hard to do well in psychotherapy, because they cannot think as rationally or as quickly as the process demands.

Ron was still in the program when I left. You hardly noticed him because he was so quiet and withdrawn. He seemed to be making progress, but it will take a skillful placement to find somewhere that he can prosper, when he leaves the prison.

## PSYCHOTHERAPY

A wide array of psychotherapy is offered to prisoners in this treatment program. All get both individual and group psychotherapy. This psychotherapy follows the style of the person who runs the individual or group psychotherapy session, but tends toward the behavioral or cognitive behavioral, with lots of emphasis on admitting what once did ("admitting one's commitment offense" as they call it at the prison), and figuring out why one did it, and how it can be avoided in the future. Prisoners also receive life planning group psychotherapy, which helps them plan how to live when they get out, e. g., how to apply for, get, and hold a job, etc.

Then, there is additional psychotherapy for special needs, e. g., sex offender treatment for sex offenders or drug psychotherapy for those with substance abuse problems. Of our two Native Americans discussed here, Jesse received drug psychotherapy because of his preprison heavy use, and problems with, alcohol and cocaine. It was in my drug psychotherapy group that Jesse acted out by giving me the finger, and throwing a ball near the window.

Most prisons offer no psychotherapy to their prisoners. As a treatment program, we had a relatively unusual orientation of offering lots of psychotherapy. Of course, psychotherapy is difficult with prisoners, as their extreme antisocial orientation, and their impulsive and nonreflective ways of being, make them difficult therapy candidates. Most probably get little out of psychotherapy, but a small percentage is perhaps changed. For all those who are changed into being more prosocial, there will be fewer victims. Thus, even a small amount of success in psychotherapy—getting antisocial people to become honest citizens instead of continuing as criminals—is a major benefit to society.

## DIAGNOSTIC CATEGORIES

Here I will explain certain diagnostic classification, that is discussed in this paper. I go by the Diagnostic and Statistical Manual of Mental Disorders-IV-TR, which refers to the 4<sup>th</sup> edition, text revision, of the official manual of mental disorders (American Psychiatric Association, 2000). This is the official legal source for diagnosis of mental disorders in the United States.

Jesse is a conduct disorder, who will, when he becomes 18 years old, probably be diagnosed as an antisocial personality disorder. Ron may well be schizophrenic. Each of these diagnostic terms will be explained.

"Conduct disorder" comes under the heading "Disorders usually first diagnosed in infancy, childhood, or adolescence." It involves repetitive violations of the rights of others, or violation of age-appropriate societal norms or rules (American Psychiatric Association, 2000). There are four main groupings for these behaviors:

- "...aggressive conduct that causes or threatens physical harm to other people or animals..."
- "nonaggressive conduct that causes property loss or damage..."

- "deceitfulness or theft..."
- "and serious violation of rules." (American Psychiatric Association, 2000, p. 94).

The onset can be in childhood or adolescence, although there is also the category of "Unspecified Onset" if the age of onset is unknown.

"Antisocial personality disorder" fits under the category of "Personality Disorders" and involves a pattern of disregard for and violation of the rights of others. One cannot be diagnosed as an antisocial personality disorder until one is 18 years old, since youths are constantly changing in their personality. Other words that have been used for this diagnosis are "psychopath," "sociopath," and "dissocial personality." Antisocial personalities are noted for being deceitful and manipulative, and are often good at getting others to like them, at least initially. They lack empathy for others, and are callous and cynical. They can do the most extreme things with little or no remorse or conscience. They often show an inflated sense of self, and also lack sufficient concern about their current or future problems. The disorder exists in about 3% of males and 1% of females. The person with this disorder often has a lifelong pattern of serious criminal conduct, seeming never to profit from experience or punishment. They are extremely difficult to treat, and some feel there is no sense in doing psychotherapy with them, as it is believed that they will just pretend to go along with the therapist, but will not change.

"Schizophrenia" is classified under "Schizophrenia and other psychotic disorders." There are many subtypes of schizophrenia, but in general the disorder shows delusions (thoughts that are at great variance with reality) or hallucinations (seeing, hearing, or tasting, etc., things that are not there). Some believe that the major symptom of schizophrenia is thought disorder, in which the person cannot think clearly. Thus, the schizophrenic is greatly handicapped in functioning in everyday life, as they have trouble realistically perceiving what is occurring. Also, they often have flat or inappropriate affect, in which they show no feelings or perhaps laugh at things that are not funny.

In all of the above diagnoses, the problem must exist to a certain extent and for a certain period of time before one can be correctly diagnosed. This protects against putting someone in a diagnostic category if they just have one or a few examples of a disorder, but do not show it on a regular, consistent basis.

It should be kept in mind that "mental disorder" or "mental illness" is different than "insanity," which is a legal term, not a psychological or psychiatric term. Insanity usually means that the person did not know the difference between right and wrong, or otherwise could not conform their conduct to do proper behavior. While many "insane" people have a mental disorder, simply having a mental disorder does not make one insane or excuse one, legally, for one's behavior. Since so many criminals have antisocial personality disorder or some aspects of it, it would be very dangerous to excuse people from legal responsibility on the grounds that they were antisocial personalities.

## CONCLUSION

Both Jesse and Ron were American Indians I treated in a prison treatment program. Both received education in the prison school. Both seemed to make some progress both in psychotherapy and in education. But, they could not have been more different in personality. Jesse is probably a conduct disorder, and might well be diagnosed as an anti-social personality (what used to be called psychopath or sociopath) when he reaches age 18 and is eligible for that diagnosis. He is potentially very violent, and may well hurt people in the future. Ron on the other hand is passive and quiet, and hurts mostly himself. He was in a family situation he could not deal with, and saw going to prison as his best answer.

I hope these two brief case histories show that people are unique, even if we call them "American Indians," "Native Americans," "Prisoners," "Criminals," or whatever. To help such people, and for the benefit of society, we have to take unique approaches to dealing with the various individuals we encountered.

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# Under the Cloud of Professionalism

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"When science triumphs, humanities are the losers": Inquiry into knowledge, science, and the inadequacies of a caring profession.

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## Abstract

The scientific paradigm, as part of 'professionalism' in health care, has reached a moral crossroads. Scientific knowledge as a priority has in many ways de-humanized the compassionate touch and the understanding of the subjective world of our recipients. The primary role of this current essay is to re-evaluate science as an epistemology in healthcare education, training, and practice. The second purpose is to increase awareness to unfortunate attitudinal trends within healthcare professions in academia as well as in practice towards living subjects, in an aim to clarify the nature of professional-client interactions. The concluding discussion will portray human relationships as non-quantifiable interactions. Change and growth fostering relationships will be characterized as having a symbiotic nature rather than a dichotomous nature.

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## Introduction

Social and behavioral sciences have borrowed their scientific notions from physical sciences (Heppner et al., 1999). However, modern sciences were also accompanied by a development of philosophical thought that suggested an extreme formulation of spirit/matter dualism. This formulation was the core of Descartes philosophy in seventeenth century science (Capra, 1991).

Psychology, as a field demonstrated its scientific rigor by modeling itself on Newtonian physics (Jordan, 2000). Ironically physics scientific emphasis was on objectification and distance from the known (Wolf, 1981). As scientific psychology was developed there was much attention to the separate self in the form of diagnostic manuals that use a medical/disease model to locate pathology in the individual (Jordan, 2000).

The promise of instrumental control given by scientific knowledge serves as a paradox to the etiquette of care and can become a blind passion (Lewin, 1996). In others a words, Western knowledge lays it's foundations on Baconian notions of mastery over nature, objectification of the known instrumentally; ironically these notions stand in contrast with other epistemologies that rely more on knowing through joining, through a compassionate unity of empathic care (Keller, 1985 cited in Jordan, 2000).

The main concern of this essay is to understand the nature of relationship, in teachings and practice, presented by contemporary 'professionalism' in healthcare occupations. As social sciences in the helping professions borrowed scientific notions, they also borrowed the need to separate between the knower and the known, which is manifested in academic curriculum that emphasizes the infatuation with knowledge, science, and social distance. Professionals also perpetuate such notions in their language and through practice (Lewin, 1996; Spiro, McCrea Curnen, Peschel, & James, 1993; Szasz, 1974).

This essay will look deeply at science and scientific knowledge as epistemologies that conflict with the core nature of healing professions, which was knowing through symbiosis with the client rather than knowing through separation. This has, in many ways, de-humanized the helping professions (Spiro, McCrea Curnen, Peschel, & James, 1993; Lewin, 1996). Unfortunate trends in teachings and relationships will be revealed, and a call for a shift in paradigm in the helping professions' education and practice will be discussed.

### Science, virtues, and the therapist

An exploration into historical psychology reveals great importunity. Freud has overemphasized individual self-interest (Doherty, 1995). Psychological theories have been holding clinicians like a chair afloat, and on an even keel. In other words, therapists gain security from their theoretical notions, as from a fetish or a teddy bear, which helps them stay organized and effective (Michels, 1983).

The contemporary, Western, post-Freudian world emphasizes happiness and self-fulfillment as a significant personal goal (Doherty, 1995). It is not surprising that in a permissive and materialistic environment in which individualistic satisfaction is the higher goal, healthcare too, will attract many who want to receive from, rather than to give to the profession. Many may be seeking intellectual gratification, prestige, or economic advantage, but often service is not the priority (Spiro, McCrea Curnen, Peschel, & James, 1993).

### Therapeutic disconnections:

Even when physics evolution called for a change in perception and in its scientific rigidity, the helping professions as a science fail to admit in the necessity for a new and alternative form of interaction. The attachment to the traditional notions of scientific interaction causes disconnection within the therapeutic arena. Therapeutic disconnections may be a direct result of a perpetuation of distance and separation in healthcare relationships (Jordan, 2000; Spiro et al., 1993; Laing, 1965).

Therapeutic disconnections are ubiquitous; people misunderstand one another and fail one another empathetically (Jordan, 2000). However, if mutual empathy is not met in the relationship, the disconnection from acute will become chronic, and the therapeutic relationship will lose authenticity, vitality, and eventually effectiveness (Jordan, 2000; Buber, 1970; Spiro, et al., 1993). Resistance to change, as a form of disconnection, often occurs when the clients feels, or perceives the caregiver as a formal, 'cold', unconnected agent (Laing, 1965, 1967; Adams, 1993; Carling, 1995).

Non-compliance, as another form of disconnection, is an evident phenomenon in Schizophrenia. Many individuals who live with the diagnosis of Schizophrenia neither recover nor improve (Modrow, 1996). Studies show that the majority of the clients who live with the diagnosis of Schizophrenia are noncompliant with medication treatment. Torrey's (1995) last explanation of this therapeutic noncompliance was the failure of doctor-patient relationships.

### Diagnostic criteria: the husk of being

Diagnosis of mental disorders is generally based on behavioral symptomatology (Szasz, 1976). However, it is evident that the diagnosis may be maintained throughout time beyond post-mortem examination- despite the absence of demonstrable histopathology or psychophysiology (Szasz, 1976). In other words, the lack of factual measures of 'objectivity' in observation of human behavior may result in a debate of opinions on the validity of a certain diagnosis (Szasz, 1976).

Laing's (1967) almost utopian analysis of behavior and experience portrays dimensions of the uncertainty of behavioral science. According to Laing (1967), our thirst for the evident stops at human behavior, with the neglect of hidden experiences. Diagnostic manuals, which are based on the

medical/disease model, are mainly concerned with the observer's view of things, rarely with the subjects' view of their own experiences (Laing, 1967; Jordan, 2000).

The nature of relationships within the diagnostic arena, the relationship between the observer and the observed, represent relationships between I and it (object) rather than I and a subject (Laing, 1967). Interactions, such as in diagnosis, offer an empty and confusing existence. If we see the world only through our experiences, then we will miss much of that which is (Laing, 1967; Buber, 1970).

### Separative dialogue in substance abuse treatment

Similar to diagnosis, the medical model of addictions views the phenomenon of addiction as pathology within the individual (Fisher & Harrison, 2000). That view influenced the relationship between professionals and clients, which included a language change. Clients who fail to comply with the counselor over certain notions of the disease model may be categorized clinically (Miller & Rollnick, 1991).

The view of addiction, behaviorally, as a disease reinforced an unfortunate trend of mere professional sarcasm tailored into everyday professional attitudes (Singer, Field Notes, 2001). The client that refuses to believe that the 'disease entity' exists in him may be viewed as 'in denial' or 'resistant to change'. Clients who may fail to adopt the common view of addiction brought by the clinical staff may be metaphorically compared to "sick puppies" or to "broken toys". When a client is viewed as a recidivist, another unofficial diagnosis that the "client is wired wrong" will be attached (Singer, Field Notes, 2002).

### Science and the academic world

Sociological analyses reveal 'professionalism' as containing several attributes. The first attribute is expert knowledge grounded in high and prestigious educational systems. The complex and discretionary knowledge is necessary for the benefits of the community. The medical profession, as well as psychology and other healthcare professions possess such attributes (Imanaka, 1997; Fry & Salameh, 1993).

The secret policy of 'publish or perish' among faculty members emphasizes the discovery of new knowledge. Promotional factors that are calculated by promotion committees often emphasize scientific achievements and involvements of staff rather than demonstration of compassionate qualities (Spiro, McCrea Curnen, Peschel, & James, 1993).

Research suggests that the process of change and growth is enhanced by mutual relationship between the professional and the client (Miller and Rollnick, 1991; Rogers, 1951, 1961; Lewin, 1996). However, academic training programs in the fields of psychiatry, psychology, counseling, and rehabilitation continue to emphasize the scientific methods through intensive curriculum (Dellario, 1996; Goodyear & Benton, 1986). As the higher education process continues from master's level into doctorate level, knowledge and practice of the scientific method is increased.

The key focus of the scientific-practitioner model in healthcare education is the development of scientific reasoning skills. This approach emphasized systemic and thoughtful analyses of human experiences and application of the knowledge gained (Rumrill & Bellini, 1999; Meara et al., 1988,).

The right balance between science and humanity indeed needs to be established for bettering the quality of care provided. However, it is apparent that science within healthcare education has monopolized certain emphasis in the academic curriculum, which may have relegated the human aspects into a secondary role (Spiro, McCrea Curnen, Peschel, & James, 1993).

Students may be expelled for lacking the essential knowledge, but only few will be expelled for

lacking empathy. In some cases, for example medical school, student selection processes emphasized scholastic achievements in entry examinations. This selective process favored academic brilliancy and competitiveness over the search for the right compassionate personality (Spiro, McCrea Curnen, Peschel, & James, 1993).

Literature suggests, that as the process of learning scientific methods to healthcare goes on, our students learn along with neutrality and objectivity, detachment and equanimity (Spiro et al., 1993; Jordan, 2000). Our infatuation with knowledge and science has priority over the delivery of compassionate care by emphasizing values such as neutrality and objectivity (Spiro et al., 1993; Jordan, 2000).

### Objectivity? Quantum mechanics, social sciences, and the paradox

Throughout the twentieth century social science as a field borrowed its quantitative model from physical sciences (Heppner et al., 1999, Jordan, 2000). Ironically, as psychology and other social sciences modeled Newtonian Physics, the creative minds of physicists moved toward an appreciation of quantum physics, indeterminism, and uncertainty. An appreciation developed towards interconnectedness in relationships, not separation (Wolf, 1981; Jordan, 2000).

The quantum leap plummeted scientists into a bizarre and unexplained underworld. This new order, the basis for the new physics, was not in the objects or particles but in the minds of the scientists. Scientists had to give up their preconceived ideas about the physical world (Wolf, 1981).

The philosophical basis of science as a rigorous determinism was the fundamental division between the I and the world as introduced by Descartes. The consequence of such division was the world could be described objectively without ever mentioning the human observer (Capra, 1991). Quantum mechanics brought to light the insufficiency of our simple mechanical conceptions. This revelation has shaken the foundation of customary interpretation of knowing and seeing (Bohr, 1958).

A paradox introduced by modern physics involved the scientists' view of science as a reasonable and orderly process of observing a phenomenon and describing the results objectively (Wolf, 1981; Capra, 1991). This notion was based on the assumption that whatever one observed as being there is indeed there. Quantum physics revealed, what seems to be nonsensical, that what one observes appears to depend upon what one chooses to observe (Wolf, 1981, Heisenberg, 1958).

The principle of uncertainty as taught by Heisenberg (1958; 1971) demonstrated that the limitations of such scientific method become increasingly apparent. The Principle of Uncertainty may also mean that to observe is to interfere, which means that the scientist cannot play the role of a detached objective observer, but become involved in the world he/she observes to the extent that one influences the properties of the observed (Wheeler, 1958 as cited in Capra, 1991).

The new physics as a science, necessitated profound changes in concepts like time, space, matter, object, cause and effect, etc... (Wolf, 1981; Capra, 1991). Within these changes, the universe was experienced as a dynamic, inseparable whole, which always includes the observer and the observed (Capra, 1991).

Today, almost one hundred years after the discovery of quantum physics, when science was shattered by change, doubt, and uncertainty, scientists are experiencing a new vast, deep way of relating to the universe (Aurobindo, 1957). The implications of the findings of quantum mechanics are crucial to the helping professions. They offer an alternative to interactions and relationships. The observer and the observed, the helper and the helped, fuse into a unified whole consisting of growth and change (Upanishads as cited in Capra, 1991).

## Alternative communication: Buberian dialogue and the relational model of interaction

Quantum mechanics and the relational model to psychotherapy share similar conclusions- the knower and the known are inseparable, and growth process depends on the mutuality in interaction. This suggests that individuals grow through and towards relationships. Mutual empathy and mutual empowerment is the core of growth fostering relationships. The relational model view growth fostering relationships as a system in which both sides contribute to the growth. In relational therapy, mutual empathy is the vehicle for therapeutic change (Jordan et al., 1991).

Relational therapy is consistent with one of the deepest and most creative philosophies of human interactions- the I-Thou dialogue as presented to us by the Jewish philosopher Martin Buber (Buber, 1970). Buber makes the distinction between two types of relationships: I-It and I-Thou. Each of these represents different qualities of relationships (Berry, 1985; Buber, 1970).

In the I-It attitude, the self does not interpret the other as having any possibilities beyond those which the self has determined for it. In hermeneutic terms, the self can be understood as constructing an image of the other in which the self imposes possibilities on the other and does not recognize it as having any other possibilities of its own. In the I-Thou attitude, the self recognizes that the other has possibilities of its own beyond those which the self expects or imposes, hence respecting the otherness of the other (Buber, 1970).

## Two ways of knowing

Knowledge can be put in two main categories: Logico-Scientific knowledge and Narrative knowledge. Logico-Scientific knowledge is used to collect and evaluate replicable, universal generalizable, and empirically verifiable data. The process is driven by hypotheses and generated by detached observers. Logico-Scientific Knowledge relies on formal operations as conjunctions and disjunctions to establish testable propositions (Charon, 1993 in Spiro, McCrea Curnen, Peschel, & James, 1993). Logico-Scientific knowledge, or Rational knowledge described by Capra belongs to the realm of the intellect, whose function is to discriminate, divide, compare, measure and categorize (Capra, 1991).

Narrative knowledge, in comparison, does not suggest more certainty, but rather mutuality and growth. Narrative knowledge and social phenomenology, as two parts of the whole, seek to examine and understand experiences of singular events contextualized within time and place. Stories, fairy tales, and scriptures are all examples of such knowledge (Charon, 1993 in Spiro, McCrea Curnen, Peschel, & James, 1993).

Through narrative knowledge and through social phenomenology, humans come to realize themselves and each other, in order to know who they are, and eventually attain the classical-‘know thy yourself’ (Laing, 1967; Charon et al., 1993). Social phenomenology and narrative knowledge, as a phenomenon, represent a symbiotic process, in which human relationships have progressed into mutual exchange and deep understanding. This process may lead to the ultimate knowledge- self-knowledge (Buber, 1970; Jordan, 2000).

## Discussion

According to Heidegger (1962), the dreadful has already happened. Therapists are specialists in human relations. However, as the dreadful has already happened, for therapists too, as beings that lives in this world. The inner does not become the outer; the outer often becomes the inner. Without understanding the inner realms of the individual, the outer loses it’s meaning; the same way quantum leaps proved our view on matter as a superficial conception (Laing, 1965, 1967; Capra, 1991).

Transaction communication occurs between systems, computers, and so on. Human relationships are

not only transactional, they're trans-experiential, being a specific human quality. The more human sciences model itself after the old physics, the greater the dissonance between the knower and the known, the helper and his/her client, the professor and his/her student (Laing, 1967; Jordan, 2000; Spiro, McCrea Curnen, Peschel, & James, 1993).

An existential analysis of language and communication as suggested by Rollo May (1972), reveals that we make our language more and more technical, impersonal, and objective until we talk primary in scientific terms. When the transformation of language and communication has been made, we as individuals become alienated from others (May, 1972; Szasz, 1974).

The break in communication, or the nature of disconnections, in diagnostic sessions, therapy, or counseling, suggests a failure to connect authentically and compassionately to our clients (Spiro, McCrea Curnen, Peschel, & James, 1993; Adams, 1993; Lewin, 1996).

Objectification of existence is a phenomenon that started with traditional science and moved into language patterns used by professionals in everyday life (Szasz, 1974; May, 1972). Objectification of the known in scientific teachings within academic curriculum, objectification of mental disorders in diagnosis, and objectification of the client in treatments, opposes the fundamental epistemology at the core of the helping profession of knowing through joining (Jordan, 2000).

Growth and change process is attained through the mirror of relationships, through the understanding of the contents of his/her own mind, and through observation and not through intellectual analysis or introspective dissection. Man has built in himself images as a fence of security -- religious, political, personal. These manifest as symbols, ideas, and beliefs. The burden of these images dominates man's thinking, his relationships, and his daily life. These images are the causes of our problems for they divide man from man (Krishnamurti, 2000).

To resolve the dichotomous nature of relationships, an authentic and mutual dialogue ought to be established between professionals and their recipients (Jordan, 2000). When one is hurt in a relationship, but is able to communicate the hurt authentically to the other and the other responds empathically, disconnection can move back into connection (Miller & Stiver, 1997). If the disconnection is not resolved, the hurt individual may apply disconnection strategies of withdrawal and isolation, which may move the relationship from acute disconnection into chronic disconnection (Jordan, 2000; Gilligan, 1982).

Sealing the article with a sense of optimism, the future of science, psychotherapy, and relationships in general, depend upon the ability of the individual to maintain open-mindedness perception and the ability to apply social intelligence such as empathy and compassion on a mutual basis (Buber, 1970; Berry, 1985; Jordan, 2000). Martin Buber's (1970) words represent a utopian vision of relationships based on humanitarian values:

*"The world is not comprehensible, but it is embraceable: through the embracing of one of its beings. Each thing and being has a twofold nature: passive, absorbable, usable, dissectible, comparable, combinable, rationalizable, and the other, the active, non-absorbable, unusable, undissectible, incomparable, noncombinable, nonrationalizable. This is the confronting, the shaping, and the bestowing of things. He who truly experiences a thing so that it springs up to meet him and embraces him of itself has in that thing known the world" (Buber, 1970).*

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## Developing Housing For Persons With Severe Mental Illness: An Innovative Community Foster Home

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### Abstract:

**Objective:** The objective of this study was to evaluate an innovative housing project that integrated a nursing assistant into a foster home for persons with a severe mental illness. The residents who were evaluated had tried to live in the community on numerous occasions, but their attempts had failed, and they returned to hospital for long periods of time.

**Methods:** The study sought to explore the perceptions of four different stakeholder groups: (1) residents living in the home (2) the nursing assistant (3) the foster home caregiver and (4) the multidisciplinary team. Semi-structured interviews and self-report questionnaires were used to gather the data.

**Results:** Findings suggest that individuals suffering from severe mental illness, who previously could not function outside of an institutional setting, can settle well into a community environment. The overall time spent in hospital by the residents one year pre-and post-evaluation differed greatly (in total 650 days before versus 124 days after placement). Supportive relationships were formed between the residents, nursing assistant and caregiver. The factors contributing to the success, as well as those elements that require improvement are discussed.

**Conclusions:** Residents were able to live in a community for the first time. Innovative ways of changing current housing structures should be considered in order to foster adjustment of these difficult to place individuals into the community.

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## Introduction

This article reports on the evaluation of an innovative foster home for persons with severe mental illness in Montreal, Canada. Over the past four decades numerous forms community based housing have been developed to meet the needs of deinstitutionalized persons with mental illness. Group homes, supervised hostels, foster homes, supervised apartments, and other forms of supported housing were created to meet the needs of these individuals (Trainor, Morrell-Bellai, et al. 1993). In Montreal, Canada, the majority of patients discharged from long-term wards of psychiatric hospitals were placed into foster homes. Traditionally, these homes provided stable housing for those people unable to maintain themselves independently in the community.

Although in recent years emphasis has shifted to other forms of alternate housing, such as supervised apartments and supported housing, foster homes are still viewed as an important residential resource for persons with serious mental illness. In certain cases, living in a foster home remains the only realistic long term housing option as patients discharged from psychiatric hospitals have lost contact with family members, and have few social supports. Often placement into a foster home is the ex-patient's permanent home and primary link to the community. In Montreal, Canada foster homes make up 51% of subsidized housing available for persons with psychiatric disorders.

Characterized as ordinary homes in the community, foster homes are regulated by the Law Respecting Health and Social Services (Bill 120). Unlike other external services for persons with serious mental illness, which rely heavily on professional staffing (i.e. Assertive Community Treatment), non professionals operate foster homes. No specific training is required to become a foster home caregiver. Foster home caregivers work in close collaboration with hospital multi-disciplinary teams, in which a case manager and a housing worker are assigned to each foster home. The multidisciplinary team oversees the overall well being of clients placed in the foster home, and responds on a case-by-case basis, when problems or crisis situations arise.

In recent years emphasis has shifted dramatically to other forms of alternative housing, such as supportive and supported housing (Carling, 1993, Hogan and Carling, 1992, Parkinson, Nelson and Horgan, 1999, Ridgway and Zipple, 1990, Srebnik, Livingston et al, 1995). Although these types of housing are popular, and may be beneficial to some persons with serious mental illnesses, there remains a group of individuals who are unable to live within the existing housing structures, and are currently occupying beds in acute care hospitals. These individuals deserve the opportunity to live in a community environment. This is not possible without the development of new approaches to support residents and caregivers in the community.

## Context

The impetus for this innovative housing project grew out of the need to develop a new housing model for a group of persons with severe mental illness currently occupying hospital beds, and unable to live within the existing housing structures. Typically, this group of "difficult to place patients", has been through the system, has a history of unsuccessful community placements, but cannot be stabilized, and thus has nowhere to go except back into hospital.

Coupled with this service need was the fact that nursing assistant positions were closed in a teaching hospital in Montreal, in the Department of Psychiatry. Individuals who previously held these positions were given the opportunity to relocate to community-based foster homes. This provided a good opportunity to test the effectiveness of transferring skills obtained in a hospital setting to the community. Researchers have suggested that nursing assistants are the primary direct caregivers of residents in long-term care facilities for the elderly (Maraldo, 1991). Studies have shown that nursing assistants form close relationships with patients, and they suggest that quality of care is based on the quality of this relationship (Bowers, Esmond & Jacobson, 2000; Schirm, Albanese, Garland, et al.,

2000).

This innovative housing project, the first of its kind in Montreal, integrated a nursing assistant into a foster home. While working with the residents in the foster home, a nursing assistant would function as a support and educator/trainer for the caregiver through role modeling the skills and attitudes necessary to care for this clientele. Sickman and Dhooper (1991) found that in a sample of foster home caregivers, a positive relationship existed between caregivers that had some form of health care training and competencies in caring for the mentally ill.

### An Overview of the Literature

A great deal of research has focused on the outcome of placement into residential facilities including: community tenure, community integration, housing stability and quality of life. Most often community tenure and re-hospitalization are used as the criteria for measuring success. Carpenter reviewed over 60 outcome studies of psychiatric patients. This included studies that examined the environment, patient selection, staffing, programming, and length of stay. Findings confirmed that it was less costly to house persons with mental illness in the community than in hospital. Murphy, Engelsmann and Tchong-Laroche used patient characteristics to measure outcome, and reported that patients living in foster homes showed no improvement in social functioning after 18 months. Another study contradicted these findings as foster homes improved social functioning within four months regardless of patient characteristics. Recent studies (Newman, 2001, Goering, Cochrane, Durbin, et al., 1997) that reviewed the relationship between housing attributes and serious mental illness concluded that while research has examined the various characteristics, experiences and outcomes of the different housing models for deinstitutionalized persons, few conclusions can be made about the effectiveness of any one model. Other studies have suggested that the characteristics of the environment are more predictive of outcome than the characteristics of the individual.

#### Objectives

The objective of this study was to evaluate the implementation of this innovative project that integrated a nursing assistant into a foster home for persons with a severe and persistent mental illness. Given that this project was in operation for only 6 months at the time of the study, the focus was on the implementation phase. The evaluation sought to explore the perceptions of the four different stakeholder groups involved in this pilot project: (1) the residents living in the home (2) the nursing assistant (3) the foster home caregiver and (4) the original planners. The factors contributing to the success of the foster home, as well as those elements that require improvement were identified and will be considered further in the Discussion section of this paper.

### Description of Project

A multidisciplinary team from a large teaching hospital in Montreal, Canada identified a number of individuals with a severe mental illness who would be good candidates for this housing project. These were people who had been hospitalized from several months to over one year and had already lived, unsuccessfully, in various types of housing in the community. A nursing assistant on staff at the hospital volunteered to be reassigned to the community to provide support to the caregiver of this foster home. A multidisciplinary team of health care professionals was assigned to provide frequent follow-up for the residents. Each groups' profile is detailed below.

#### Residents

Six individuals (5 males and 1 female) ranging in age from 24-54 years were placed from an acute care hospital into the foster home, though only four of these residents agreed to participate in the study. All residents were diagnosed with schizophrenia and all had an extensive history of unsuccessful community placement and repeated hospitalizations. Previous living arrangements included the Salvation Army, rooming houses, and homelessness.

### Caregiver

The caregiver had previously worked as a teacher and though he had no specific experience with this clinical population, he had the potential and enthusiasm to take on this challenge. Prior to accepting the residents, the caregiver visited the hospital in order to get acquainted with those patients who would be moving into the home. The caregiver was responsible for the overall functioning of the home. He lived on the premises and provided room and board, and supervision for the residents. He also had a network of extended family who were able to provide support to him in the home. The caregiver assisted in the implementation of the treatment plan, developed for each resident living in the home.

### Nursing Assistant

The nursing assistant who chose to work in the foster home was an employee of the hospital for 27 years. He had extensive experience working with a psychiatric population in an acute care setting, and was familiar with all of the residents as a result of his work in the hospital. It is important to note that this nursing assistant had always worked in an institutional setting, and no specific training was provided to him in this pilot project. Unlike the rotation work pattern of a hospital, he maintained a regular Monday-Friday, eight-hour day, work schedule. Using a "hands-on" approach in the home the nursing assistant's role was twofold: (1) to support residents living in the home, and (2) to act as a role model for the foster home caregiver. Given his previous experience with this population, the nursing assistant provided intensive intervention with residents on a daily basis. For example, the nursing assistant had knowledge of patients' medications and previous experience working with the multidisciplinary team. The nursing assistant supported the caregiver and assisted him in the day-to-day management of the residents' activities of daily living. Ultimately, it was hoped that the nursing assistant would transfer his knowledge and expertise to the caregiver. This would entail on the job training, education and support for the caregiver with the goal of maintaining this difficult population in the community.

### Multidisciplinary Team

This hospital-based multidisciplinary team, composed of a psychiatrist, a social worker and a nurse, visited the foster home on a bi-weekly basis. This team provided regular on-going support and guidance to the caregiver and nursing assistant. The team assessed problem behaviors and proposed adjustment of medications. The nurse was available to assess problematic situations, and acted as the contact person for emergency consultations. The social worker dealt with the administrative tasks such as welfare payments, and access to community resources. The psychiatrist was viewed as a key player in the home. He participated in team meetings, reviewed medications and met with the residents individually if required.

### Housing Worker

The housing worker was involved in the foster home from the outset and coordinated the implementation of the project. She was responsible for supporting and supervising the caregiver, as well as ensuring the foster home was functioning adequately.

### Methods

When the project was in place for 6 months, an evaluation committee was organized to assess the foster home's effectiveness. Data was collected in 1999-2000.

### Residents Profile

In order to develop descriptive information about the residents living in this foster home, a short questionnaire was drafted and included the following data: demographic information, hospitalization and placement history, and family involvement. Patient hospital files were also consulted to provide a more detailed description of the patients' housing trajectories.

### Interviews

Semi-structured interviews were conducted with (1) residents living in the group home at the time of the evaluation; (2) the caregiver; (3) the nursing assistant; and (4) the planners and multidisciplinary team. A group interview format was used to interview the residents living in the foster home. Residents were asked about their lives prior to arriving in this residential setting, how this home compared to other living arrangements, and what suggestions they had for improving the foster home. Individual interviews were conducted with the nursing assistant and the caregiver. The same interview guide was used for both. Each respondent was asked to describe the program, his responsibilities, whether the project had reached the targeted population and the strengths and weaknesses of the project. A group interview was held with the original planners of this pilot project and the hospital-based multidisciplinary team.

Interviews lasted between 60 and 90 minutes. All except the group interview with residents were tape recorded and transcribed verbatim. Detailed notes were taken in the group interview with residents in the foster home. Data was then organized into two major themes (1) factors contributing to the success of the home and; (2) factors that created obstacles that may be improved.

### Ethical Considerations

Participation in the study was voluntary. People were free to refuse to participate or to answer any specific question(s). Residents were first approached by the Nurse Manager and asked whether they would be interested in participating. Residents participating in the group interview gave their informed consent and were given a small financial compensation for their participation. In reporting the findings, every effort was taken to ensure confidentiality, and no identifying information has been used.

### Results

Data was collected on the pattern of hospitalizations for the residents in the year prior to and after they moved into the foster home. Residents were taken to the Emergency Department slightly more frequently after moving into the foster home (12 visits prior to placement versus 15 visits post placement). However, the one-year pre and post analysis of hospitalization differed greatly -in total 650 days before versus 124 days after placement. The disparity in hospital costs for these residents for the year before and after living in the community was calculated to be \$455,000 and \$86 800 respectively.<sup>2</sup> Although these costs comparisons are at best approximate they suggest that this type of community resource can provide an important alternative to hospitalization, in terms of cost.

During the evaluation process, the stakeholder groups were asked to provide feedback on the functioning of the foster home. These groups reported on the elements of the home that were beneficial to its success, as well as the areas that required improvement.

### Residents

The residents expressed their overall satisfaction with the foster home, preferring it to others they had lived in. The residents felt that the foster home provided a home-like environment, in which they felt they belonged. The residents appreciated the structure and routine that was put into place. They felt that the nursing assistant played an important role in resolving daily problems. The residents also appreciated the administration of their medications.

The residents had some complaints around the day-to-day functioning of the home. They found that the location was not convenient, that a group-living situation was not ideal, and that noise levels were sometimes disruptive. Some residents also found the food to be unsatisfactory, and policies around smoking cigarettes to be inconvenient.

### Caregiver

The nursing assistant acted as a model for the caregiver in his interactions with the residents, and the caregiver learned how to handle most difficult situations. This knowledge fostered confidence in the caregiver to resolve problems by himself. The caregiver was enthusiastic in describing the residents' development and stability after a short time in the foster home. He also highlighted the sense of "family" and security that the residents gained from being in the home. The structure allowed the residents to engage in activities outside of the home. A sense of trust between the caregiver and residents fostered positive communication between them. The caregiver described the nursing assistant's presence in the home as invaluable. The nursing assistant also provided structure and routine in the home, ensuring that self-care tasks were completed and medications taken. The multidisciplinary team provided much needed support to the caregiver.

However the caregiver found that an unequal distribution of work existed between himself and the nursing assistant as the caregiver was on call 24 hours a day, and the nursing assistant was only available for 8 hours a day. Though an emergency system was supposedly available to the caregiver at all times, this system proved inadequate after-hours, leaving him responsible to resolve crises himself. Finally, the caregiver would have liked to resolve the problem of finding suitable daily activities for each resident, as they all had various interests.

### Nursing Assistant

The nursing assistant found that close relationships had formed among himself, the residents and the caregiver, and felt that low resident turnover and low rate of re-hospitalization was attributable to these relationships. He believed the residents were fairly comfortable in the home and were averse to the idea of returning to hospital. The nursing assistant found that the multidisciplinary team's involvement had a positive impact on the foster home, as the team provided support and feedback to the nursing assistant when problems arose.

However the nursing assistant found communication between himself and the caregiver was insufficient. He also found that the responsibilities expected of him were not clearly defined at the outset and that overlap occurred with the caregiver when performing certain tasks.

### Multidisciplinary Team

Although the multidisciplinary team was not involved in the implementation of the first stages of the foster home, but was called in after the home was established, they stated that the residents adapted well to the community environment. The team's biweekly visits provided the caregiver with support through easy access to the psychiatrist (e.g. changing medications when required), as well as the nurse (e.g. providing knowledge for the nursing assistant around out-patient issues).

However the multidisciplinary team found that the mandate of the foster home was not clear, creating confusion around the issue of rehabilitation versus maintenance of the residents. The caregiver and nursing assistant were working 'in parallel' with the residents, but with different goals. The team found that communication between the caregiver and nursing assistant was inadequate and that the roles of the nursing assistant, caregiver and even their involvement, were not clearly defined at the outset of the project.

### Areas of Consensus

All groups agreed that the residents were stable in the community for the first time. This stability allowed for trusting relationships to form and positive communication between the residents and the caregiver and nursing assistant. The three staff groups agreed that the roles of the caregiver, nursing assistant and multidisciplinary team were not adequately defined before the implementation of the project. Inadequate communication between the caregiver and nursing assistant was agreed to be a

factor that needed improvement.

## Discussion

Overall the implementation of this innovative foster home has proven to be a success. The residents, who in the past were unable to adjust to living in the community, were able to settle into this environment. The stability of these residents in the home resulted in the formation of trusting relationships with the caregiver and nursing assistant, and consequently a more home-like environment for the residents.

The findings suggest that the support provided to the residents by the caregiver and nursing assistant had a positive impact on the functioning of the home. Researchers have found that a positive relationship exists between an individual's social network and their well-being (Hall & Nelson, 1996; Nelson, Hall & Walsh-Bowers, 1998). The residents of the foster home appreciated the accessibility of the nursing assistant for the provision of medication, the resolution of problems, and other forms of support. The caregiver was available around the clock if problems arose, and acted as a family member to the residents, enhancing their support network.

The support that was available for the caregiver was also an important factor in the success of the foster home. The nursing assistant's experience with this population was instrumental in teaching the caregiver helpful methods of interacting with the residents and resolving problems as they arose. The caregiver was also able to depend on the nursing assistant for help, which fostered his confidence in running the home.

As a result of this evaluation process, several factors were identified that require improvement. A mandate describing the function of the foster home may help to eliminate problems around conflicting expectations of staff. For instance, the organizers of the project did not define whether the aim of the home was to rehabilitate the residents or simply to maintain them in a community environment. This proved to be an important factor for the caregiver and nursing assistant. By defining the function of the home at the outset, both the nursing assistant and caregiver could have worked together more effectively to meet the objectives of the home.

Clarification of roles for the caregiver, nursing assistant and multidisciplinary team may help to eliminate conflicts. The lack of formal job descriptions for the caregiver and nursing assistant caused overlap in tasks during the day, and left the caregiver solely responsible after work hours. Decisions regarding workload could have been defined at the outset, and problems would have been eliminated. Training of the caregiver and nursing assistant may have improved the functioning of the foster home (Raskin, Mghir, Peszke et al., 1998). The nursing assistant, who had no experience working in the community would have been more effective to the caregiver had he understood the differences of working in the community as opposed to an institutional setting. The caregiver would have benefited from training as well. Raskin et al. (1998) found that the introduction of a psycho educational program for caregivers, which involved the provision of information about the population they were caring for, as well as contact with other caregivers, resulted in decreased re-hospitalizations for the residents in their care.

The multidisciplinary team felt that they were not as focused on the residents as they could have been because they spent a great deal of time involved in discussions with the caregiver around issues related to the functioning of the home. This problem could have been resolved with clear job descriptions given to all stakeholder groups involved.

Despite these areas requiring improvement the findings from this study suggest that individuals suffering from severe mental illness, who previously could not function outside of an institutional setting, can settle well into a community environment. Innovative ways of changing current housing

structures should be considered in order to foster adjustment of these difficult to place individuals. This study has demonstrated that the introduction of a nursing assistant into a foster home to provide knowledge and training to the caregiver, as well as a direct hands-on approach, is one method of structuring the community environment for these individuals. Future studies can use this method, as well as resolve the problems that were found in order to formulate a housing structure that will meet the needs of certain individuals with severe mental illness.

Finally it should be noted that 5 of the 6 original residents of the foster home are still currently residing there at this time (24 months later) and the nursing assistant has moved on to support another first time group home caregiver. This project inspired other Montreal based hospitals to integrate nursing assistants into residential teams working in the community.

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# Depressive Symptoms and Family Functioning in the Caregivers of Recently Hospitalized Patients with Chronic/ Recurrent Mood Disorders.

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## Abstract

**Background.** Our aim was to determine the relationship between family dysfunction and depression in caregivers of patients with chronic / recurrent mood disorders.

**Method.** 16 caregivers of patients with chronic / recurrent mood disorders were recruited during their relative's in-patient psychiatric stay and completed self-reports instruments including the CESD, FAD and measures of burden and reward.

**Results.** Caregivers were mostly male (56%) and spouses (69%). Despite reporting significant amounts of strain and burden, caregivers felt that care giving was rewarding. 72% of the caregivers scored positively for depressive symptoms. Caregivers who reported poor family functioning had dysfunction in all areas of family functioning and were significantly more likely to report depressive symptoms.

**Conclusions.** Family functioning and depression are closely associated in the caregivers of patients with chronic / recurrent mood disorders. The experience of reward and burden are not mutually exclusive.

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## Introduction.

Historically, studies of the families of psychiatric patients have focused on outcome measures for patients. For schizophrenia, successful family intervention decreases mean cost of patient care by 27% (1) and reduces relapse rates and improves quality of life (2). For patients with bipolar disorder, high levels of caregiver burden have been shown to predict subsequent adverse clinical outcomes in bipolar disorder patients (3). Multifamily group therapy treatment for bipolar patients and their families reduces patient relapse rates and improves patient quality of life (4). Families of patients with affective disorders experience high levels of caregiver burden (5). Moreover, there is evidence that a large

number of caregivers have rates of depressive symptoms as high as 38% to 60% (6,7). These family members often go untreated. Thus there is evidence that a systemic view that includes family members of the patient may be warranted for the best outcome for both the patient and family members.

It is time therefore, to assess family caregivers and intervene if necessary, with the aim of improving the health of the caregiver and the patient. This study will examine the relationship between family functioning and depression in caregivers of patients with chronic/recurrent mood disorders.

Several research tools have been used to assess family functioning in families with a relative suffering from chronic psychiatric illness. One of the oldest tools measures "expressed emotion" (EE), the attitude that a relative has towards a family member with a psychiatric impairment. Families that demonstrate high levels of criticism, hostility or emotional over-involvement are known as high EE families (8). Families with high expressed emotion have been shown to be a "significant and robust" predictor of relapse in psychiatric illnesses (2). Expressed emotion, however, looks at only one aspect of family functioning whereas a more comprehensive measure is often preferable. One model of assessment and therapy, McMaster Model of Family Functioning (9) and the Problem Centered Systems Therapy of the Family (10) is ideally suited to assess a broad range of family functions. This model assesses several dimensions of family functioning such as affective involvement, affective responsiveness, roles, communication, behavior control and problem solving. Other measures of family functioning that may be applicable in the assessment of caregivers, include the Family Hardiness Index (11) that measures family transition crises and adaptation for acute and long term stressors and the self report Family Inventory (12) that allows measurement of family functioning across several domains, such as competence, cohesion, leadership and emotional expressiveness.

Caregiver coping strategies are linked to caregiver burden although the strength of this association is not clear (13,14). However, healthier coping strategies such as problem-focused coping strategies, which include positive communication and increased social involvement, may be associated with less burden (15). Family caregivers of bipolar patients more often use healthier strategies than caregivers of patients with schizophrenia. Possible reasons include improved inter-episodic functioning and the fact that caregivers of bipolar patients tend to be spouses rather than parents. Thus the family may enjoy more adult problem solving rather than regressing to a parent-child relationship.

In spouses of psychiatric patients suffering from depression, anxiety or schizophrenia, female spouses have prevalence rates for all psychiatric illnesses of 1.8-2.5 times that of male spouses and twice the rate of depressive illnesses (16). Many caregiver variables have been reported as being significantly related to depression in caregivers, such as the general stress of coping with chronic psychiatric illness (17) and the grief associated with having a spouse with chronic psychiatric illness (18).

Several studies have tried to evaluate the links between family functioning and depression. Assortative mating has been suggested as a factor resulting in the higher incidence of depression among spouses of patients with psychiatric illness (19,20). Longitudinal studies of depression and family functioning show that depressed patients with persistent family dysfunction had poorer clinical outcome at 12 months (21). The relationship between poor family functioning and depression is certainly present, but it is unclear if the family dysfunction maintains the depression or if the depression maintains the family dysfunction.

We report the results of a study that looked specifically at links between caregiver burden, family functioning and depressive symptomatology in families of patients with chronic/recurrent mood disorders. Our aim was to determine the extent to which family dysfunction and depression were related and to identify how these variables were related to the perception of caregiver burden and reward.

## Method.

16 caregivers of patients with chronic/recurrent mood disorders were approached during their relative's in-patient psychiatric stay by a trained researcher who obtained informed consent and recruited them into the study. Approval for the study was obtained from the Hospital Institutional Review Board prior to the study beginning. Chronic/recurrent mood disorders were defined by chart review, as having had 3 or more episodes in the past two years, or by being continuously symptomatic for five years. Patients with concurrent axis I, axis II and axis III were included although primary substance abuse diagnoses were excluded. If caregivers scored positively on the screening for depressive symptoms or family dysfunction, they were informed by telephone and offered referral for further assessment.

## Instruments.

Basic socio-demographic information was collected as well as information on social support and other care giving roles. Family functioning was assessed using the Family Assessment Device (22) and a visual analog scale. The Caregiver Strain scale (CSI) (23) and visual analogue scales measured the strains and burdens of care giving. The family member's perception of the patient's functional level was measured with the Family Member's Activities of Daily Living Questionnaire (24). The CES-D, Center for Epidemiological Studies Depression Scale, (25), measured the caregiver's level of depressive symptoms and the Satisfaction scale, a sub-scale of the care giving instrument by Schofield et al. (26), measured the caregiver's level of satisfaction in caregiving.

## Analyses.

Characteristics of the sample were described using univariate statistics. Bivariate analyses comparing gender, diagnoses, length of time care giving, and depression included chi-square analyses for categorical factors and t-tests for continuous variables. Correlation analyses were used to examine how family functioning was related to depression, strain, burden, and rewards.

## Results.

Caregivers were more likely to be male (56%) and spouses (69%). The mean age of caregivers and patients was 55 and 53 years respectively. Despite reporting strain and burden, caregivers felt care giving to be rewarding. Caregivers reported that the rewards of care giving (7.4 sd 3.3) outweighed the burden (4.2 sd 3.2).

Table 1. Selected characteristics of caregivers of recently hospitalized chronic / recurrent mood disorder patients (N=16).

	n	%	
Caregiver gender			
Female	7	43.8	
Male	9	56.3	
Caregiver role			
Spouse	11	68.8	
Child	2	12.5	
<u>Other</u>	<u>3</u>	<u>18.8</u>	
	Mean	sd	Range
Caregiver age	54.8	13.2	20-73
Patient age	53	12.9	27-76

Caregiver scores.

Strain <b>(a)</b>	5.88	3.67	13-Jan
VAS-Burden <b>(a)</b>	4.19	3.17	10-Jan
Rankin-Burden <b>(a)</b>	2.5	1.5	0-5
VAS-Rewardb <b>(b)</b>	7.38	3.3	10-Jan
CESD	22.3	13.2	May-49

**(a)**= higher score is worse

**(b)**= higher score is better

Family Functioning.

	<u>x</u>	<u>s.d.</u>
Problem solving	2.15	0.36
Communication	<u>2.41</u>	0.43
Roles	<u>2.42</u>	0.41
Affective Responsiveness	<u>2.15</u>	0.45
Affective Involvement	<u>2.23</u>	0.42
Behavior Control	<u>1.95</u>	0.33
General Functioning	<u>2.11</u>	0.56

*Unhealthy scores underlined.*

Using a cut-off score of 19 on the CES-D, 72% of the caregivers scored positively for depressive symptoms. When we used 21 as a cut-off, 56% scored positively for depressive symptoms.

Caregivers who reported poor family functioning were more likely to meet report depressive symptoms (Table 2).

Table 2. Relationship between depression<sup>1</sup> and family functioning<sup>2</sup> (N=16)

	Family Functioning		<u>x<sup>2</sup></u>	p
	<u>Good</u>	<u>Poor</u>		
Depressed	2 (28.6)	8 (72.7)	3.38	0.066
Non-depressed	5 (71.4)	3 (27.3)		

*Depression measured by a CES-D score of 21  
Measured by the General Functioning score on the Family Assessment Device (FAD)*

Comparisons between the depressed and non-depressed caregivers show significant differences in several areas of family functioning (Table 3). The depressed caregivers reported dysfunction in all areas of family functioning.

Table 3. Depression and dimensions of family functioning<sup>1</sup> (N=16)

	Depressed Mean (sd)	Non-depressed Mean (sd)	t	p
Problem Solving	2.40 (.44)	1.92 (.25)	-2.69	0.018
Communication	2.68 (.43)	2.21 (.35)	-2.41	0.031
Roles	2.69 (.37)	2.10 (.25)	-3.67	0.003
Affective Involvement	2.41 (.39)	1.98 (.39)	-2.21	0.045
Affective Responsiveness	2.41 (.55)	1.98 (.31)	-1.94	0.072
Behavior Control	2.01 (.35)	1.93 (.33)	-0.49	ns
General Functioning	2.56 (.51)	1.75 (.30)	-3.8	0.002

*Family functioning measured by the Family Assessment Device.  
Unhealthy scores are underlined.*

## Discussion.

This study of 16 caregivers of patients with chronic/recurrent mood disorders explored the relationship between caregiver burden and reward, family functioning and depressive symptomatology. The majority of these caregivers are spouses and males. We believe that the higher number of male caregivers in our sample is a reflection of the higher incidence of major depression in women and our population of chronic/recurrent mood disorders. Although caregivers reported significant satisfaction in caregiving despite reports of burden and strain, they also reported significant impairment in several areas of family functioning as well as high levels of depressive symptoms.

Firstly, caregivers reported a significant level of satisfaction in caregiving, despite reports of burden and strain. Caregivers' comments focused on the level of affective or emotional involvement and the gratification in knowing that one's help is appreciated. Caregivers stated that they enjoyed giving back to a spouse who had taken care of them in earlier years and that their care ensured that the spouse was getting their needs met in the best way.

Secondly, caregivers reported difficulties in almost all areas of family functioning. When the sample was divided into depressed and non-depressed caregivers, the depressed caregivers accounted for almost all of the family dysfunction. Role difficulties in this sample of predominantly men may indicate difficulty with the care giving role or housekeeping roles, which are seen as traditional female roles. Communication difficulties and poor affective involvement may reflect intimacy and closeness difficulties when a spouse or family member is mentally ill.

Thirdly, 72% of the caregivers reported depressive symptoms and the most severe family dysfunction. Thus, the correlation between depressive symptoms and family dysfunction is supported. The CES-D is the most widely used self-report screening tool in community studies and its psychometric properties have been shown to be strong in many populations (27). However, a criticism of the CES-D is that the relationship between self-reported symptoms of depression on the CES-D and the diagnosis of a depressive illness may only be modest (28). Scores of 16 and above are generally believed to indicate individuals at risk for clinical depression. We chose a cut off of 21 to be sure that depressive symptoms are problematic and to improve sensitivity (29).

Although caregivers reported depressive symptoms and family dysfunction, they declined treatment referral, stating that their problems were situational or that they did not have the time to seek treatment. Studies of caregivers of patients with chronic psychiatric illnesses support this finding; few caregivers seek out help for themselves even though the evidence for the benefits of treatment is high. Treatment refusal rates with intervention studies of caregivers of are reported at 25-50 % of caregivers



refusing treatment (30,31,32). Reasons suggested for treatment refusal included: "no acute need" at the time of enrollment, perception of blame by the mental health services, denial of illness and lack of understanding of rationale for intervention. Knowledge of other families struggling with the same problems and increased emotional support has been found to increase a family's sense of competence and produce better functioning for the patient (33). Family members' quality of life has also been shown to improve with services that support, education and involve family members (34).

This study supports the relationship between depressive symptoms and family dysfunction. Overall, caregivers reported more reward than burden and reward. The experience of burden does not preclude the experience of reward. Caregivers with poor family functioning accounted for most of the caregivers with depressive symptoms. Causality is unclear but may involve many factors such as assortative mating, pre-existing depression or family dysfunction as well as a response to the caregiving situation. It is of concern that caregivers themselves were not receptive to treatment interventions after discharge and it is therefore important to try to engage these families during the time of the patient's hospitalization.

Limitations of the study include the small sample size, a selective recruitment from a hospital setting, which reflects a crisis time in the life of a caregiver. Although the use of self-report questionnaires could be considered a limitation, they are cost efficient and reflect caregiver perceptions, the focus of our question. The homogeneity of the sample suggests little ethnic variety, which may be important as there is evidence that different ethnic groups respond to the demands of care giving differently (35).

The next step in our research involves the longitudinal study of caregivers, using psychiatric and family assessment / intervention for those caregivers with depressive symptoms and family dysfunction. We also plan on assessing the effects of caregiver intervention on the well being of the identified patients, by monitoring readmission rates and quality of life indices.

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# Psychiatric Rehabilitation: The Need for a Specialized Approach

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## Abstract

Many rehabilitation professionals are neither aware nor appropriately prepared to provide the level of services that are needed by individuals with psychiatric disabilities to re-enter the community and function in the workplace. This article discusses the complexities of psychiatric disabilities, the significance of work for individuals with psychiatric disabilities, and intervention approaches that have been found effective in assisting individuals with psychiatric disabilities enter the world of work for the first time or re-enter after acquiring a psychiatric disability.

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## Introduction

More than two thousand years ago, Hippocrates' observation that our own well-being is affected by our settings established a fundamental cornerstone for Western medicine (Gallagher, 1993). There appear to be many sociological factors that can affect a person's adjustment to disability. People with any disabling condition must face the task of adjusting to their conditions, disabilities, and to their environment. According to Lazarus and Folkman (1984), psychological stress results from a particular relationship between the person and the environment, one that persons with disabilities often may perceive as either taxing or exceeding their resources and endangering their well-being.

It is estimated that more than 40 million people in the United States have psychiatric impairments; of that number, 4 to 5 million adults have a severe psychiatric disability (National Institute on Disability

and Rehabilitation Research, 1993). Severe psychiatric disabilities are described as persistent mental or emotional disorders that significantly interfere with a person's ability to carry out such primary aspects of daily life as self-care, household management, interpersonal relationships, and school or work (Task Force on the Homeless and Severe Mental Illness, 1992). Primarily, these psychiatric diagnoses include schizophrenia, affective disorders, and anxiety disorders (Bond, 1995).

The treatment of mental illness underwent a dramatic shift in the United States during the 1960's and the 1970's with the introduction of psychotropic medications. Before the development and introduction of these medications, individuals with psychiatric disabilities were institutionalized for decades, with many individuals living out their lives in institutions (Smart, 2001). The passage of the Mental Health Centers Act of 1963 (P.L. 88-164) caused a major shift in the type of care provided for people with psychiatric disabilities. Subsequent amendments defined the specific services that mental health centers were required to provide (Peterson et al., 1996) serving as the catalyst for more movement toward the development of a decentralized community-based treatment system. However, many individuals with psychiatric disabilities were released from state hospitals after years of institutionalization prior to the establishment of necessary community support systems. The deinstitutionalization effort ultimately resulted in the discharge of many thousands of people with psychiatric disabilities into communities that were neither prepared nor willing to accept them (Gerhart, 1990; Rogers, Anthony, & Jansen, 1991).

The new directions in psychiatric rehabilitation include a variety of strategies to increase the community integration and independence of people with psychiatric disability. Unfortunately, many rehabilitation professionals are neither aware nor appropriately prepared to provide the level of services that are needed by individuals with psychiatric disabilities to re-enter the community and function in the workplace. To this end, this article will discuss (a) the complexities of psychiatric disabilities, (b) the significance of work for individuals with psychiatric disabilities, and (c) intervention approaches.

### Complexities of Psychiatric Disabilities

People with psychiatric disabilities experience numerous limitations in everyday functioning, some of which include difficulties with interpersonal situations, (e.g., misinterpreting social cues, inappropriate responses to situations), problems coping with stress (including minor hassles, such as finding an item in a store), difficulty concentrating, and lack of energy or initiative (Bond, 1995). Whether persons with psychiatric disabilities have never learned social skills or have lost them, most of these individuals have marked skill deficits in social skills and interpersonal situations (Bond, 1995). Traditionally, medication and psychotherapy were the two major treatment approaches for people with psychiatric disabilities, with little attention given to preventing or reducing functional limitations or handicaps to social performance. Traditional approaches such as medications, hospitalization, and dynamic psychotherapy have had limited effectiveness when applied to the socialization and work aspects of individuals with psychiatric disabilities (Chan et al., 1998).

Rather, the preferred modes of intervention include strengthening both the client's skills and the level of environmental supports. Client skill strengthening approaches involving social and independent living skills training, symptom management, and job finding clubs have been recognized as having a strong positive effect for individuals with psychiatric disabilities. Critical environmental support strengthening approaches include family behavior management and the use of peer groups in the transition to community living. Supported employment has been cited as a crucial service component that places equal emphasis on the strengthening of client skills and environmental supports (Xie, Dain, Becker, & Drake, 1997).

According to the Task Force on the Homeless and Severe Mental Illness (1992), community treatment of the person who has a psychiatric disability needs to include a focus on teaching coping skills that are necessary to live as independently as possible in the community. It is the presence or absence of such skills that is often the determining factor related to rehabilitation outcomes, rather than the client's actual psychiatric symptoms. Rehabilitation programs must encompass the development of learning or relearning of skills and competencies required for successful interpersonal and social functioning as well as those needed for specific vocational pursuits.

According to Anthony, Cohen, and Farkas (1990), the preferred method of increasing a client's capacities in social situations is a skills-training approach. In such an approach, the intent is to identify those specific client skill deficits that are preventing the person from functioning more effectively in his or her living, learning, and/or work community. For example, clients may need help in learning social skills, interpersonal skills, coping skills, personal hygiene, and self-care, as well as symptom management (Corrigan, Rao, & Lam, 1999). Bellack, Mueser, Gingerich, and Agresta (1997) described social skills as interpersonal behaviors that are normative and/or socially sanctioned. They include such elements as dress and behavior codes; rules about what to say and not to say; and stylistic guidelines about the expression of affection, social reinforcement, interpersonal distance, and so forth. Deficits in these areas can make it quite difficult for a person with a psychiatric disability to establish and maintain relationships that are necessary for social integration

### Significance of Work for Individuals with Psychiatric Disabilities

Like other people, individuals with psychiatric disabilities wish to lead normal lives and view work as a signifier of normal adult life (Becker & Drake, 1994). In Western culture, work is highly valued and is considered a socially integrating force; however, many persons with severe psychiatric disabilities have been excluded from the world of work (Ahrens, Frey, & Senn Burke, 1999). In fact, estimates of unemployment are at a rate of 85 percent for working-age members of this population in the United States (National Institute on Disability and Rehabilitation Research, 1993). Despite a strong desire to work, functional competencies, and educational qualifications, many of those who have severe and persistent psychiatric disabilities have no long-term attachment to the labor market (Garske, 1999). Even when persons with psychiatric disabilities seek vocational services, they have success rates only about half of those persons with physical disabilities (Marshak, Bostick, & Turton, 1990).

Employment can serve as a normalizing factor since individuals who are unemployed and lack alternative societal roles are often stigmatized. Through work, individuals can obtain daily structure and may also develop a network of interpersonal contacts (Bond, Drake, & Becker, 1998). Involvement in work can help combat negative symptoms by facilitating a higher level of self-esteem and perceived quality of life (Fabian, 1992; Van Dongen, 1996). Therefore, the mission of psychiatric rehabilitation is to assist persons with long-term psychiatric disabilities increase their functioning so they are successful and satisfied in the environments of their choice with the least amount of ongoing professional assistance (Anthony, et al., 1990). Comprehensive psychiatric rehabilitation programs combined with effective medication management help such individuals meet the challenges of managing their disability (Lieberman, Corrigan, & Schade, 1989).

Psychiatric rehabilitation programs have sought to develop strategies to increase the community integration of people with psychiatric disabilities, including schizophrenia. To help people with psychiatric disabilities become and remain integral members of society, rehabilitation, vocational training, and assistance in work settings are essential. However, in many communities, the majority of people with psychiatric disabilities have only two options: to be unemployed or to work in entry-level positions with low pay and little chance of advancement (Carling, 1995). Work is a key component, some would argue the most important component, of services designed to achieve community

integration. In the context of psychiatric rehabilitation, work can be seen both as an outcome and as a highly effective treatment modality in enhancing meaningful community integration (Ahrens, et al., 1999).

## Intervention Approaches

Psychiatric rehabilitation can be a complex and formidable task. Without proper training and exposure to effective psychiatric rehabilitation strategies, the unprepared rehabilitation professional will easily be overwhelmed and may have difficulty contributing to successful intervention planning with individuals who have psychiatric disabilities. Moreover, the rehabilitation professional may lack the skills necessary to effectively negotiate important adaptations for the individual with the psychiatric disability on the worksite, with co-workers and employers alike (McReynolds & Garske, 2002). The current unemployment rate for individuals with psychiatric disabilities is more than 85 percent (Nobel, Honberg, Hall, & Flynn, 2001), in part because individuals with psychiatric disabilities often struggle with a wide variety of challenges and needs which likewise challenge the rehabilitation professional. Strategies for helping people with psychiatric disabilities obtain meaningful work have changed significantly in recent years. Successful work assistance approaches appear to have a number of common characteristics and include individualized career planning, help with job access, and aid in job retention; peer support; coordination with other social services and benefits; and assurances of confidentiality (Carling, 1995).

The recovery model, as described by Pratt, Gill, Barrett, and Roberts (1999) and as touted by Deegan (1988) and Anthony (1993), is a fundamental shift in perception regarding individuals with psychiatric disabilities. Recovery is viewed as a "reformulation of one's life aspirations and an eventual adaptation to the disease" (Pratt, et al., 1999, p. 91). Within this concept of recovery lies the belief that individuals with psychiatric disabilities can and do adjust to psychiatric disabilities by a process of acceptance of the disability and the development of a positive self-image. Further bolstering the recovery model are developments in improved medications, the use of supported employment, and the debunking of long-held myths perpetuating stigma and discrimination of individuals with psychiatric disabilities.

According to Bond (1995), psychiatric rehabilitation provides individuals with psychiatric disabilities the opportunity to work, live in the community, and enjoy a social life, at their own pace, through planned experiences in a respectful, supportive, and realistic atmosphere. Psychiatric rehabilitation typically involves helping individuals to gain or improve necessary interpersonal skills and provides a level of support required for clients to obtain their goals. The mission of psychiatric rehabilitation, therefore, is to assist persons with long-term psychiatric disabilities increase their functioning so they are successful and satisfied in the environments of their choice with the least amount of ongoing professional intervention (Anthony et al., 1990).

According to Lamb (1988), no part is more important than giving clients a source of mastery over their internal drives, their symptoms, and the demands of their environments. Various models have been developed in the United States that have provided individuals with psychiatric disabilities opportunities of community integration that were heretofore not possible and are discussed as follows:

### ***Clubhouse Model***

The Clubhouse Model is a comprehensive group approach that focuses on practical issues in informal settings (Bond, 1995). Clubhouses are community-based rehabilitation programs for people with psychiatric disability offering vocational opportunities, planning for housing, problem-solving groups, case management, recreational activities, and academic preparation. Individuals can learn or regain skills necessary to live a productive and empowering life. The Clubhouse Model provides for the

societal, occupational, and interpersonal needs of the person as well as medical and psychiatric needs (Fountain House, 1999).

Developed at the Fountain House in New York, transitional employment (TE) is an integral part of the Clubhouse approach. Clients, or members as they are called, are placed in part-time entry-level positions for three to nine months and are supervised by one another and/or rehabilitation professionals. Members work at a place of business in the community and are paid the prevailing wage rate by the employer. The placements are part-time and limited generally to 15 to 20 hours a week. The program is designed to develop a client's self-confidence, current job references, and improve work habits necessary to secure permanent employment (Anthony et al., 1990). TE continues to be an effective rehabilitation strategy in many mental health systems (Bond, 1995).

### ***Individual Placement and Support (IPS)***

The Individual Placement and Support (IPS) program was developed at the New Hampshire-Dartmouth Psychiatric Research Center (Becker & Drake, 1993). The IPS Model recognized that "work is so many things to so many people, we might define it simply as a structured, purposeful activity that we usually do in exchange for payment" (p. iii, Becker & Drake, 1993). The model draws from several psychiatric rehabilitation intervention models (e.g., ACT, choose-get-keep) in which clients choose from a range of work possibilities including full-time to various levels of part-time work to pre-vocational activities. Competitive employment is generally encouraged; however, non-paid employment options are likewise given consideration when deemed most appropriate for the particular individual's needs.

The vital component of the IPS model incorporates the success-driven concept of follow-along support provided by a core group of people who function as a team. The team generally consists of employment specialists, rehabilitation counselors, psychiatrists, and other mental health staff as needed. The treatment team approach provides a more seamless method of service delivery versus receiving separate services from various professionals in a non-coordinated manner. Clients are encouraged to be active and fully involved in the job-search process and are then supported through their employment with on-going follow-along (Becker & Drake, 1993).

### ***Community Support System***

The National Institute of Mental Health (NIMH) began the community support system (CSS) initiative in 1977. The intent was to assist states and communities in developing a broad array of services to assist people with psychiatric disability. This initiative eventually became known as the NIMH Community Support Program, with case management as one of the essential services (Anthony et al., 1990).

One of the leading models of CSS is the assertive community treatment (ACT) approach that works with clients on an individual basis providing services primarily in the client's home and neighborhood rather than in offices. ACT programs are staffed by a group of professionals who work as a treatment team in the community (Bond, 1995). In most ACT teams, staff provide a range of services to clients in their natural surroundings which include, but are not limited to, assisting with social service agencies, medication management, housing, employment, family issues, and teaching clients coping skills (Chinman et al., 1999). ACT, first developed in Madison, Wisconsin, has spread throughout the United States in recent years, especially in the Midwest (Bond & McDonel, 1991). The ACT team maintains frequent contact with clients and assists with client's concerns around activities of daily living (i.e., budgeting money, shopping, housing, taking medication, employment, problem solving on the job).

Community-based treatment of persons with psychiatric disability, as provided in the ACT model, focuses primarily on the teaching of basic coping skills necessary to live and function as autonomously as possible in the community. These coping strategies consist of activities of daily living, vocational



skills, leisure time skills, and social or interpersonal skills (Bond, 1995). Several characteristics of the ACT approach make it distinctive. The first of these is assertive outreach in which staff members initiate contacts rather than depending on clients to keep appointments. A second characteristic of ACT is its emphasis on continuity and consistency whereby care is ongoing and the services are integrated. Finally, ACT programs combine treatment and rehabilitation in a comprehensive and interdisciplinary approach (Bond, 1995). This case management approach has been widely adopted across the United States, especially for persons with psychiatric disability.

### ***Supported Employment***

Supported employment (SE) is another promising approach to helping people with psychiatric disability to succeed in the community. SE is one of the models of vocational rehabilitation that has been successful in helping individuals with psychiatric disability secure competitive employment (Ahrens, et al., 1999). It emphasizes direct placement in a community job, assistance in locating the job with the consumer, and ongoing job-related problem-solving and support after consumers obtain work. Individual placement is the key vocational strategy nationwide (Wehman & Revell, 1996). An evaluation of an SE program for persons with psychiatric disabilities found that clients were able to exercise more control over their career choices due to the client-centered approach used in SE programs (Block, 1992). By 1995, a national survey had identified 36,000 persons with mental illnesses who were employed in SE jobs (Wehman, Revell, & Kregal, 1997).

### ***Supported Education***

Although long overdue, another vocational improvement for people with psychiatric disability is in the area of education. Supported education programs have surfaced and expanded in the last few years, partly in response to problems experienced by people with psychiatric disability in more traditional vocational rehabilitation approaches (Mowbray, Mowbray, & Brown, 1993). Like supported employment and supported housing, supported education takes a rehabilitation approach in providing assistance, preparation, and advocacy to individuals with psychiatric disabilities who desire to pursue post-secondary education or training (Mowbray, Bybee, & Shriner, 1996).

Supported education as a program model has been nationally recognized as a promising method to improve employment rates (Anthony, 1994). A variety of supported education approaches have been identified, of which two of the most common are the structured classroom and on-site support (Mowbray, Moxley, & Brown, 1993). In the structured, or self-contained classroom, students attend classes with other students with psychiatric disability. In the onsite support model, students attend regular classes. Support is provided by the staff of the educational facility (Unger, 1990) and according to Mowbray and Megivern (1999), supportive education programs can and do work.

### **Conclusion**

Individuals with psychiatric disabilities have many of the same desires as other individuals in society – namely, to feel a part of the larger community. Work can, in many ways, help individuals with psychiatric disabilities achieve integration by providing a means to develop valued societal roles, reduce stigmatization, increase social connectedness, and serve as a normalizing factor. Rehabilitation professionals can play an integral and valuable part in the lives of individuals with psychiatric disabilities by integrating and implementing a variety of strategies designed to increase the community integration and independence of people with psychiatric disabilities through successful employment outcomes.

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# Make yourself at home: People living with psychiatric disability in public housing

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## Abstract

To be successful, community integrated supported public housing for people with psychiatric disability, must not only provide shelter but must also allow people to make the house a home. This study explores the ways people with psychiatric disability in an Australian supported public housing program experience their houses. The supported public housing program evaluated is SNAP Gippsland Inc. located in regional Victoria, Australia. This study employs in-depth, semi-structured interviews to explore individual, personal experiences. The interviews reveal that, to differing degrees, all of the participants experienced their houses as home and the major criteria which participants identified as contributing to the creation of the home were stability, privacy, identity, physical comfort, domesticity and support. However, lack of personal, domestic relationships and renting rather than owning the property limits the ability of some participants to identify their houses as home. The narratives of home presented by the participants also suggest that creating a home can assist with managing psychiatric disability.

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## Introduction

*I live in a two bedroom fully furnished unit. I feel safe. It is my home. I had the sort of lifestyle where I've been flitting from one place to another never spending any more than a year at the same place. Whereas now, thanks to Human Services and SNAP I've got a home for the first time. It's my home, they can't take it away from me unless I do something drastic which I have no intention of doing. It's*

*my home and they've made it feel like my home. You can put your plants and your pictures and have your friends around (Sheila).*

Sheila lives in a regional town in East Gippsland in Victoria, Australia. She is a client of SNAP Gippsland Inc (subsequently referred to as 'SNAP'), a psychiatric disability support agency that assists people with a psychiatric disability to live 'independently' in the community.

In this study we look at how people living with a psychiatric disability in supported public housing create 'a home'. We explore the ways they experience their houses and the meanings they place on their homes. Insights and information have been gathered through in-depth, semi-structured interviews with clients of SNAP. This evaluation of the SNAP Housing and Support program is based on our reading of the opinions and experiences of the clients themselves.

In 1995 Belinda Robson completed a comprehensive evaluation of the Victorian Housing and Support program (Robson, 1995). Robson's evaluation was based on semi-structured interviews and focus groups with tenants and support workers from a range of agencies within the program. Robson concluded that the program was highly successful in providing high quality housing and appropriate support and that clients' quality of life significantly improved while on the program.

In contrast to the broad parameters of Robson's evaluation, this study focuses exclusively on the experiences of the participants themselves and concentrates on one disability support agency - SNAP. The aim of this study was to assess the success of the SNAP housing and support program from the point of view of the clients. Unlike Robson's study, which focused on the physical housing environment, management and support, the intention of our study was to gauge the emotional responses and opinions about the non-material aspects of a home as well as the physical environment.

One of the essential criteria of successful supported housing, we believe, is that the accommodation is experienced as home (Ridgeway & Zippel, 1990:116). Therefore, an essential part of evaluating a housing and support program is to consult clients about their opinions and experiences of their housing. This study explores whether SNAP clients experience their houses as home and, if so, what 'home' means to them. It looks beyond shelter and physical comfort to the emotional, non-material aspects of a home. In doing so, it tries to give voice to people recovering from psychiatric disorders. From this we gain some understanding of the success of a supported housing program.

### **Snap housing and support program**

Australian, United States', Canadian and Scandinavian studies report that people with mental illness want to live in individual dwellings in the community, alone or with a companion of choice (Lambert et al., 2000; Owen et al., 1996; Tanzman, 1992; Tanzman, 1993; Middleboe et al., 1998; Keck, 1990). They also desire some level of support with everyday living that would be available when needed. In the last ten to fifteen years a 'supported housing' approach has emerged in North America, Western Europe and Australia which attempts to meet these fundamental needs of people with serious mental illness and ongoing disability. Carling suggests that supported housing is based on three interrelated principles of consumer choice, integrated community housing and flexible services (Carling, 1993:439). It aims to provide stable and affordable housing which emphasizes the principles of independence, integration through community living, enhanced quality of life, consumer choice and support as required and which is integrated into the general community (Hogan & Carling, 1992; Ogilvie, 1997).

In Victoria, Australia in the early 1990s the Mental Health Branch and the Office of Housing (sections of the Victorian State Government Department of Human Services) worked with psychiatric disability support organizations to establish a supported housing program for people with psychiatric disabilities in rural and metropolitan Victoria. This program is known as the Housing and Support Program.



SNAP became involved in the Victorian Housing and Support program in 1993/4 and now has 22 two-bedroom properties. Clients for the program are selected on a needs basis. They occupy their house alone, with children or a housemate of their own choice. Residents are tenants of the Office of Housing and receive disability support services from SNAP. The type of support provided is shaped by the clients' needs and desires but may include assistance with budgeting, shopping and other domestic activities. All clients require support when they join the program but, for some clients, the need for support may decline over time. They may stay in their houses as long as they wish, even if they no longer require support from SNAP.

The Office of Housing purchased fifteen units for the SNAP Housing and Support program in the regional towns of Bairnsdale, three units in Sale and four units in Lakes Entrance in East Gippsland. East Gippsland is a rural, predominantly agricultural area with dairy, wool and timber industries. It is sandwiched between the Victorian Alps and the Southern Ocean and has large tracts of relatively remote forest and mountain areas. The service center for East Gippsland is Bairnsdale, with a population of 11 000, located 277km east of Melbourne, the State capital. About 65 km west of Bairnsdale is Sale which, with a population of 13 400 is the largest town in the region and the administrative centre for offshore oil and gas industries and a RAAF military base. Both Sale and Bairnsdale have SNAP offices, where staff are based and recreational activities for clients are organized. Lakes Entrance is a small coastal tourist and fishing industry town east of Bairnsdale, with a population of 5250.

SNAP houses were spot purchased by Office of Housing and are located individually in residential areas about one kilometer from the shopping and service areas of the towns. Due to the unavailability of one-bedroom units, Office of Housing purchased two bedroom units in which clients have been housed individually. All the units are brick or brick veneer, built within the last 20 years. In addition to the bedrooms they have a kitchen, lounge/dining area, bathroom and laundry, small rear garden, and many have a garage. They are decorated in neutral colours and carpeted throughout the bedrooms and living areas. If needed, SNAP uses State government funding to supply a refrigerator, washing machine, television, dining table and chairs, cutlery, crockery and soft vinyl covered lounge suite.

## Methods

The project was funded by the Monash University Small Grants Scheme and ethics clearance was granted for this project by the Monash University Standing Committee on Ethics in Research Involving Humans.

At the time of the interviews twenty-one clients were involved in the SNAP Housing and Support program. (Two SNAP clients lived in the same house and two other houses were vacant while renovations were being completed). All of the clients were approached and four declined to be interviewed, two were hospitalized and one could not be contacted. In addition, one former SNAP resident, who left the program two years previously, was also interviewed. Therefore, fifteen people (eleven women and four men) volunteered to participate in this study.

The participants whose stories are told in this study are: Deanne, Helen, Jackie, Bill, Mick, Cathy, Jacko, Paul, Anne, Sheila, Barb, Heather, Maureen, Deborah and Joanne. They have been assigned pseudonyms to match the character, gender, age and ethnic origin of their real names. The participants all experience chronic psychiatric disability associated with schizophrenia, bipolar disorder and depression. Their ages range from late thirties to early fifties, except one participant who is in her mid twenties. With the exception of one Aboriginal person, all participants are of Anglo-European decent. Two participants recently began sharing a house but the others all live alone or with one child. While all of the participants' narratives inform this paper, we have focused on the stories of Deanne, Helen, Barb, Sheila, Cathy and Jackie whose stories exemplify the experience of the clients of this housing

and support program.

Rebecca Jones conducted in-depth, open-ended interviews with thirteen of the participants and John Monahan, a SNAP volunteer, conducted two interviews. Participants were interviewed individually and the interviews were tape-recorded then transcribed verbatim. Prior to the interview the project and its outcomes were explained to each participant, both verbally and in written form. Participants were then asked to sign a consent form agreeing to be interviewed and having excerpts from their interviews published anonymously. In the interview, a series of open-ended thematic questions encouraged participants to speak in their own words with few interruptions. Participants were asked: 1) to describe their house (both physically and emotionally); 2) what they liked and did not like about their house; 3) if the house felt like home and why or why not; 4) how their experiences of their houses have changed over time; 5) to describe their ideal house; 6) their opinions of the support services they received from SNAP. These thematic questions were followed by a series of prompt and clarification questions about the house, visitors, the neighbourhood, domestic activities, SNAP services and support, and demographic details of the participants.

The in-depth interview does not set out to obtain 'objective' information; its intention is wholeheartedly subjective and is designed to generate an individual's narrative and give interviewees scope to explain, in detail, their feelings, thoughts and experiences (Crabtree & Miller, 1991:146).

Interviewees elected where they wished to be interviewed, an approach designed to ensure the participants felt as comfortable as possible. Thirteen of the participants chose to be interviewed at home and these interviews were supplemented by observations of the house made by the interviewers. Two participants, Paul and Helen, chose not to be interviewed in their houses and were interviewed in SNAP offices.

### What makes a house a home?

Houses are places prickling with meanings. When a house becomes a home it ceases to be simply a shelter and becomes a space that contributes to emotional, non-material needs and well-being. Shelter and physical comfort are basic requirements of a house but do not, by themselves, constitute 'a home'. A home is constructed by attaching meaning to the physical environment.

Our theoretical understanding of the idea of 'home' has been shaped by the work of Somerville (1992), Csikszentmihalyi & Rochberg-Halton (1981), Rapoport (1981), Allan & Crow (1989) and Saunders (1989). Peter Somerville, in his analysis of home and homelessness, argues that home is both a socially constructed set of imagined ideals *and* an experienced reality. He identifies seven key signifiers of home: shelter, hearth, heart, privacy, roots, abode and paradise. 'Shelter' and 'hearth' relate to the basic physical aspects of a house such as the built structure, physical environments of warmth and, hopefully, coolness in the hot Victorian summer, while 'heart' represents emotional comfort and a sense of well-being. 'Abode' describes the home as a base for domestic activities and everyday living and 'paradise' describes the house as a place where ideals and aspirations are realised. Home as a private place is discussed by Somerville (1992) as well as by Allan & Crow (1989) and Saunders (1989). They discuss the importance of a sense of privacy, control and maintaining boundaries in developing a home. Macgregor Wise (2000) expands on this concept of privacy and control in exploring the ways people define personal territories in and around their houses. Somerville's concept of 'roots' describes the home as a source of identity, a place in the world as well as a retreat from the world. This idea is taken up by ethnographers, Csikszentmihalyi & Rochberg-Halton (1981) and Rapoport (1981), who focus on the role of the home in affirming and creating identity and explore the relationship between identity and physical environment. Csikszentmihalyi & Rochberg-Halton examine the importance of objects in personalizing space for urban residents of the United States of



America, while Rapoport provides a cross-cultural examination of the representation of personal and group identity in domestic buildings.

These theoretical discussions of home help us to understand the complex ways houses are experienced by their occupants and provided the context for interpreting SNAP clients experiences of home. Somerville's definitions were also particularly useful in helping us to shape the thematic questions used in the in-depth interviews with participants. As this project focuses on the housing experiences of the clients themselves, we did not allow the theories of home proposed by these theorists to dictate the structure of our findings. Rather, we concentrated on themes that emerged strongly in the client interviews and used the theories of home to broaden our understanding of SNAP clients' experiences. In the section below, we organize our findings using themes that emerged strongly in the interviews.

### **What the SNAP participants told us**

In common with the subjects of the studies mentioned above, the most important attributes of home, which emerge in these interviews with SNAP clients, are stability, identity, privacy, ownership, physical comfort, domesticity and love. In the following sections the participants of this project identify those things that make a house a home and discuss their significance to their lives.

#### Identity

*I guess it felt a bit sterile because it was quite modern and neutral and it didn't have a definite style or feel, a bit like a blank canvas. It also had vertical blinds. To me it just felt a little bit clinical, especially since I had previously lived in a mud brick cottage with lead light windows and a loft and wood fire cooking that was filled with character. So to make it less clinical I picked up some prints. It was great because we were allowed to hang things on the walls and I burnt candles and essential oils. In an op shop I picked up a lovely Chinese satin robe and pinned it up on the wall. It was gorgeous. I added my own touches, which made a difference. I bought bright colourful throw rugs ... I started to feel like it was my home and my son's home and took even more pride in it by planting a garden out the front. We planted lots of lavenders and daisies and a couple of really nice special things, a weeping cherry tree and a tree for a friend of mine who suicided. I wanted to plant something for him (Deanne).*

Personalizing her house with objects, décor, furniture and garden has made a characterless house feel like home for Deanne. One of the most important roles of a home is to reflect a sense of personal identity (Rapoport, 1981; Csikszentmihalyi & Rochberg-Halton, 1981, Somerville, 1992). SNAP clients do this by filling their houses with objects that they feel reflects their taste, life or personality. Deborah, whose unit is a repository for 200 Barbie dolls and 160 porcelain dolls that march in battalions across her lounge room walls, takes this need to extreme. Despite the fact that there is little room to move in her house she continues to acquire dolls and mentioned mildly: *I've added a few touches of my own.*

Furniture, while being functional, is also a means by which many people express individuality in a house. However, all but one of the participants use furniture provided by SNAP that conforms to a standard design with a choice of colours. SNAP clients were grateful that furniture was supplied and recognize its functionality but Deanne and Jackie both regret that they do not have 'their own' furniture that expresses themselves. As Jackie says: *Eventually I'd like to save up enough money that I get my own lounge suite, my own vacuum cleaner, my own TV. I don't like having things that are other people's. I like having my own things.*

Maintenance and decoration also creates a sense of ownership of a house through impressing individuality on its physical structure (Csikszentmihalyi & Rochberg-Halton, 1981). However, painting, carpets and structural repairs are too costly for most participants to contemplate and are the responsibility of the Office of Housing. Although this ensures an adequate physical living environment, it deprives residents of an opportunity to personalize their houses (Rapoport, 1981:21).

Only three participants made little attempt to impress personal identity on their houses. Mick, Anne and Jacko have almost no personal items, decorations or furniture other than that provided by SNAP. For Anne and Mick, home is elsewhere (with parents and with a fiancée, respectively, as discussed below). Jacko hasn't made his unit into a home because he has a desire to move away from Gippsland and live elsewhere. For these reasons, all three participants put little energy into maintaining, modifying and personalizing their houses.

#### Privacy and autonomy

*It's my home. No one can take it off me. It's safe. If I don't want anyone there I can tell them where to go. Its mine... I like having my own home because I can do just what I want to. I can have who I want to there. I can eat when I want to and go to bed when I want to... I know its mine. No one can tell me what to do there. I've become very possessive of it because I've never had anything before (Helen).*

In lives marked by psychiatric disability, hospitalization and, for some, abusive relationships, control over personal space is a reality, which, prior to moving into their SNAP units, has eluded most participants. Helen's SNAP house is the first opportunity she has had to have some control over her immediate living environment. This control gives her a sense of ownership.

Similarly, Paul sees his house as a place to withdraw, where he can do as he pleases: *I like to know I can go home and say, think and do more or less what you like in your own premises.* A home allows residents to retreat to a private world away from the scrutiny of others. It is a place where they have a sense of autonomy because it is a space over which they have control (Macgregor Wise, 2000; Allan & Crow, 1989; Saunders, 1989).

Living with a very active two-year-old, Jackie is less certain that she has complete control over everything that happens in her house so she has created a small space within the house where she can withdraw from the demands of the world. Pointing at the armchair in the corner of the lounge room she said, *you can sit in that seat and get away from whatever is going on in the house, even if it's really busy you kind of feel like no-one can get you.*

One of the ways personal space or territory is delineated is by including and excluding others (Allan, 1989). Bill described how important it is for him to control who enters his house and describes visitors as 'invaders'. *I can't handle people invading my space. When people come to visit me I get very anxious, worried and generally feeling uneasy.*

Despite feelings of satisfaction at the privacy and control that the SNAP houses afford, there are whispers of uncertainty from some participants about the degree of their control, as participants acknowledge the authority of the Office of Housing. When discussing changes they would like to make to the décor of their units participants used the term "If I am allowed" deferring to the external control of Office of Housing. Paul explained the importance of abiding by the rules of the housing authority: *You have got to abide by rules and if you can abide by rules you can conform and that is half the battle won.* Barb was more rebellious about submitting to external control. She was disgusted that her autonomy and sense of responsibility is undermined by being required to call SNAP to report maintenance problems rather than ringing Office of Housing directly: *It makes me feel as though I'm a little kid. If you're supposed to get better in your illness, why don't they let you try and do it yourself? Why can't they give you the responsibility?*

#### Stability

*I'd moved out of a relationship and I'd been moving around different caravan parks and different places and I was on my fifth move in a couple of years when they came up with this house. They brought me round here and I went 'I can't believe I've got this place'. Yes, it is really good. Really good. I mean if it wasn't for them I don't know where I'd be now, probably still be in a caravan park*

*or who knows where... This is the longest I've ever been in a place and I've been in here two years... .  
I'm*

*sick of moving around. The old brain thinks 'oh God I wonder how long I'm going to be here for before I've got to move again'. In relationships and as a child all I've done all my life is move from place to place and I tell you what, I'm sick of it. I'm really sick of it. You can never call any place your home (Barb).*

Stability and security of tenure is a theme that emerges as a vital factor in participants' experiencing their houses as homes. Most of the participants in this project, like many people with serious mental illness, have a history of disjointed housing and many have been homeless, living for extended periods in boarding houses, caravan parks and other temporary accommodation, or moving regularly between rented accommodation. For these participants, a SNAP house is the first opportunity many participants have had to enjoy stable, affordable accommodation.

Offices of Housing's tenancy agreements inform SNAP clients that as long as they meet their obligations (such as paying the rent and keeping the house intact) the units are theirs for life, or as long as they wish even if they no longer require support from SNAP. Participants expressed their relief at the stability this allows. Helen says defiantly: *It's my home. No one can take it off me. [This is] SNAP's house but its mine. SNAP don't get it back until I move. I'm going to die when I'm 80 so they will have to wait another 30 years. I don't have to give it up.*

Jackie feels simultaneously blessed and bound by the stability offered by her SNAP unit. While she enjoys the feeling that the unit is 'hers for life', she also finds the security restrictive. Because she is a tenant and not owner of the house, she is not able to leave her SNAP house without forfeiting her right to return. She therefore feels that she can't leave her house and her choices are restricted.

#### Physical comfort

*It is all really good. They haven't scabbed out. It wears well. It looks nice. They don't just go 'oh that will do'. It all looks very nice and they've tried to match it up. They don't send you into a place that's got holes in the wall, broken windows. You go into a nice place (Cathy).*

*The thing that I loved the most of all was the new carpet. It was a lovely feeling to walk in and find new carpet. Knowing that no one's been on that carpet before makes a big difference (Maureen).*

Physical comfort is an important criterion for a home. In these interviews, it emerged as a significant backdrop against which the emotional aspects of the home such as identity and privacy can be realized. Office of Housing selects units that represent a physically high standard. All the units were built within the last twenty years of brick or brick veneer and are well maintained. The furniture provided by SNAP is new (although subsequent tenants may 'inherit' the previous tenant's furniture). All of the participants were satisfied with the physical quality of their units. The newness and quality of the building, fittings and furniture impress tenants and give them a sense of pride and self worth. As Sheila summed up: *It makes you feel rich.*

#### Domesticity

*You keep the place clean and tidy, keep yourself clean and tidy, showers, vacuuming, just do your washing and clean up... make sure everything is clean and tidy. That you've dusted and vacuumed, garden is looking good and the front's been swept up. Everything that you do at home. If you had your own little home you'd keep it nice and clean and tidy (Heather).*

Heather chants these phrases like a mantra, as if she is reminding herself of the domestic tasks done by a 'well' person. She is playing the role of 'housekeeper' and her house is a home because she is doing the tasks 'normally' expected of a person living 'at home'. Home is a place where people conduct their everyday life and is associated with particular daily activities such as cooking, cleaning, sleeping and washing. These tasks take on additional importance for SNAP clients because they represent

‘normality’. Domestic activities can be important in creating purpose, particularly when a person does not have paid employment or child-raising responsibilities. Housekeeping becomes, in itself a purpose and an activity instilling the certainty of a routine into everyday life (Higgins, 1989: 167). Some participants also believe that the routine and order of housekeeping can assist them to maintain a sense of mental order: *"As you can see I keep the place pretty neat and tidy and organized. But that's mainly my state of mind. If I don't have things organized I become disorganized within myself. When I'm becoming unwell, if I know where everything is it doesn't take as much mind power"* (Jackie).

However, without the practical support of SNAP support workers most of these clients would be unable to maintain their homes.

#### Support

*I was able to get a support worker that would see me once a week and help with basic budgeting and food shopping. That was a big help because I'd been in a defacto relationship, been very unwell on and off during that time and so I hadn't had to completely look after myself on my own for more than ten years. I didn't know anyone in Bairnsdale and had no family. So I really need housing and support... I had to virtually learn to look after myself and my son all over again. How to budget, how to plan menus on a limited budget and shop appropriately. How to cope with the numerous disruptions because I was still unwell... We put in place a written plan. Its something you do together with your worker. It's a positive thing. You can sometimes fall off the track if unexpected things crop up so it gives you as sense of direction and also a sense that we are both working together, not them taking over your life (Deanne).*

For people whose lives have been fractured by illness or disability, everyday living can be a struggle. Without support services provided by SNAP, most clients, like Deanne would be unable to create and maintain a home and the linking of these services is clearly crucial to the success of the program. All SNAP clients require support when they first move into their houses but for some people their need for support declines over time. All of the people interviewed for this project received support except Maureen who now lives successfully without SNAP support.

#### Home ownership

*I guess I'm really lucky that I was able to find a way of buying a place. The irony is that I could have stayed in the SNAP housing for the rest of my life if I wanted. It was affordable, better condition and twice the size of the place I'm living in now you know what? Buying my house is the most wonderful experience. It is mine (Deanne).*

While most clients achieved a sense of ownership of their house by stamping their personality on the place with objects or through a sense of privacy and control, three clients felt their SNAP units could never be a true home because they did not legally and financially own it. Deanne left her SNAP house two years ago and now has a mortgage to purchase a house in a small town near Bairnsdale. For her, home ownership held an allure greater than modern housing and quality appliances. Similarly, when asked, *do you feel that this is your home?* Heather responded doubtfully *it takes a lot more money than what I've got to buy this place....* Jackie considers her lack of home-ownership to be an indication of lack of success, which makes her unhappy. Seventy percent of Australians own their own homes, either with or without a mortgage (Australian Bureau of Statistics, 1999: 5). Home ownership is often referred to as the ‘Australian dream’, indicative of security, independence and success and some SNAP clients, like many people in the general population, aspire to this dream.

#### Love

*I have no partner and no one to talk to at home. I never imagined I'd be a single mother. I get very, very lonely as a single mum 'cause you don't get much communication with your child. The most interaction I have is my thoughts when the TV is on, which is pretty pitiful from someone who was one*

*of the most popular girls in high school... To just living a lonely existence, going out once a fortnight, doing a shop, getting what you need to survive. My only friends are my caseworkers (Jackie).*

Jackie, like most of the participants in this project is haunted by loneliness and the absence of loving relationships has left a deep sense of loss. Home is a place conventionally associated with family, particularly the nuclear family, (Allan, 1989: 143) however family is notably absent from the lives of the SNAP clients and this absence prevents many from experiencing their houses as home.

When asked what would make his place feel like home, Paul, who lives alone, responded gloomily *People that are in it. People that are in it.* While Paul's loneliness is generalized, other participants deeply regret that children, parents and partners – the chief ingredients of the nuclear family - are not living with them. Anne believes 'home' to be the house where her parents live. Similarly, Bill comments: *My ideal house: I'd like my two children to live in the house with me (but I don't care about my ex, she can live in the shed!).* Only Cathy, who lives with her teenage daughter and is regularly visited by her fiancé Mick, does not appear to yearn for love.

In the absence of domestic relationships Barb, like many of the participants, symbolically brings children, grandchildren and parents into her house through photographs even though she is estranged from most of her family. Barb says the photographs make the house feel like home.

For some, like Helen, pets are a substitute for human affection: *Do you know what really makes it a home? Helen asked the interviewer. My two cats, because they are special. Try and take 'em off me – I'd move first.* Office of Housing tenancy regulations prevent most SNAP residents from having pets and until regulations changed in early 2002, the body corporates of many of the units also forbade pet ownership. Perhaps as compensation for not being able to own a dog, Barb has a one metre high stuffed English Sheepdog and a large ceramic German Shepherd in her lounge room.

## Discussion

The interviews with SNAP clients, undertaken as part of this study, serve as a means of evaluating the success of the SNAP Housing and Support program. They reveal the outstanding success of the SNAP and Office of Housing in assisting clients to make their houses into homes. The participants' stories also reveal the difference the program has made to the quality of their lives. Through the interviews, participants told us not only that they experience their houses as home but also what they believe their home to be.

The narratives of home presented above demonstrate that these clients of supported housing experience their houses as home in five key areas: stability, identity, privacy, domesticity and physical comfort. Stability emerged in these narratives as a crucial factor in allowing these participants to experience their houses as home. The opportunity of a permanent home was particularly important to clients, although some, such as Deanne, chose not to exercise that choice. A sense of home was also achieved by providing a space that can reflect residents' sense of identity and that they can personalize and stamp with a sense of themselves. A small number of participants chose not to personalize their space because they had reservations about their houses as home. SNAP units are also a space where clients have privacy and control; where they have autonomy to do as they wish and can create a personal territory by choosing who to include and exclude. The units are a place where, with the help of SNAP support services, residents can undertake domestic activities and maintain or reaffirm their sense of normality and 'wellness'. Finally, SNAP units are comfortable and well maintained giving residents a sense of pride and self worth. These last aspects of home described by the participants (identity, privacy, domesticity and physical comfort) correspond with five of Somerville's (1992) key signifiers of home: roots (a source of identity, a place in the world) privacy (territory and power to control one's boundaries) abode (a site for everyday living and domestic activities) shelter (the

physical structure & the material conditions which provide protection) and hearth (physical warmth and comfort). However, Somerville's remaining two signifiers ('heart' and 'paradise') are largely absent from clients' experiences of home, as described below.

The stories told by SNAP clients reveal three areas in which clients do not experience their houses as home. These are: 1) SNAP houses can't ensure that clients experience meaningful relationships; 2) a sense of control and ability to personalize their houses is somewhat reduced by the external control of Office of Housing tenancy regulations; 3) a small number of clients felt that their house was not a home because of their lack of equity in the physical structure. Of these three issues, the most strongly articulated is residents' lack of intimate, personal relationships. Participants felt that intimate personal relationships are an important aspect of a home, an idea supported by Somerville (1992), and yet they do not have them and their stories are infused with loneliness: either Paul's diffuse, generalized loneliness or Bill's, Anne's and Jackie's loneliness for specific people, such as children, parents and partners. For these participants, their current experience of home is associated with a sense of loss and is defined by something missing. However, in the absence of the particular relationships they desire, most SNAP clients chose to live alone, possibly recognizing the conflict between 'privacy' and 'heart' – autonomy and relationships – that is inherent in home life.

Psychiatric disability has affected personal relationships in the lives of these participants. Often the symptoms of their psychiatric illnesses such as depression, mania, and paranoia, combined with social stigma have contributed to the breakdown of domestic relationships. These symptoms also make it difficult for clients to share a house with friends. For clients of supported housing, the importance of relationships with friends, family and people other than staff has been documented as vital in maintaining a sense of well being, purpose and connection to the world (Robson, 1995; Goering et al., 1992). However, supported housing with its emphasis on living independently has, ironically, resulted in greater social isolation and loneliness than institutional living or group homes with their 'inbuilt' community (albeit an artificial one). SNAP's Housing and Support program attempts to alleviate the isolation of living 'alone' in the community by providing and encouraging social interaction between clients. This is facilitated through recreational activities provided at the SNAP offices in central Bairnsdale and Sale where clients voluntarily participate in activities such as community garden building, craft, bowling and a weekly 'drop-in' morning tea. While SNAP can, and does, provide opportunities for social interaction, providing intimate relationships is simply beyond the capacity of a disability support organization.

The second issue which participants mentioned as reducing their experience of home (although much less strongly than absence of personal relationships) was their perception of external control by Office of Housing. Clients' feelings of privacy and control and their ability to stamp their personal identity on their houses is modified by Office of Housing tenancy regulations which prevent participants from modifying the structure of their houses and limits tenants' abilities to personalize their environment and to own a pet. In supplying public housing, it is necessary for Office of Housing to balance the need to maintain high physical standards against the individual needs of the tenant. Office of Housing must also work within an allocated budget and assure the quality of life of neighbours. However, within these parameters Office of Housing and SNAP could investigate the possibility of, where appropriate, relaxing tenancy regulations and introducing a greater level of personal choice, autonomy and choice being one of the fundamentals of supported housing (Carling, 1993; Hogan & Carling, 1992; Ogilvie, 1997). In this way individuality may be accommodated and assist in increasing the 'homeliness' of the houses. Areas to be investigated could include tenant participation in purchasing, maintaining and decorating units.

Animals need regular feeding and care therefore pet ownership is problematic for people who often experience periods of hospitalization. However, rather than forbidding all SNAP clients from owning



pets, the individual circumstances of each tenant could be assessed, and pet ownership could be allowed in some circumstances, thereby again recognizing the individuality of people's circumstances.

The third issue which participants identified as preventing a sense of home is home ownership, which, to some extent corresponds with Somerville's (1992) 'paradise' as it embodies occupants' ideals and aspirations. Home ownership was expressed as an ideal by three of the participants in this project and one participant (Deanne) has left the program and is buying her own house. The current arrangement of the SNAP Housing and Support program relies on accommodating clients in public housing, a system which cannot currently allow personal ownership of the unit although it can, as noted, provide stability through security of tenure. SNAP and Office of Housing could work towards a system that allowed residents to purchase their units. This would give clients options and for some lead to a greater sense of home. However, in order to continue to provide a much-needed supported housing resource it would be imperative that these units were then replaced by additional housing stock.

It is important to note that lack of control and ability to personalize their houses as well as lack of home ownership is caused as much by poverty as it is by Office of Housing regulations. All of the participants interviewed are on the very low income of a disability support pension and home maintenance and decoration, let alone home ownership, is not a financial possibility. These issues may also be experienced by other members of the community without psychiatric disability such as renters of both public and private houses and other people on low incomes. While it is important to acknowledge these contradictions in participants' experiences of home, they do not detract from participants' overall experience and understanding of their houses as places where, with support, clients can create a home.

Participants identified with some aspects of home more than others, indicating that home is a place experienced not only in different ways, but also to differing degrees. Four men (compared to ten women) were interviewed reflecting the differences in numbers of male and female SNAP housing and support clients (fourteen women compared to six men). Therefore we can only draw tentative conclusions about gender differences in the understandings and experiences of home among SNAP housing and support clients. However, two points should be noted. Firstly, female participants valued home as a place for domestic activity more than any of the male participants did, reflecting traditional roles of women as 'housekeepers'. Secondly, there appeared to be no strong gender divide in the need to have significant domestic relationships. Given the lack of variation in age and cultural background among the participants and the lack of information on class background, few inferences can be drawn about these factors.

Houses are not just a physical structure but are an important way a resident can realize emotional and non-material aspirations. While important to many people, home is particularly significant for these participants because it allows them space to create many of the things that are lacking in their lives. The symptoms of psychiatric disability and associated social marginalisation that the participants experience has resulted in factors such as lack of control over their lives, poverty, instability, inability to perform tasks of everyday living and social isolation. The significance of creating a home is that it can give people with psychiatric disability a sense of self identity through personalizing their space; a sense of control through maintaining a private place where they can do as they like and can control who enters and exits; a sense of purpose through domestic activity; a sense of self worth through material quality; and, finally, it provides a sense of stability by maintaining a permanent dwelling. The support they receive from SNAP is crucial to their ability to achieve this sense of home, a finding which supports Robson's (1995: 88) conclusion that for people requiring psychiatric disability support, housing and support are integral to each other and each will not truly succeed without the other.

The creation of a home, even with the ambivalences that this entails for people with psychiatric disability living in public housing, is one means by which people living with chronic psychiatric

disability can create a space that belongs to them and to which they, in turn, belong. In addition, there is some correlation between the well being of individuals with psychiatric disability and their housing conditions with better physical housing conditions related to greater quality of life (Baker & Douglas, 1990; Nelson et al., 1998; Earls & Nelson, 1988; Robson, 1995). As noted above, comments made by participants in this study suggest that 'making themselves at home' may assist people to live with and manage psychiatric disability by providing order.

## Conclusion

The narratives presented in this study have provided a means of evaluating the success of the SNAP Housing and Support program. By listening to and analyzing these stories we have been able to assess whether the clients of the program consider their houses to be home and how they define that home. To be successful, mental health services must reflect clients' preferences and desires. Consulting clients about their opinions is an important part of any mental health service, particularly a supported housing program. This study, employing in-depth interviews, reveals individual stories and experiences and focuses on narratives of the participants themselves. The answer that resonates loud and clear is that SNAP and the Office of Housing are very successful in assisting clients to create homes in their houses and that this is integral to the success of this supported housing program. This study reveals that the SNAP housing and support program successfully provides valuable opportunities for clients to make public housing into homes by providing stability, a sense of identity, privacy and control and a space for domestic activity. However participants revealed that their sense of home was modified by the lack of loving relationships, some tenancy regulations and lack of home ownership. While SNAP already encourages friendships among clients, creating loving relationships is beyond the scope of a disability support agency or the Office of Housing. SNAP Housing and Support program is encouraged to seek ways to accommodate home ownership for those who desire it and a greater sense of control and individuality, while continuing to balance responsibilities to clients and the general community.

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# Psychosocial rehabilitation in Brazil: the impact on everyday life

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## Abstract:

This article describes the centralization of the therapeutic work on the aspects of everyday life of the users' mental health service, emphasizing psychosocial rehabilitation, while a social practice geared towards the rebuilding of identities and possibilities for mentally ill people. This study was developed at the Mental Health Community Center in São Lourenço do Sul/RS, Brazil, the so-called "Nossa Casa", taken as a practical mark in a new way to approach mental diseases. This research consists of a qualitative study in which we make use of the Marxist referential, with the dialectical materialism as a theoretical substrate in order to interpret reality. The instruments used were semi-structured interviews with ten persons from the mental health staff. The thematic analyzed consisted of the centralization of therapy work on the average users' life aspects focused by the interviewees, such as the possibility of searching autonomy and citizenship.

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## The scenery of the study:

This study was developed at the Mental Health Community Center, São Lourenço do Sul/RS, Brazil. The mentioned institution is characterized by offering integral attention to mentally ill patients, through a network of attention services to mental health. This institution started to be structured in the year 1988 attending the initial necessity of taking care of mentally ill patients in town. The Mental Health Community Center comprises a mental health network, as follows: Psychology and Psychiatry Ambulatories; "NOSSA CASA" – CAPS - Psychosocial Attending Center and the parent-cell of the project; Therapeutic workshops; a Psychiatric Unit at the General Hospital; Children and Adolescent House; "Nosso Lar"- protected home. The network is accredited by "Sistema Único de Saúde" (SUS) and gives attendance to the rural and urban population of the municipality. The mental health service

runs daily, from Monday to Friday, through interdisciplinary teams. The emergencies are attended at the local hospital, which is the entrance door for hospitalization cases. In "NOSSA CASA" the daily average number of users is from 25 to 30 patients. The number of attendance is about 1.300 patients per month.

The users of the Mental Health Community Center comprise patients with mild to severe mental disorders – neurotics, psychotics, those discharged from psychiatric hospitals, organic psychosis. The average time for internment in the Psychiatric Unit is approximately 10 to 12 days, a considerably short time, because as soon as the patient shows improvement on the reasons that took him/her to the hospital, he/she is then transferred to "NOSSA CASA". In this place the remaining time is discussed with the team, and also factors and facts which were relevant for the current situation, such as his/her familiar situation, social network, employment, among others.

"NOSSA CASA" team is composed by one nurse, two nurse attendants, eight therapeutic attendants, a psychiatric doctor, three psychologists, one home economist, two general service attendants, one cook, one driver and one office boy. One of the authors (A. H.) used to work in this duty for 10 years as a therapeutic attendant, as a nurse and as an administrative coordinator.

The Mental Health Community Center is aimed towards the community mentally ill patients under the perspective of psychiatric reform, and focuses on: (i) permanence of patients in their own environments, them patients to remain closer to their families and social environments; (ii) integral attendance to meet individual needs; (iii) the respect of individual differences; (iv) rehabilitation practices and social reinsertion.

### The path of the study

This is a qualitative study that uses the Marxism referential, the dialectic materialism, as a theoretical background for the interpretation of reality. Abstracting the question negation-overcoming for the referential of psychosocial rehabilitation from the dialectic conception, we considered necessary to deny the assistance reality of the individuals with mental problems centered in the model of the damage, in the deficit towards the rescue of centralization of the focus in the abilities, and the search of work to reach the aims of psychosocial rehabilitation, citizenship and quality of life.

We recurred to the definition of psychosocial rehabilitation produced by experts from several countries and compiled in a document called "Declaration of Consensus in Psychosocial Rehabilitation" which states that psychosocial rehabilitation is a process which facilitates the opportunity for the individuals – who are prejudiced or disabled by a mental disorder – to reach a great level of working independence in the community. This implies both professionals and users to improve competences and introduce environmental changes in order to create a better quality of life possible to people who experiment a mental disorder, or have a mental deterioration which produces a certain degree of inaptitude (WHO/MNH/MND/96.2).

The instruments used were semi-structured interviews with ten integrants of the mental health team. An official letter was sent to explain the thematic of the research requiring collaboration in the phase of interviews. Thus, the conventional directions started and the subject was discussed in meetings of the team. After the testing of the instrument (the interview itinerary) the ten semi-structured interviews were performed with the workers from the Mental Health Community Center, such as, psychologists, psychiatrics, therapeutic attendants, nursing attendants and workshop instructors. As a delimitation criterion, the individuals were selected among the employees working for, at least, five years in the institution. The interviewees are identified in the text by letter "A" and the number of the interview (for instance: A1, A2, ...).

## Centralization of therapeutic work in the aspects of users' everyday

This thematic area contemplates the actions of the individuals, in their the everyday service and the importance attributed to the different practices of psychosocial rehabilitation. The user's conception, while a person not as a nosology adding leads the actions for intervention centered in the individuality of each human being. The approach in everyday life aspects constitutes itself in attendance practices implanted in the service. The practices considered consistent with the philosophy of doing but not ruled on the traditional model are addressed. Dissociation between illnesses and person is evidenced, and also the centralization of practices toward the person, without disregarding the aspects concerning the treatment.

*The practices of everyday life are the first step for psychosocial rehabilitation of the individual and, mostly what makes one a citizen... When we give a person a treatment we treat things differently than when we treat a diagnostic. This is the practice of this service. To treat people, citizens. With identification card, address, family (A1).*

Goldberg (1996a, 1996b) emphasizes that in front of the patient we cannot place ourselves a priori in the knowledge of the object. He illustrates that with the psychiatric clinics, in which he always tries to learn with the patients' disturbs, not to reproduce them. He also suggests that the centralization towards the symptoms constitutes itself the referential adopted in institutionalized models, which reduces and includes the patient in standardized behavior, independently of the presented psychosocial characteristics. The clinics, according to the author, based on institutionalized models, admits typifying the manifestation of diseases, while a strategy to reach the specificities. However, he emphasizes that only an operative and an ethics clinic will be able to establish differentiated therapeutic interventions.

We understand that the new services should correspond to a renewed clinic, with differentiated treatments, and where concomitantly or in sequence, therapeutic projects that contemplate the psychosocial needs of the involved people be developed. This is what might effectively bring a person to be a citizen. It is important to point out that the projects cannot constitute themselves as models built from professionals, but built collectively with the most interested people: the users.

According to Saraceno (1999) the services are constituted as a variable that has influence on the rehabilitative process. The author points out the capacity of the service in looking after all patients and giving them possibilities of rehabilitation as a high quality service. He states that the services, which do not offer these possibilities, generate intervention hierarchies and those who are less qualified are excluded from the process. Saraceno (1999:96-97) points out that a high quality service should be permeable and dynamic, with high internal and external integration "... a service where the permeability of knowledge and resources prevail on the separation of them", and in which the organization is "oriented towards the necessities of the patient and not the service".

We understand that internal and external integration is due to the movements which transpose the treatment and the psychosocial rehabilitation. This integration will be possible and concrete if professionals visualize the importance of no dissociation, and assume both the treatment and the rehabilitation. The idea of this proposal faces a resistance that is sometimes established in everyday services: the treatment given by some and the rehabilitation by others.

In "Nossa Casa", most of technicians are detained on the treatment and on the formulation of rehabilitative proposals on intellectual level, while non-technicians make the proposals to work on a practical level, that is, a separation between who provides treatment and who provides rehabilitation prevails. The attempts of re-approximation occur through meetings of the team, where specific cases are discussed individually, and where a rescue and an integration of both treatment and rehabilitation



are approached.

Bandeira (1994), analyzing the importance of communitarian infrastructure in the social re-insertion program, in a controlled group evaluated during three years, concluded two essential aspects for the increasing of successful probability of mentally ill patients social reinsertion, such as, quality of the program, where the basic abilities for everyday life in the community is included, individualized follow-up and attendance to patients in crisis. The second aspect is concerned to the quality of home environment. Patients' active participation in the activities of the house, the establishment of objectives, individualized orientation is included in this item.

*We try to make our patients to retake their lives closer to reality, as much as possible. We try to make them retake some daily activities that they have lost, sometimes, because of the illnesses. Activities like personal hygiene, ..., shower, shaving, nails, hair, in order they get their vanity back. Besides, we try to retake some activities with them, some in the kitchen-garden, who have already done this kind of work, others in carpentry, others in protected factories... To try to look after their own houses, to take care of their own lives, to have leisure... (A9).*

Through the talk it gets clear that the centralization of therapeutic work firstly begins on the difficulties installed with the illness, in relation to the development of activities people can do in their everyday life. That is, common elements of a person's everyday life are worked, which for people who have disabilities or are handicap are not really common, to gradually open the options of intervention. The rehabilitation process has its beginning in everyday activities, such as to take care of their own body. Then, the aspects concerning activities developed before the illnesses are worked on. The work runs from a protected context to the occupation of real spaces in the community. The users' priori abilities are considered and reinforced, and the disabilities are worked.

Bandeira (1998), searching psychotics' social competence, through social validation of specific abilities, regarding verbal, non-verbal, paralinguistic, of expressivity's components and abilities of solving problems, concluded that the higher difficulties happen in relation to the verbal component and problem solution. The aim of the author was to evaluate the training of social competence of mentally ill patients, compared to a reference group of their own community. According to Bandeira's (1998) review of literature, the results of social abilities training improved the level of social competence and decreased the number of patients' re-hospitalization. The author understands that the efficacy is higher when many components and several social situations are worked. She also highlights the importance of including the practices performed in the natural setting where the patient is inserted.

From this research we can apprehend the importance of recognizing the environment in which the individual is inserted, so that the formulated proposals be coherent with the social environment and its demands for mentally ill people. We understand that the environment contextualization, the culture in which the person is inserted works as a thermometer in determining the validity and importance of the aspects to be focused in the training of social competence.

*When a person is treated, his/her inter-relations, way of dealing with the family, with the work, with the house, with the recreation, with that entire are treated. What is good for myself is good for the employee and is good for the patient. The traditional practices many times forget this. From the point of view of clothing, name, housing, of all these concepts which are very important for us and that become important in the model of psychosocial rehabilitation, where we first rehabilitate the person, his/her working conditions, then his/her condition out of the treatment.*

(A1)

The work also appears as a rehabilitation factor on the interviewees' speeches. It is important to highlight that this is not as accessible to mentally ill patients as it seems to be. This is a reality which cannot be denied, mostly if we consider that São Lourenço do Sul is a small town, with relative difficulties in work market for the "normal individuals". This reality is not different from the reality in other cities, with similar population characteristics. Regarding big cities, difficulties will certainly be bigger: firstly, the dispute for job is bigger, and, secondly, small centers probably take advantage regarding protected work.

We have mentioned a situation that has been characterized as a protected work: daily patients followed by an attendant used to go to a big workmanship, which was going to be repaired to be a branch of a supermarket in the city. These users, in a protected policy, worked effectively on civil construction. Businessmen who welcomed the proposal followed the whole process. The work for mentally ill patients, besides the challenge which represents, needs primordially discussion on mentally ill patients' rights and the recognition of these rights by society.

According to Saraceno (1999, p. 131) "... the work is identified as an "instrument" of rehabilitation, subordinated to healing and, successively, as an indicator of success of the healing itself, thus, a return to normality indicator".

Some authors like Cohen (1990), Ciardello and Bell (1991), Pitta (1996), Saraceno (1999) and Pratt et al (1999) have deeply discussed about the work while a promoter of psychosocial rehabilitation having in one's mind the possible benefits acquired in the personal, relational and communitarian context, deriving from there. The occupational rehabilitation (vocational rehabilitation), principally in the Anglo-Saxon model of psychosocial rehabilitation, is explicit as a central principle of the process. In the pragmatic model, people are requested to produce in economical terms. In Latin American countries, a focus has been given on the rights of mentally ill patients. This is a basic necessity to be worked with society. Without this previous understanding from society, the effective occupational rehabilitation will not have chances to be materialized as a right, but as a concession.

Rehabilitation, according to the interviewees, is divided into distinct moments in which "... first we rehabilitate the person, his/her work condition, then his/her life out of the treatment" (A1). Goldberg (1996b) points out that treatment and rehabilitation are in dissociable. He states that for a patient to be rehabilitated it is necessary to offer continuous treatment.

We understand that the initial treatment of productive symptoms is the first intervention to be done. Within a broader perspective, we consider the diagnosis of this person's life extremely important, and the subsequent establishment of a therapeutic project from the context in which the person is inserted. They must be sufficiently flexible to incorporate changes, and to possible re-dimension. We highlight the necessity of reading the context within a change of optics. Usually this reading is done over the deficits, the negative aspects. To emphasize the forces, the health aspects, is an important transition in the treatment and rehabilitation process is as well as the notion in unsociability of both of them.

Lieberman (1998) states that the programs of communitarian support serve as environmental protectors, through the reduction of harmful effects of the critics, absence of support, social and emotional over involvement in vulnerable individuals. According to the author, communitarian support might strengthen the protective effects in the training abilities of chronic mentally ill patients. The author points out that the learning of abilities to solve problems, conversation and vocational abilities, and self-help abilities, within a communitarian support context, capacitate the vulnerable individuals to

establish realistic aims and to promote clinical and social aspects. Communitarian participation is viewed as the responsible for the decreasing of recurrence and for a suitable social adjustment. As well as the learning for changes and to solve problems of everyday life.

*I am going to quote some examples that we use in our everyday life... we have here a big group which we take it to play soccer; there are two schedules and gymnasiums and take these people. So, about fifteen people we always take (A2).*

*We also have leisure activities. Soccer, we go to the community to play. We have a choral, which makes presentation in several places, here, in the city, and also out of it... we have ...tickets, leisure excursions with them, and journeys to the beach. We go to "Rei Clube" to play snooker, ping-pong, among other things... (A9).*

The using of collective spaces in "normal" times is a current practice in the service. Sports here are also an aggregated factor, which provides entertainment and leisure. The fact of arrogating legitimately social spaces, is not a concession or a favor, it is a conquest that was reached over the years. Not always the establish relations with the community were like these. If by one side there were requests for a kind of assistance which would bring resolution and put an end to revolving door, initially the fear, the preconception and the stigma raised barriers, walls, which were thrown down along of the time.

Morgado & Lima (1994) comment upon the models of de-institutionalization, having this process in countries like the United States, Italy, Canada and England as the basis for its analysis. Regarding the United States, they refer to the process of de-hospitalization. This understanding, however, cannot be conceived as de-institutionalization, since in this country this practice was reduced to de-hospitalization. The authors point out five serious consequences of de-hospitalization, such as: abandonment of critical patients, high rotation of patients – characterized as revolving door, non-monetary cost by mental disease, problems with justice/police and policies of de-institutionalization movement.

Although not agreeing with the analysis of Morgado and Lima (1994) regarding de-institutionalization (de-hospitalization), we agree with the authors in relation to the characteristics of a good mental health model. Two pre-requirements are considered essential for the implementation of the program, which are: acceptance of the program by the community and the preparation of human resources. Regarding the acceptance of the program by the community, two aspects were characterized, such as the assurance of the participants' objective conditions for the effective engagement in the activities, and subjective dimension of living in community with mental ill patients. In relation to the latter, the authors point out that this dimension is clear by its opposite, that is, the tendency to internment. Well-prepared human resources include the secure handling of basic pharmacology, focal psychotherapy and family therapy, communitarian psychiatric nursing and social service.

We understand that in the service under study these requirements were totally reached and even overcame in several aspects. In structuring the service, the community was always actively involved. This involvement was formal, when the presentation of the program to the alderman chamber and informal through the establish interactions with the community, such as, talking about mental health in several collective spaces (churches, associations, schools, means of communication), in promotions, in the invitations to the community in anniversaries of the institution, in the trade of vegetables from the kitchen-garden produced by the users to the community, in festivals, as well as the visits of the

community to the house, firstly impelled by curiosity then by solidarity. This involvement happened through several ways, such as, through visitation of school children, aiming to know the service, and also by the work of professionals in schools to talk about mental health and insanity. These actions produced a favorable impact in the demystification of insanity. In the community, it was possible to observe clearly the dialectic jumping: from initial rejection – a house for crazy people located in a noble area of the beach – to projects developed with businesspeople in town.

In the analysis of the communitarian infrastructure formulated by Morgado & Lima (1994), it is evident that the community interactive context is central for the establishment of a good attendance system in mental health. The authors visualize the revolving door as the best indicative of communitarian assistance and the direct indicative of hospital assistance.

We agree with the authors and we consider the community engagement crucial for the formulation of any proposal of de-institutionalization. However, we considered a tendentious perception of the authors that, through the example of revolving door, want to make people believe that there are not available means to keep patients inside the communitarian structure. We understand that transformations occur, more concrete, in the micro spaces, through the deconstruction of a maniacal model strongly deep rooted in the professionals and the common sense. This means to take responsibility with the process of renovation, while the attribute to other organisms, results in non-responsabilization.

*Another thing is, for example, a patient who is willing to ... I'm going to buy a piece of cloth. We go out with these people and go through the city, to the shops and we choose clothes for them, they will look ... this fits on me, this one doesn't... we help him/her to buy, with his/her money. Another thing we do, in the example of everyday life ... we have a choral ... it is a choral here in the house, but it is open for the community (A2).*

Small everyday acts are shared with therapeutic fellows, such as go shopping. These acts end in a routine practice which does not cause amazement to sellers and store owners. Very soon patients are recognized and identified by being from "Nossa Casa". This recognition is not just because of the "faces" of mentally ill patients, but because it is a small city where people know each other, and mentally ill patients lived and established relations with the population. These factors corroborated for the city to show itself as the best setting for the development of real changes, where through real situations, with their variables, the difficulties of the users can be worked out. This "real laboratory", in real life, is revealed to be the best school of psychosocial rehabilitation for the users and a learning for the team.

*I think like that, I think it is not only they do something in the workshops, you know, to sew, to embroider, etc. I think like that, ... it changes the hygiene, that ... think like take care of the house, we talk a lot about that with them (A3).*

*Another rehabilitated mechanism ... is the self care... we try somehow to make the patient like any other human being that walks in our city ... Anyway the hygiene, that is practiced by nursing, it is ... it is one of the factors not only in relation to people's health to keep clear, but also a rehabilitated thing, in the sense he/she doesn't feel ashamed. Many times, when the crisis is over she feels the same way of any other person that is within the team that is going to the house (A8).*

The care with him/herself, through healthy and suitable hygiene habits, the management of the house

and the several aspects involved here are discussed with the users. The making in the workshops appears as a non-priority factor for re-habilitation, firstly the capacity of performing everyday tasks appears, inserted in a specific context, because the latter two are seen as activities that change important aspects in the users' life.

We rescue the differential between the entertainment and rehabilitation approached by Saraceno (1999). To do something is seen as a synonymous of entertainment, fulfilling the time, even if many times it is automatic, useless, repetitive and non provided of finality. In this context, the entertainment reduces the human being to a mechanic, stereotyped repetition of some activities, in order to fulfill the time, since inactivity is not tolerated.

We share Saraceno's (1999) opinion regarding the search of disruption of entertainment in the services of mental health. This disruption must be approached in two fronts: the disruption of entertainment of the team which gives assistance and the disruption of users' entertainment – who are the receivers of entertainment formulated by the teams.

*And I think like that, that he/she in the workshop, he/she learns something. Because we have carpentry, we have upholstery, there are the packs, there are several workshops. And I think that he/she learns something, and I think this brings benefits for him/her ... after he/she leaves here, even at home, if he/she wants to do something to sell or ... I think this will benefit, the workshop itself (A4).*

The learning, in this context, starts being noticed in a different way from to do, of the entertainment. There is the being here and afterwards, to do something to keep him/herself. Thus, there is the idea of transitivity, the passage through the institution and the return to life he/she had before getting sick. Nossa Casa, after the users' discharge, becomes a reference point in which they run to help when they need.

*Well, knowing the users, knowing their history, we start working on things they have missed because of their disease, for example: if he/she was a rural worker, we try to engage him/her in an activity in this sense ... (silence). Always putting him/her inside its reality ... helping, supplying, many times facilitating, the best way (A10).*

The centralization of therapeutic work having as its base the story of life and not the deficits, in the diagnosis, in summary, the disease is taken as a rehabilitated factor for the users. The respect to habits and these users' culture and the reinsertion in their origin activity is evident. The respect to culture can be expressed, also, through simple everyday activities, such as, a home visit to a patient that only speaks German and/or 'pomeran' dialect by a worker who understands and speaks the same language, is a routine practice.

An activity that workers understand and express themselves in 'pomeran' is the therapeutic group in the rural zone. During many years one of the authors (A. D.) took part in this group. Because of the same language and culture, the users express themselves easily, naturally. To facilitate the best way does not mean to choose by the people. It means to help, to be present, in the choice of several possible ways and to provide support during the process.

Analyzing the data obtained, we learn that everyday life practices constitute themselves a priori in the service. The focus is directed for a responsible care, based on real appropriation of collective spaces. The rehabilitative process is centered in the individuals' necessities and possibilities, in their life stories where previous abilities are considered and reinforced and the cultural context in which the

person is inserted.

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# Access to Higher Education for the Mentally Ill: A Review of Trends, Implications, and Future Possibilities for The Americans With Disabilities Act and The Rehabilitation Act

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## Abstract:

Significant strides have been made for those with disabilities in obtaining access to higher education for the purpose of pursuing independence, life goals, and being productive members of society. Yet, one area of disability that has not made as significant gain as others is mental illness. Those who have a mental health diagnosis—regardless if the diagnosis is being controlled or is resolved—face undue discrimination in spite of legal protections afforded by such federal legislation as Americans with Disability Act. This article provides an analysis of several contemporary United States federal court cases involving students who have or had a mental illness. This analysis sets out to demonstrate that "otherwise qualified" has a different interpretation when applied to the mentally ill.

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## Introduction

The diagnosis of a mental illness is a powerful social label. For those diagnosed, the social stigma of mental illness too frequently becomes a master status. Not only do many in society look at the mentally ill with moral disgust, hostility, and fear, but also for those diagnosed there is often the reality of social isolation, an absence of self-esteem, and a bleak outlook for the future (Link & Phelan, 1999). Perhaps the true strength of this stigmatizing label is witnessed best at that time the patient becomes asymptomatic. The stigmatizing effects of mental illness can long outlive the disorder itself. Not all forms of mental illness represent lifelong conditions. Mental illness can resolve. Moreover, many types of mental illness do not render the patient completely dysfunctional. Some people who suffer from mental illness are able to function at relatively high levels especially when following through with an ongoing treatment plan.

Those who once suffered from mental illness or must manage and control their psychiatric symptoms face intimidating obstacles in their effort to become reintegrated back into mainstream society (Link & Phelan, 1999). Bearing in mind many forms of major mental illness such as schizophrenia often manifest initially in late adolescence or the early 20s, it would seem logical that for many former mental patients the process of reestablishing a healthy life would include the pursuit of formal higher education. Higher education is a socially accepted means by which we pursue our life goals and meaningfully participate as productive members in society. Yet, the walls within higher education do not readily offer sanctuary for the mentally ill from the stigma of their condition. "[M]ental health service providers may not be providing these individuals with support for their educational endeavors" (Mowbray & Megivern, 1999, p. 32).

It is the purpose of this paper to point out that for the asymptomatic mental patient and former mental patient access to the world of higher education poses yet one more obstacle. The institution of higher education is a reflection of the larger society; it is a microcosm for the larger society. We will find within it the same values, beliefs, and prejudices that we find in society as a whole. This paper will explore the legal standards established by the courts and policies of higher education in addressing issues of admission and access for the asymptomatic patient and former mental patient. Specifically, this paper will explore the legal protections afforded to the mentally ill in seeking access to higher education by reviewing the 1973 Rehabilitation Act and by reviewing the Americans with Disabilities Act. This paper will go on to analyze how the courts have interpreted these protections for the asymptomatic and former mental patient by reviewing several contemporary federal court cases. Finally, recommendations for potential policy revision and reform will be offered.

### The Rehabilitation Act and The Americans with Disabilities Act: How it Ought to Be

Students with disabilities, such as mental illness, who are otherwise able to meet the criteria for admission and academic performance are afforded various protections in the United States under two pieces of federal legislation: The Rehabilitation Act of 1973 and the Americans with Disabilities Act. These two acts collectively help to ensure that institutions of higher education make reasonable accommodations to those with disabilities by using federal funding as political leverage. In this section, we will briefly explore the basic foundation and purpose for each of these two federal acts.

With its passage in 1973, the Rehabilitation Act (RA) required that all postsecondary institutions receiving federal funding make their programs accessible to those students with disabilities. Institutions that participated in federal funding programs were now prohibited from denying access to students with disabilities. Such access did not, however, apply to all students with any disability. Rather, it applied to those with a "qualifying handicap." As the RA states:

No qualified handicapped student shall, on the basis of handicap, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any academic, research, occupation training, housing, health insurance, counseling, financial aid, physical education, athletics, recreation, transportation, other extracurricular, or other postsecondary education aid, benefits, or services to which this subpart applies. (§104.42)

This concept of a "qualified handicap" was clearly defined in the landmark Supreme Court Case of *Southern Community College v. Davis*. Ms. Davis, a nursing student, was denied continued admission in her clinical nursing program because she was deaf. The community college she



attended believed that her hearing disability posed a safety risk to patients and there was no "reasonable" means for the disability to be accommodated. Ms. Davis sued and the community college initially prevailed. Ms. Davis appealed the decision, and the higher court then found in Ms. Davis' favor. The court ruled that Southeastern Community College must evaluate Ms. Davis without consideration of her disability. The college appealed to the United States Supreme Court. The Court was essentially being asked to decide if "otherwise qualified" means that one is able to perform in spite of the disability or that the disability may not be considered in assessing the candidate's propensity to perform in the academic program. The Court ruled that "An otherwise qualified person is one who is able to meet all of the programs requirements in spite of his handicap" (*Southeastern Community College v. Davis*, 1979, p. 406).

Therefore, institutions may deny access to the disabled if their disability inhibits their ability to reasonably complete the course of study, but not if the disability can be reasonably accommodated for rendering the student "otherwise" able to perform. For instance, a technical college could deny admission into a dental hygienic program to a blind student because there exists no reasonable way to accommodate for the disability. But, admission could not be denied to the same student into a history department because the disability could be reasonably accommodated. Reasonable accommodations may include, for instance, having books read onto tape, classroom note-takers, use of tape recorders, or the use of service animals.

With the passage of the Americans with Disabilities Act (ADA) in 1991, the implications of the RA were broadened. Title II of the ADA not only applies to schools receiving federal funding, but it also applies to all public entities regardless if they receive such funding. The ADA also expresses broader goals. As McGovern (1992) explains, the ADA is motivated by two far-reaching goals. First, it is the intention of the ADA to advance a primary goal of eliminating the stigma and discrimination too frequently associated with disability. Second, the ADA expresses the goal of minimizing the impact of a disability on a person by maximizing the person's growth and development as an autonomous person.

Clearly then it has been established that students cannot be discriminated against simply due to a handicap. Moreover, this same argument applies to those with mental illness as well (Stefan, 2001). In other words, postsecondary institutions cannot deny access to higher education programs merely due to a student's psychological disability. Schools, of course, may deny access if the student's mental disability cannot be reasonably accommodated for. For instance, if a student suffering with schizophrenia is actively experiencing psychosis and is acting dangerously to himself or others, he may be denied access. As Alikhan explains, "A person who poses a 'direct threat' to the health or safety of others will not be considered a 'qualified person' with a disability" (2001, p. 165). In contrast, however, a student being treated for schizophrenia with the use of antipsychotic medication may experience significant uncontrollable tremors of his or her hands. Providing the use of a tape recorder or note-taker for class lectures and discussions could reasonably accommodate for such side effects.

In summary, those with mental illness are afforded the same protections under RA and ADA as others suffering from physical disabilities. However, as we will come to see, institutions of higher education do not apply the RA and ADA as vigorously to those with mental illness as is applied to those with a physical disability. Not all forms of disability are equally stigmatizing.

### **Higher Education and Accessibility for the Mentally III**

In some respects, higher education has been rather distinguished in its employment of accessibility for the mentally ill. As Stefan (2001) points out, academia has been forthcoming in making reasonable accommodations in several respects. For instance, many students with

diagnosed learning disabilities and other recognized disabilities such as Attention Deficit Hyperactivity Disorder are granted increased time for examinations; classroom note-takers aid students in getting the professor's lecture down on paper, and by providing private testing environments, students are better able to manage the distractions or anxieties brought about by their psychological conditions. In addition, institutions of higher education are now readily omitting from admissions application questions concerning mental health history. Asking a student what sort of psychological disorders he or she has been treated for is no longer appropriate, or necessary admissions data. These are certainly positive changes from the perspective of those with mental health disabilities. Clearly, some of the walls have been broken down.

Higher education, however, is also a social institution within a much larger society, and as a social institution, higher education represents a microcosm of the larger society. We can see within this institution ethnocentric reflections of what is believed to be right and wrong, just and unjust, and we can find expressed the prejudices the mentally ill face in the larger society as well. In spite of several gains, higher education has at the same time maintained undue challenges and obstacles for the mentally ill in their quest for access to higher education. We can see these challenges evolve out of the civil litigation brought by students seeking relief from the courts under the RA and ADA. In this section, we will examine several contemporary civil cases and explore the implications of accessibility for the mentally ill.

### ***Doe v. New York University: U.S. Court of Appeals, Second Circuit (1981)***

Doe, a medical student at New York University (NYU), sought legal intervention from the court because she was denied readmission to NYU due to a psychiatric disability. Doe suffered from Borderline Personality Disorder. On appeal, the Supreme Court found in Doe's favor.

Jane Doe's mental health history begins in childhood with several questionable instances of pathological events. The Court's opinion cites that in the third grade, Doe experienced difficulty with her grade school teacher that resulted in some sort of intervention with a psychologist. At the age of 14, there was another mental health intervention by a psychiatrist who treated Doe after she and her parents had an argument, and Doe attempted suicide by taking five sleeping pills. These isolated descriptions noted in the Court's opinion was not sufficient to confirm any presence of childhood psychopathology.

In Doe's early to mid 20s, her pathology appears more established. Prior to her application to medical school in 1975, there are several events that clearly call her mental status into question. Specifically, there were several incidents where she caused significant physical harm to herself—although it is not stated that these attempts were actual suicide attempts. For instance, she cut herself several times, and on one occasion the self-inflicted injury necessitated a blood transfusion. She violently—but not lethally—attacked several of her psychologists and psychiatrists. These behaviors resulted in several psychiatric hospitalizations. It is also important to point out that these assaults took place when Doe's psychologists were attempting to involuntarily commit her.

In spite of her psychological difficulties, Doe was able to be in a position to make application to medical school. The Court's opinion does not speak of her undergraduate accomplishments, but it stands to reason Doe must have completed her undergraduate degree with some level of success, been able to earn a respectable score on her medical school admissions examination, and secure encouraging letters of recommendation in order to be accepted by NYU. NYU admitted Doe in 1975 to pursue the M.D. degree.

Doe's accomplishments, however, were not all honestly stated. In her application, she falsely represented "...that she did not then have and had not had any chronic or recurrent illness or emotional problems" (*Doe v. New York University*, 1981, p. 766). As part of the entrance requirement upon starting her first year's classes, Doe was required to complete a medical physical by a physician representing the university. Upon her physical examination, the doctor noticed several scars from Doe's previous self-injurious activities. It was at this time, Doe acknowledged her mental health past. This admission prompted the university to require Doe to undergo a more thorough mental health evaluation.

Upon the completion of her psychiatric evaluation, the university initially recommended that Doe withdraw from the university. Doe objected, and the university agreed to allow Doe to pursue her medical training as long as she "...undertake psychiatric therapy with a medical follow-up by the Student Health Service. Doe accepted these conditions and was advised that if she had further psychiatric trouble she would be expected to withdraw from the school" (*Doe v. New York University*, 1981, p. 766). Further psychiatric trouble occurred soon after when Doe bled herself with the aid of a catheter as a means of dealing with stress. A leave of absence was given.

Doe left New York and returned back to California where she began psychiatric treatment by a team of two psychiatrists. In July of 1977, Doe made application for readmission back to NYU medical school. Both of her treating psychiatrists provided positive letters of recommendation to NYU on Doe's behalf. NYU denied her request.

In short, the university claimed that Doe suffered from a psychological condition known as Borderline Personality Disorder (BPD). Furthermore, BPD is a condition that responds poorly to treatment; thus, there was little hope that she would be able to fully overcome her illness. Any duration of time where Doe was asymptomatic merely reflected a dawdling in her condition. It would only be a matter of time, the university feared, before she would become symptomatic again.

In response to NYU's decision, in October of 1977, Doe sought legal intervention for the purpose of being reinstated in the medical program. Doe claimed that she had been denied readmission because of a disability that was in direct violation of the 1973 Rehabilitation Act. Schools receiving federal funding are not permitted to deny access to a candidate on the mere basis of a disability. On September 25, 1981, Judge Goettel ruled that NYU had in fact denied Doe's readmission on the basis of her disability. The judge stated in his opinion:

[Ms. Doe would] ... more than likely than not be able to complete her course of medical studies and serve creditably as a physician...[and] NYU had failed to sustain its burden of going forward and proving Doe was not an otherwise qualified handicapped person or that her application for readmission was rejected for reasons other than her handicap. (*Doe v. New York University*, 1981, p. 772-773)

Doe returned back to NYU medical school in October of 1981.

The Doe case establishes several important factors in the admissions process for the mental patient. First, as Kaplin and Lee (1995) point out, the burden of proving to the court that the alleged mental disability does not inhibit the successful completion of the course of study falls on the plaintiff, not the defendants. It was Doe who had to substantiate to the court that she was otherwise qualified. Second, "...the court considered the fact that she had a recurring illness, even though it was not present at the time of the readmission decision" (Kaplin & Lee, 1995, p. 395). And, it is this second observation of Kaplin and Lee's (1995) that establishes

the most consequential implication for the mental patient. It becomes the diagnosis that takes precedence over actual behaviors.

The patient's label is now held in greater scrutiny than his or her actions. For example, referring back to the Doe case, in the time between 1977 and 1981, Doe was accepted into a graduate program at Harvard and completed a M.S. degree in the College of Public Health. She was gainfully employed at a professional-level with the Department of Education and Welfare in Washington, D.C. following the completion of her master's degree. During which time, her supervisors rated her performance as "excellent."

### ***Boyle v. Brown University: U.S. District Court (1995)***

The defendant—Brown University and various members of the administration—won the case on summary judgment arguing that the alleged events took place prior to the enactment of the Americans with Disabilities Act. Nonetheless, this case provides valuable practical insight on the administrative authority higher education attempts to exert over those suspected of having psychological problems. This case was brought fourth by Ms. Sarah Boyle, a first-year medical student at Brown University College of Medicine. Ms. Boyle claimed that she suffered from Chronic Fatigue Syndrome (CFS) and also claimed that the university discriminated against her as a result.

Ms. Boyle had never placed the administration on notice about her alleged CFS disability, but she had independently negotiated with various faculty special testing accommodations. After receiving examination scores that were not to Boyle's satisfaction, she complained to the faculty that the special testing accommodations had not been sufficient. At this time, the faculty went to the dean of the college raising questions about Ms. Boyle's psychological fitness. The dean responded—without even having first spoken to the plaintiff—by giving Ms. Boyle one of three options before she would be able to proceed further with her medical studies. First, she could undergo a psychiatric evaluation. Second, she could meet with the Independent Medical Students Committee (IMSC). The IMSC—not a specific committee of the university—was established to provide various forms of support for medical students within the state. Finally, if the plaintiff refused the previous mentioned options, she could face unspecified administrative actions from the university. With reluctance, Ms. Boyle opted to meet with the IMSC.

The IMSC shared with the dean the content of the meetings that took place between Ms. Boyle and the IMSC. Apparently, Ms. Boyle raised some concerns regarding her "behavior" that prompted the dean to formerly respond to Ms. Boyle in a letter stating in part:

[It would appear] ...that you do not have an emotional or psychological problem of such duration or severity as to affect academic performance ...[and] although you apparently are able to perform academically, the behavioral issues remain. These issues must be resolved, particularly as you enter the clinical years where your professional behavior with patients, peers and faculty will be judged with equal weight as your cognitive knowledge. (*Boyle v. Brown University*, 1995, p. 749)

Ms. Boyle also claimed in her action, that the administration shared with the faculty concerns of her psychological fitness.

Although the case was dismissed, it does raise at least two interesting points for consideration. First, do institutions of higher education have the right to mandate a student seek mental health treatment or evaluation? At what point does the institution's concerns for professional development of the student exceed the privacy and right of self-determination of the student? In the facts presented, it is clear that the university's administration considered her academic

performance as acceptable. The concern raised is the possibility of inappropriate behavior/interactions with patients and peers. Therefore, the university is justified in requesting the student to seek out psychological intervention. Again, does this exceed the pedagogical authority of the university? Second, to what extent should knowledge of a student's mental status be disseminated to faculty? Do faculty have a need to know this information? What useful purpose does it serve for faculty to know information that otherwise ought to be private? Again, there did not appear to be any problem with Ms. Boyle's academic performance in the classroom. Information that would normally be considered private and confidential should be treated as such by administration and faculty who become privy to such knowledge from other departments within the university.

### ***Maczaczj v. State of New York: U.S. District Court (1997)***

Mr. Maczaczj (plaintiff) sued Empire State College of the State of New York when the college failed to accommodate the plaintiff's disability. The plaintiff was admitted into a master's degree program at the college upon the completion of his undergraduate degree. Although the majority of the graduate program was delivered in a nonresidential format, the program did require 12-credit hours of residency through week long intensive "orientations."

The plaintiff notified the college that he suffered from a host of anxiety disorders such as Panic Attack Disorder, Generalized Anxiety Disorder, and Agoraphobia. As a result, he requested from the college an accommodation for his disability. Initially, the plaintiff requested he be excused from participating in the "orientations." The college responded by offering the following accommodation to the plaintiff:

The plaintiff would (1) be able to be accompanied by a friend or advisor of his choice, (2) have access to a vacant room to which he could retreat whenever the need were to arise, (3) be excused from those portions of the residency which were deemed predominantly of a social nature (i.e., lunch period and coffee break periods), and (4) have his choice of location within the meeting area where the residency is to be conducted. (*Maczaczj v. State of New York*, 1997, p. 405)

The plaintiff rejected the college's plan for accommodation claiming that any face-to-face interaction was too anxiety provoking. The plaintiff then countered requesting the college to make the orientation available via video conferencing or telephone conference calling. The college denied the request.

In February 1997, the plaintiff sought legal relief from the court. He was claiming that he was being denied reasonable accommodation by Empire State College under Title II of the ADA. "The protections afforded by the ADA ensures that with or without reasonable accommodations of programs and services, a disabled individual who meets the essential eligibility requirements to participate in the program ... is not discriminated against by reason of the disability" (*Maczaczj v. State of New York*, 1997, p. 406).

The college argued to the court that the plaintiff's request for telephonic or two-way video attendance at the required "orientation" would result in pedagogically undermining the academic integrity of the program. Therefore, the proposed accommodation was unreasonable. The court found the defendant's argument the more compelling argument. The court denied the plaintiff's request.

Clearly, this case differs from *Doe v. New York University* in that here the plaintiff's pathology is active. He is currently experiencing his debilitating anxiety. With Doe, however, she was asymptomatic at the time of her claim. The concern with Doe was her propensity for future pathological behavior.

One important implication that potentially derives from this current case, however, is the court's position on technological interventions as a possible "reasonable accommodation." The court took the position of the college that teleconferencing would erode the academic integrity of the curriculum. The concern that arises is whether college administrators may be afforded the opportunity to declare that any technological intervention—like teleconferencing—compromises the pedagogical quality of their program. But, as more classrooms become standardized with this sort of costly technology, the reasonableness of using such technology as an accommodation increases as does the cost of applying it to the home of a single agoraphobic.

### ***Larson v. Snow College: U.S. District Court (2000)***

The plaintiff, Ms. Michelle Larson, brought suit against her former college—Snow College—claiming that the college violated her civil rights and discriminated against her in violation of the ADA. In the fall of 1996, Ms. Larson experienced what is vaguely described as "mental health problems" (*Larson v. Snow College*, 2000, p.1290) causing her to seek professional mental health treatment. Upon her return back to Snow College two days later, the college administration required that Ms. Larson sign a "Wellness Contract." The contract required, among other criteria, that Ms. Larson be placed on probation of social activities, academic probation, and be relieved of her position as Vice-President of the student government. Ms. Larson's complaint alleges that the college employed the use of the Wellness Contract "... as a mechanism to keep her from associating with fellow students and student government officers, to stop her from exercising her free speech rights, and to control her behavior and spy on her while she was in the privacy of her school living quarters" (*Larson v. Snow College*, 2000, p. 1290).

At this time, Ms. Larson's complaint has not been resolved by the court. It is ongoing; however, the allegations expressed in the lawsuit provide another level of discussion to the stigmatization the mentally ill face in access to higher education. *Access* does not merely involve admittance to the classroom, but *access* also involves passage to those activities typically associated with the status of student—such as student government involvement and dorm room life. Restricting her access to these activities renders Ms. Larson as a marginal student—a stigmatized student.

### ***Davis v. University of North Carolina: U.S. Court of Appeals (2001)***

Ms. Davis brought suit against the University of North Carolina (UNC) following the university's actions to have her removed from a teaching certification program. Ms. Davis was previously diagnosed with Dissociative Identity Disorder (DID). DID refers to a condition where the patient experiences marked changes in personality and memory without any apparent organic explanation (American Psychiatric Association, 2000). In Ms. Davis' case, she experienced occasional blackouts.

It would appear logical based on the facts so far given that UNC was acting within the guidelines of RA and ADA to deny Ms. Davis continued admission in the program. It is necessary for a teacher working with small children not to experience blackouts to ensure the safety of her students. Such a limitation cannot reasonably be accommodated. However, what is alarming about this case is how the appeals courts interpreted Ms. Davis' DID diagnosis. The court argued that RA and ADA did not apply to this case because a psychiatric condition such as DID is too ambiguous to be recognized as a legitimate diagnosis. "Davis has failed to make a prima facie showing that she is disabled within the meaning of the ADA or the Rehabilitation Act ..." (*Davis v. University of North Carolina*, 2001, p. 102).

DID is a recognized by the American Psychiatric Association as a legitimate disorder. It is correct that DID is diagnosed entirely on subjective criteria; however, this is the case with almost all mental illnesses such as depression, mania, schizophrenia, and somatoform disorders. The concern raised here is the court's judgment is determining one disorder legitimate and another illegitimate.

### **Analysis and Suggestions for Ameliorating Accessibility for the Mentally Ill Lessons Being Taught**

In conclusion, it appears that institutions of higher education have within the United States employed the use of federal protections, specifically the Rehabilitation Act and the Americans with Disabilities Act, for those dealing with the effects of a mental illness in such a way as to restrict accessibility. Again, it is not my position that institutions of higher education deliberately attempt to restrict access, seek to discriminate, punish, or humiliate the mentally ill. Rather, institutions of higher education serve as reflections of the larger social system. Such actions find deep roots in the values and belief systems within the larger culture. This point may help to explain the various examples of discrimination and inaccessibility discussed in the previous section of this paper, but it does not serve as an excuse for such behavior, nor rationalize its continuation. Institutions of higher education must be concerned with the lessons it teaches to its students through both the formal curriculum within the classroom and the informal curriculum taking the form of administrative policy on the college campus. What then are the lessons being taught to students on college and university campuses?

First, the mentally ill are perceived to be dangerous; higher education administration needs to protect their faculty and students from potentially dangerous people. It can be argued that it was Doe's and Boyle's perceived possibility for violence that may have motivated the administration's policy actions against these students. Was the administration correct in holding such fears? Do the mentally ill have a greater propensity for violence? Are such fears rooted in reality or myth?

Researchers addressing this question would conclude that such fears are seated more in myth than in reality (see Angermeyer, 2000; Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999; Taylor & Monahan, 1996). Those with mental illness pose no meaningful addition of risk to the physical safety of the general population. Angermeyer even goes as far to say that strangers "... appear to be at an even lower risk of being violently attacked by someone suffering from severe mental disorder than by someone who is mentally healthy" (2000, p. 63). Public perception, however, would suggest otherwise. Perhaps, the public's fear of violence at the hands of the mentally ill is a false projection instituted by the media. As Mulvey and Fardella (2000) argue, the media provides disproportional coverage of isolated acts of violence by the mentally ill creating in the public a misrepresented belief that all mentally ill people must behave similarly. The public has demonstrated a clear absence of comfort with being physically near people known to have a history with mental illness (Link et al., 1999). Unfortunately, it does not appear that these views of the general public will ameliorate soon. Rather, "... research suggests that stereotypes of dangerousness are actually on the increase and that the stigma of mental illness remains a powerfully detrimental feature of the lives of people with such conditions" (Link et al., 1999, p. 1328).

There is a second lesson seen creeping through these profiled court cases. The mentally ill are not capable of functioning in society at an adequate level. Thus, what the mentally ill have to contribute to society is little at best. They can't ever function at a level necessary to perform as

academics, physicians, lawyers, or artists. Certainly for many of those who experience mental illness, their ability to function is inhibited to a great extent. But, this is not always the case. History has shown us otherwise. There are countless examples of those with mental illness that have overcome their symptoms, participated and contributed much to the betterment of society.

As a psychotherapist, I have learned as much from my patients on the realities of life and psychological functioning as I ever have from textbooks and lectures. As Kay Redfield Jamison notes when sharing about her own personal experience with Bipolar Disorder:

The countless hypomanias, and mania itself, all have brought into my life a different level of sensing and feeling and thinking. Even when I have been most psychotic—delusional, hallucinating, frenzied—I have been aware of finding new corners in my mind and heart... I cannot imagine becoming jaded to life, because I know of those limitless corners, with their limitless views. (1995, p. 218-219)

### **Suggestions for Policy Reform**

In this final section, two suggestions are offered for the purpose of promoting positive social change. First, higher education administration needs to focus their concerns on behaviors, not diagnosis. A diagnosis is not, in and of itself, a clear predictor for future behavior. One's current and most recent behavior is a better predictor. Asking an admissions candidate about his or her past psychiatric history does not paint as clear of a picture as asking behaviorally relevant questions. In short, any questioning should focus attention on the student's capacity to carryout his or her academic responsibilities (Alikhan, 2001).

A second substantial way higher education can address the concerns raised in this paper would be to lobby and advocate more strenuously to professional licensure agencies and associations at both the national and state levels. The extent of discrimination faced by the asymptomatic or former mental patients from state bar examiners, for example, is even more severe than those discriminations faced within academia. As Alikhan points out, only seven state bar associations have forgone mental health questioning all together as part of the bar application process, but 32 states still engage in a wide range of inquiry as to an applicant's mental health history (2001). Applicants could face discriminatory questions such as "Have you, within the past five years, been treated or counseled for a mental, emotional or nervous disorder" (Alikhan, 2001, p. 159). As Reske explains, one of basic assumptions for employing broad questioning to bar applicants has been the belief that having sought treatment for a mental condition poses a greater danger to the public's safety both physically and professionally (1995). "[T]he bar is feeding stereotypes which pervade society, including an attitude that those who seek psychological counseling are deviant, weak, or prone to error" (Alikhan, 2001, p. 163).

Such a rationale is misguided on several accounts. First, as previously stated, the mentally ill—even those actively experiencing psychosis—pose no significant risk to the safety of the rest of us. Second, such broad inquiry may fail to take into consideration the extensive range of mental conditions that are legitimately recognized by the American Psychiatric Association (APiA). The extent of possible mental illness that one could be diagnosed with is perhaps broader than the degree of questioning by state bar examiners. For instance, the APiA's primary classification system used to diagnosis psychopathology—*The Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition—Text Revision*—includes the following diagnostic labels: Nicotine Dependence, Parent-Child Relational Problem, and Caffeine Dependence (2000). For example, if one has been prescribed Zyban by the their physician to help them stop smoking, one has technically been treated for a recognized



psychiatric condition. Finally, this rationale discourages people from seeking help. "[M]ental health inquires might keep people from seeking counseling or treatment, or cause those in treatment to be 'less than totally candid with their therapist' for fear of disclosure" (Reske, 1995, p. 24).

At some level we are all different and face the possibility of discrimination and unfair treatment based on our differences whether they be the color of our skin, gender, religion, disability, or place of national origin. For the mentally ill, however, such discrimination appears to be more inherent within the subtleness of daily social life. Discrimination for the mentally ill is not a discrete event.

It is vital to point out that, in spite of its ideals, institutions of higher education also play a role in the continuation of stigma and discrimination of the mentally ill on college and university campuses. Such actions are not intentional, but nonetheless they are present, and lives are impacted as a result. If the goal of education is to assist in fostering independence, compassion, creativity, and excellence in students, it is vital for higher education to be fully aware of its own limitations and strive for excellence in seeking resolution.

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# Consumer/Survivor Stories of Empowerment and Recovery in the Context of Supported Housing

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## Abstract

We examined the stories of empowerment and recovery of five psychiatric consumer/survivors who participated in supported housing programs. Interviews with these five participants and members of their social networks were used to gather qualitative data on their lives prior to supported housing, their experiences with supported housing, and the impacts/changes that they experienced through supported housing. Changes in personal empowerment, community integration, and access to valued resources were reported in each of the five stories. The qualities of the supported housing programs that were reported to contribute to individuals' empowerment and recovery included individualized and consumer-controlled support, diverse sources of support, and assistance with accessing basic resources. The implications of these findings for research and practice were discussed.

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## Introduction

In the past decade, there have been two emerging areas of inquiry in community mental health concerning adults with serious mental health problems: (a) empowerment and recovery and (b) supported housing. While these two bodies of research have developed independently of one another, they are both guided by a paradigm that emphasizes the values of empowerment, community integration, and social justice and de-emphasizes the traditional medicalized view of "mental illness" and "psychiatric patients" (Carling, 1995; Nelson, Lord, & Ochocka, 2001). Our aim in this paper is to tie these two areas together by studying consumer/survivor empowerment and recovery in the context of supported housing. We begin by providing a brief overview of these two areas of research.

## Literature Review

### Consumer/Survivor Empowerment and Recovery

For many years, the medical model emphasized the "chronic" nature of mental illness. However, the notion of chronicity has been challenged by recent research. Harding et al. (1987) followed up a sample of people who had been diagnosed with schizophrenia and admitted to the Vermont State Hospital in the 1950s. While the outcomes were quite variable, 20-25 years later, more than half the sample showed considerable improvement or recovery. With the accumulation of research on recovery (McGuire, 2000), the hopelessness of "chronicity" is yielding to a more hopeful view of "recovery," which Anthony (1990) has argued should be the guiding vision for the mental health system.

Recently, several qualitative studies have been undertaken to understand the processes of empowerment (Lord & Hutchison, 1993; Lucksted, 1998) and recovery (Baxter & Diehl, 1998; Smith, 2000; Kloos, 2001; Weaver Randall & Salem, 2001; Young & Ensing, 1999) of people with a history of serious mental health problems. But what are empowerment and recovery? Both of these concepts have been used to focus on change, growth, and improvement, and both emphasize the development of strengths, the process of change, and the importance of contextual factors in contributing to change. At the same time, however, the concepts of empowerment and recovery have had somewhat different emphases.

The term empowerment has an explicit focus on power and politics (Chamberlin, 1990) and is part of an alternative paradigm in community mental health that is guided by three core values: (a) individual empowerment, (b) community integration, and (c) access to valued resources (Nelson et al., 2001). The value of empowerment means a reversal of the traditional power imbalance that psychiatric consumer/survivors typically experience with mental health professionals, choice, control, skills, and self-esteem (Chamberlin, 1990, 1997; Lucksted, 1997). Second, empowerment theorists have argued that community integration is a part of empowerment, that the development of self occurs through relationships with other people and participation in typical community settings, not segregated service facilities (Lord & Hutchison, 1993). Third, access to valued resources, such as housing, employment, education, and income, is critical to the empowerment process. These three values suggest that empowerment is a multilevel construct, which includes individual, community-relational, and socio-economic resources (Rappaport, 1987).

Recovery, on the other hand, has been defined as "the development of new meaning and purpose in one's life as one grows beyond the catastrophe of mental illness" and the redefinition of "attitudes, values, feelings, goals, and skill and/or roles" (Anthony, 1993, p. 19). The development of self, a reconstituted identity, finding meaning and purpose, and securing valued social roles are central aspects of the concept of recovery (Baxter & Diehl, 1998; Smith, 2000; Kloos, 2001; Weaver Randall & Salem, 2001; Young & Ensing, 1999).

Like empowerment, recovery is viewed as both a process and an outcome with tangible changes in one's life experiences and circumstances. However, recovery has been constructed more in terms of internal psychological qualities, whereas empowerment has been constructed more in terms of transactions between the individual and the environment.

### Supported Housing

In the 1990s, Carling (1993) proposed a new paradigm in housing for people with serious mental health problems called supported housing. This new approach stands in contrast to the traditional custodial and supportive housing approaches (Trainor, Morrell-Bellai, Ballantyne, & Boydell 1993; Parkinson, Nelson, & Horgan, 1999). In custodial housing, private owners operate what are often large residences and provide "care" services for profit; there is typically little emphasis on rehabilitation, empowerment, or community integration; these settings have an institutional character and a dependency orientation; and residents have little power in such settings and are often subjected to numerous rules and restrictions (Parkinson et al., 1999). Board-and-care, lodging, and nursing homes are examples of custodial housing.

Supportive housing developed as an alternative to this type of residential care. The concept of a residential continuum, ranging from high support group homes to more independent clustered apartments, is an integral part of supportive housing (Ridgway & Zipple, 1990b). As residents improve in their functioning, they progress through the continuum from highly staffed settings to more independent settings. In supportive housing, the housing and support are provided by a non-profit housing or mental health agency; there is an emphasis on rehabilitation by staff who are often present in the residence; and residents have little choice over where they live (Parkinson et al., 1999).

In contrast to these two approaches, supported housing emphasizes consumer/survivor choice and control and community integration in "normal" housing. In the supported housing approach, consumers are encouraged to "choose, get, and keep" the type of home that they want. The supported housing approach makes a shift from patient (custodial housing) or resident (supportive housing) to citizen with normal tenant and social roles and rights to community participation and valued resources (Carling, 1993; Ridgway & Zipple, 1990b). The supported housing approach is oriented to the strengths of the person supported (Ridgway and Zipple, 1990a). Staff operate from an attitude of "How can I best assist?," as opposed to "I know what's best" (Pyke & Lowe, 1996, p. 8). Services are not forced on consumer/survivors if they do not believe they require them, and housing and support are "delinked" in supported housing, so that the individual can choose the type and amount of support that she or he desires, rather than having staff located in their home (Ridgway & Zipple, 1990a, 1990b). Supported housing is based on the values of empowerment, community integration, and access to valued resources, which also underlie the philosophy of empowerment described in the previous section.

Outcome studies of supported housing are relatively new (Parkinson et al., 1999; Ridgway & Rapp, 1997). The most common findings are that supported housing programs increase resident stability and independent living and decrease rates of homelessness (Depp, Dawkins, Seizer, Briggs, Howe, & Toth, 1986; Dixon, Friedman, & Lehman, 1993; Goldfinger, Schutt, Tolomiczenko, Seidman, Penk, Turner, & Caplan, 1999; Hurlburt, Wood, & Hough, 1996; Newman, Reschovsky, Kaneda, & Hendrick, 1994; Tsemberis & Eisenberg, 2001). Living in a home found through supported housing has also been shown to lead to reductions in hospitalization rates (Brown, Ridgway, Anthony, & Rogers, 1991; Burek, Toprac, & Olsen, 1996) and psychiatric symptoms (Dixon, Krauss, Myers, & Lehman, 1994).

However, there is considerably less research on supported housing that has examined quality of life and psychosocial outcomes for people who have access to supported housing. Depp et al. (1986) found no differences between supported housing participants and non-participants on measures of housing satisfaction, social network composition, and community integration, and Burek et al. (1996) found that the majority of participants in their study wanted but were unsuccessful in obtaining employment. Moreover, some studies have reported problems of social isolation of people who have accessed supported housing (Champney & Dzurec, 1992; Depp et al., 1986; Pulice, McCormick, & Dewees, 1995).

### Consumer/Survivor Empowerment and Recovery in the Context of Supported Housing

Much of the research in community mental health consists of outcome studies of different programs. While valuable, this type of research is limited in several important respects. First, when the program is in the foreground, the persons who participate in the research are reduced to aggregated outcome statistics. Second, outcome measures do not capture the richness of the many different experiences of the individuals under study, both related to the program and to other factors in their social environments. Third, with its emphasis on determining cause and effect, outcome research designs portray the individuals as passive, people who are influenced by the program, rather than as agents who actively cope with their life circumstances. In a recent article, Stephanie Riger (2001) has suggested that community research should overcome these limitations by pursuing research in which: (a) persons are in the foreground, not programs; (b) multiple dimensions of people's experiences are examined; and (c) the agency of individuals is emphasized.

We believe that the new paradigm in community mental health, which emphasizes consumer/survivor empowerment and supported housing (Carling, 1995; Nelson et al., 2001), lends itself well to Riger's (2001) suggestions about how to frame research questions. In this research we examined the following question: What role does supported housing play in consumer/survivors' journeys of empowerment and recovery? While we did not formulate hypotheses for expected results, we were guided two analytic concepts: (a) the core values of the alternative paradigm (empowerment, community integration, and access to valued resources) and (b) time (life prior to supported housing, involvement in supported housing, and the impacts of supported housing). We wanted to know if consumer/survivors experienced changes or positive outcomes related to the three core values and how supported housing contributed to such changes.

## Methodology

### Narrative Approach

In this research, we engaged participants, asked questions, and utilized the findings in a manner consistent with the value of empowerment (Nelson, Ochocka, Griffin, & Lord, 1998). A story approach was chosen as the narrative has been credited for suggesting "new ways to become more sensitive to such voices" (Rappaport, 1995, p. 799). The accounts given are stories, limited by a beginning and end and containing linked information (Riessman, 1993). The definition of a narrative approach varies widely, but for this study, narrative is viewed as an individual's personal construction of reality (Riessman, 1993). This construction is a representation of a person's situation in a particular time and context, which are major influences on his/her interpretation. Therefore, the narrative is continuous and undergoes transitions, but the account given is that person's reality at that point in time and in that specific life context (Crossley, 2000; Rappaport, 1993, Riessman, 1993). Stories not only recount events, but they involve meaning as the storytellers understand the situations that they have experienced. The essential components of the narrative/story approach were to involve and understand the person as a whole, support the person

to share the parts of his/her life that were meaningful to the process, and use the opportunity to promote growth and understanding. While the stories offered an in-depth look at individual experiences, a thematic analysis allowed us to identify patterns across stories.

### Context

Two organizations which provide supported housing hosted the research. One is located in western Canada and one in southwestern Ontario. Both of these organizations had previously followed a supportive housing approach, but made a conscious change in their organizational philosophy, programs, and services in the early 1990s to move to a supported housing approach. Staff from both of these organizations were interested in the research and worked collaboratively with us to shape the research questions and approach.

### Participants and Interviews

We gathered five stories of consumer/survivor empowerment and recovery, three from the supported housing program in western Canada and two from the supported housing program in southwestern Ontario. The participants were three women and two men, all of whom had been involved in one of the supported housing programs for at least one year. The participants were purposefully selected to reflect diversity in terms of age, gender, and stage of recovery. An interview guide was used to conduct semi-structured, qualitative interviews with the participants. For the most part, individuals openly told their stories of involvement and the interview guide questions were used only to probe or clarify points of the stories. The interview guide was organized to gather information about what their lives were like prior to supported housing, experiences of their involvement in supported housing, and changes that they had experienced since entering supported housing (particularly in terms of empowerment, community integration, access to valued resources).

In the western Canadian program, we also asked participants to identify a trusted friend or family member and a staff person who could provide information on their perceptions of the individual's story. In the program in southwestern Ontario, we asked the individuals to nominate a friend, a family member, a peer (someone with whom they worked or participated in some activity in the community), and a staff support worker. These interviews provided multiple perspectives on the consumer/survivor's experiences before and during their involvement in supported housing. This network approach was used to establish the trustworthiness of the data and to provide a rich story from the experiences of the individuals and key people in their lives. Each of the individuals gave their consent for us to contact these network members. We purposefully decided to emphasize depth over breadth in this research. While the stories of only five individuals were examined, they were studied in depth. Moreover, interviews with 19 different people were completed.

### Data Analysis

Each of the interviews was transcribed and given back to the participants for their review and comments prior to the data analysis. The perspectives of the participant and their network members were then integrated into a summary story, which was given to the five participants for their review and approval. The consumer/survivor's account formed the basis of the story with the other participants' comments inserted to support the individual's account, provide additional information, or offer differing perspectives. The transcripts were also coded to provide an overall thematic analysis of the similarities across the five stories.

## Stories and Themes

Due to space limitations, we present only one of the stories. This is followed by an overall thematic analysis of the five stories.

### Anne's Story

Prior to Anne's involvement with the supported housing program, she had several hospitalizations causing her to lose her housing and forcing her to deal with a stressful experience of moving into unsatisfactory accommodations. Anne's support network was comprised of a negative relationship with a hospital psychiatrist and her family, on which she was quite dependent despite conflict and poor communication. Anne experienced loneliness, and she felt used by friends.

When Anne came to the supported housing program she felt: "I didn't know how to look after myself. Well, I knew how to wash my clothes and stuff like that, but I guess I mean being able to stand up for myself, being assertive, communicative, things like that." Anne was described by network members as "quite hard on herself" and "it was hard for her to start stuff" and follow through. Anne desired education, but found school to be stressful and overwhelming.

When she first became involved in supported housing, Anne experienced many difficulties with her education which eventually led to her leaving school. A period of crisis, disappointment, suicidal thoughts, and disengagement in her recovery process ensued. Finally, Anne realized that she "had had enough garbage and I wasn't going to do it anymore."

Anne began working on self-esteem and communication. She joined a discussion group organized by the program, assisted with committees of the supported housing program, and volunteered in the community at a flexible and understanding organization. Anne believes that these experiences of connecting with other people and community settings improved her mental health.

Anne also took an empowerment program provided by the supported housing organization to work on assertiveness and learn to "stand on my own two feet." Becoming independent from her parents was part of that process, and her community worker assisted with resources, skill development, and advocacy. Although Anne's housing was stable while in the program, she was dissatisfied with her housing. Her community worker assisted her in finding the type of housing that she wanted. Due to income restrictions, Anne found housing that met many but not all of the qualities that she desired. Importantly, Anne managed the move independently and, over time, showed less of a need for staff support. Anne's community worker's final role was to link Anne with a supported employment program to fulfil her goal of obtaining employment. At the time Anne told her story, the staff worker was in touch with Anne only on "as needed" basis.

At the time of the interview, Anne's mental health was quite stable and positive. She had not been hospitalized in two to three years. She was still depressed at times, but she had developed coping skills and "she doesn't experience such severe ups and downs." Anne believed that her newly found skills and friendships accounted for her recovery. However, Anne's physical health was poor, and in addition to lack of income, poor health impeded her employment and activity.

Anne's friendships had improved as she picked friends "that are really friends. I guess I've learned what I want in a friend and what I don't want in a friend, setting limits." Through the program, Anne met some friends and a boyfriend who has become an important person in her life. Together they have found a lot of happiness but continue to struggle with their illnesses. Anne displayed increased self-esteem and communication skills in several situations, which has made her more independent by "learning to depend on myself, they've taught me that."



Anne's mother commented that the program gave her control over her life and "the ability to stand on her own two feet. She's not as dependent anymore." Family relationships have improved as well.

### Comparison of Stories

The comparison of the five stories identified consistencies in consumer/survivor experiences before entering the program, while involved, and the impacts experienced. The cross-story analysis is examined in terms of the core values of the empowerment paradigm in mental health and time.

### Prior to Involvement in Supported Housing

Empowerment. *Powerlessness* was a theme that emerged from all the interviews to describe the participants' situations before entering the program. The individuals' lives were unstable, with frequent hospitalizations and poor mental health. Four individuals had attempted suicide. This lack of control over health was coupled with a lack of control over most areas of their lives, including decision-making, resources, time, family relations, addictions, friendships, jobs, and housing security and quality. Powerlessness was coupled with a lack of confidence, skills, and income to achieve what they wanted. Physical ailments that controlled or limited activities were also common. Three individuals were dealing with addictions and two had lost custody of their children. The "chaotic," "needy," and "self-destructive" state of the consumer/survivors' lives was described with an absence of hope and a lack of power to make change.

In search of answers to their problems, these individuals turned to professionals for help. However, the typical experience was that professionals decided what was best for them. One participant shared that she "did what I was supposed to do, what everybody was telling me. . . that's existing." Closely related to experiences of powerlessness were feelings of *dependence*. One participant described herself as always compliant with professionals because she was "too scared to not do anything." Another participant said: "I was very needy. . . I needed to be with somebody 24 hours a day. . . I was scared." Another participant said "hospital became my way of life."

Community integration. All of the participants experienced *conflict in their relationships with family and friends*. One participant described the abuse she suffered at the hands of her alcoholic parents. A sister of another participant made the following comment about her sister's marriage. "Oh, it was a rotten marriage. It really was." Another participant who was living with his brothers reported that he moved out because he was experiencing considerable conflict with one of the brothers.

Despite the dependence on professionals and others noted above, *isolation* was common. Two of the individuals spent most of their time in bed. One participant explained that he "didn't see anybody for days. . . I was just eating and sleeping." Another person interacted only with her living companions, who had also experienced mental health problems. Participants indicated that they often felt lonely and withdrawn.

Access to valued resources. Another theme that emerged from all the participants was *poor housing situations*. Each of the individuals had lived in a variety of housing situations that were unstable and/or of poor quality. Safety was often an issue. Apartments were chosen without much research or knowledge of options as individuals entered the community or fled the last uncomfortable situation. One individual explained that he "was living in a real dump of

a place. I took it because it was the first place I could get out of the hospital. I had to have a place to go when I got out of the hospital." Two individuals found themselves unsettled and staying with friends or family to avoid their apartments. Another person lived for short periods in boarding homes and eventually ended up homeless.

### Involvement in the Program

Empowerment. One theme was consumer/survivors' *readiness for change*. For example, in the stories of individuals the supported housing program in Ontario, individuals described the initial security of quality and comfortable housing where they were able to make friends. This set the stage for further changes. In the other supported housing program, staff spend considerable time helping people to prepare for change. The length of this process varies depending upon the individual. While four of the five individuals began to focus on what they wanted shortly after acquiring supported housing, one individual struggled for two years before she became more clear on what she wanted. As one participant stated:

"I felt comfortable as soon as I came over. As soon as I came to the apartments here I felt comfortable. I knew I was ready to work on myself - some things that I had to get out of the way. And also, too, I felt good just right from the beginning. You know, I've had a good roommate. She made it feel like home, so I was lucky."

Across both settings, *individualized support controlled by consumer/survivors* was mentioned as an important factor in the empowerment process. Participants stated repeatedly that the community support workers listened and understood their individual situations, and they described themselves as being in control of the support process.

"I'm not told what to do and how to do it, this is what you think always. I'm writing the play."

"She [community worker] just seemed to listen more than other workers I've heard about."

In this manner, individuals received holistic support because all areas of their lives were addressed and could become a focus if chosen. The support was described as individual, flexible, and ongoing, so support was adapted or implemented as it was helpful, appropriate, or agreeable to the consumer/survivor. Consumer/survivors were able to learn skills and information and develop a focus that was specific to their interests.

The participants reported a variety of *empowering support/experiences to believe in oneself*. The support they received from their community workers was focused on increasing their beliefs that they could accomplish their goals. All interview participants described efforts to increase self-esteem and validation of skills, capabilities, and opinions. Several volunteer, employment, and educational experiences were important opportunities in assisting consumer/survivors to recognize that they could work successfully and competently. Three individuals described opportunities to work within the organizations to develop confidence and skills. Encouragement and recognition of skills was emphasized as participants were supported to believe in and care for themselves. Community workers commented that they focused on strengths when working with individuals on their goals.

Community integration. During involvement in the programs, participants identified that they had developed a range of supports that were both informal and formal. This *diversification of support* extended beyond the worker from the supported housing program and included a range of mental health professionals, other medical professionals, self-help, generic supports or services, friends, neighbours and family. In those cases in which the

individuals had ongoing relationships with friends and family, staff worked with them to make these relationships more supportive and healthy. Meeting new friends for supportive relationships was a common experience that was facilitated through supported housing. Workers encouraged the people they supported to participate in supportive environments, including the supported housing organizations themselves. Individuals met friends through activities and opportunities through these settings. For example, one participant made many good friends with other people who live in the apartments, and she regularly attended the Residents' Council meetings and social events held by the supported housing organization.

Access to valued resources. All participants desired resources, such as education, employment, housing, activities, and rights information within and outside the organizations, and all reported receiving *assistance with resources*. The program in western Canada has funds available that each individual accessed for items that enhanced their recovery. Also, community workers assisted consumer/survivors to obtain access to resources they deserved through advocacy. Self-advocacy skill development was supported and facilitated so that individuals could learn to meet their own needs.

### Impacts

Empowerment. Each participant and network member reported *stable mental health* as an impact of supported housing. Participants' mental health at the time of the interviews contrasted sharply with the unstable mental health, crises, and frequent hospitalizations that characterized their lives prior to their involvement in supported housing. The individual stories showed less severe fluctuations in mental health, improved coping skills and self-awareness about one's mental health problems, and decreased hospitalizations. No one had attempted suicide since entering supported housing, whereas this was a common theme in their life stories prior to entering supported housing. When asked what difference the supported housing organization had made in her life, one participant said the following:

"I wouldn't have had a life. I would have been dead probably – just would have self-destructed eventually."

The following quotes illustrate improved mental health outcomes:

"She's certainly less depressed. . . She's not suffering clinical depression anymore, sure she gets down but she's not into this big black hole anymore and she can kind of take it in stride and she's got some coping skills, yeah she's more satisfied. She's maybe more at peace than when she first came in her and her life I don't think is as chaotic." (Community worker)

"I can't really see her getting back into the hospital trap again." (Community worker)

There are several areas in which each participant displayed more *power and control*. Common examples were developing assertiveness, communication, self-esteem, boundaries, self-respect, individual identity, healthy sleep patterns, an understanding of entitlements, choices, and skills for independent living and social interactions. The following quotes from the participants illustrate this theme.

"Learning that I didn't have to do what I was told, it was a choice."

"I'm not going to take any more garbage, and standing on my own two feet and I've learned to pick friends that are really friends."

"I'm in more control of my life."

Increased confidence was part of this heightened power and control. Confidence inspired the individuals to take on more opportunities to practice and use decision-making and assertiveness in the individuals' homes, support networks, and communities. Additionally, participants developed independence, which contributed to and was influenced by the amount of control they possessed and the opportunities to use it. Specific opportunities such as employment, committee work, and an empowerment program were credited as significant factors in promoting independence.

*Developing and fulfilling dreams* was another theme. Each participant was able to outline his/her plans or goals and expected more from themselves. The impact was described as regaining hope as "[community worker] had always thought that I could work in human services, and I thought 'no, that's a fantasy, it would be nice but no'. . . I had lost something, [community worker] was able to pull it back." There was significant work to do to achieve many of these dreams, but supports were in place to help people towards their goals. Individuals were able to see a brighter future and to experience more enjoyment of the present.

Community integration. Enhanced *community integration* was a theme expressed by all participants as each person had become more involved in the community for recreation, volunteering, employment, education, or shopping. Lack of money to regularly attend activities of interest was a problem mentioned by two individuals. However, each is comfortable in his/her neighbourhood, visiting friends and family, and participating in activities. In comparison to the isolation experienced beforehand, these individuals feel more involved and active.

There was agreement among all those interviewed that relationships had improved for the consumer/survivors. For two individuals, relationships with children had improved due to several factors (i.e., confidence, better mental health, better apartment, cooking skills, communication). Four consumer/survivors were closer with family now and had addressed family issues through the program. Friendship was another domain impacted for all individuals. Friendships were more plentiful, healthy, reciprocal and of their choice. Friends were recognized as long-term, dependable supports for all but one participant who continued to work on building more friendships. Despite varying levels of social connectedness, isolation was reduced for all. These *improved relationships* were also characterized by trust. One participant stated that she has changed from being a withdrawn, cold, and confrontational young adult into a person who is more open and giving. Moreover, she no longer feels isolated and lonely, but meets often with friends, whether at her daily trips to the coffee shop, or in the evening watching videos together.

Access to valued resources. The homes that the consumer/survivors researched and obtained all were described by them as feeling like home or beginning to feel like home. Personal touches and being hosts or developing skills to be hosts helped develop the *sense of home* feeling. Moreover, each individual had increased stability in his/her home. Individuals with a new apartment appreciated that they had support to find an affordable option, usually subsidized public housing, which they had been unable to find on their own. The homes were also described as better quality than previous accommodations and "comfortable" due to the surroundings and, sometimes, the friendly neighbours.

As the consumer/survivors were seeking valued roles in society, *employment* was desired. Two individuals were successful in securing meaningful employment. Others had connected with volunteer opportunities and a supported employment program, but stable employment had not yet been obtained.

## Discussion

The five stories provide in-depth information about the processes of recovery and empowerment experienced by psychiatric consumer/survivors in the context of supported housing. We begin by considering changes/impacts that the participants and their network members reported. Next we consider the way in which the supported housing programs helped to contribute to these changes/impacts.

Stories of Empowerment and Recovery

The broad themes/values of the empowerment/community integration paradigm provided a useful framework for understanding the impacts/changes experienced by the five individuals in this study. While evaluation research typically reports personal changes as outcomes on standardized measures, the in-depth narrative approach that we used is consistent with the view that empowerment (Lord & Hutchison, 1993) and recovery (Baxter & Diehl, 1998; Weaver Randall et al., 2001) are processes that unfold over time. While each story is unique, we found some common themes in these stories.

As can be seen in Table 1, all of the individuals in this study reported lengthy periods of powerlessness and dependence prior to their involvement in supported housing. Lord and Hutchison (1993) also found that powerlessness and dependence were common experiences of disadvantaged individuals in their examination of the process of personal empowerment, and Baxter and Diehl (1998) found that the lives of mental health consumers are often plagued by repeated crises. However, after settling into supported housing, all of the individuals reported positive changes. One area of empowerment for the individuals was control over their illness as they became more aware of and better able to cope with mental health issues. Both Lord and Hutchison (1993) and Weaver Randall (2001) found that empowerment and recovery begins with an awareness and recognition of how one's life circumstances impact on one's sense of self and quality of life. This increased awareness resulted in more stable mental health and fewer hospitalizations and crises, which is consistent with previous reports of reductions in hospitalization rates (Brown et al., 1991; Burek et al., 1996) and psychiatric symptoms (Dixon et al., 1994) for individuals who access supported housing. The individuals' lives became more stable and less chaotic.

Table 1  
Key Dimensions of Consumer/Survivor Experiences Over Time in Relation to the Core Values of Empowerment, Community Integration and Access to Valued Resources

Core Values of the Alternative Paradigm	Prior to Involvement in Supported Housing	During Involvement in Supported Housing	Impacts/Changes Experienced in Supported Housing
Empowerment	* Powerlessness * Dependence	* Readiness for change * Individualized support controlled by individuals * Empowering support/experiences to believe in oneself	* Stable mental health * Power and control * Developing and fulfilling dreams
Community Integration	* Conflict in relationships with family and friends * Isolation	* Diversification of support	* Community integration * Improved relationships
Access to Valued Resources	* Poor housing situations	* Assistance with resources	* Sense of home

			* Employment
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The findings of this research go beyond previous research in demonstrating that consumer/survivors living in supported housing experienced increased power and control and the opportunity to develop and work towards their personal dreams that were either lost or unimaginable given their earlier life circumstances. The ability to regain a sense of self-respect and hope for the future provided energy to work towards more personal life goals and ambitions. Components of power and control included assertiveness, communication skills, self-esteem, individual identity, and skills for independent living and social interaction, all of which are part of what consumer/survivors define as empowerment (Chamberlin, 1997). In their study of the process of personal empowerment, In their descriptions of recovery, Baxter and Diehl (1998) note the importance of rebuilding independence; Young and Ensing (1999) speak of "returning to basic functioning" (p. 224); and Smith (2000) reported a sense of control and independence.

As we noted at the beginning of this paper, empowerment and recovery develop in the context of relationships and community (Kloos, 2001; Lord & Hutchison, 1993; Smith, 2000; Weaver Randall, 2001). Prior to their involvement in supported housing, the five individuals were profoundly disconnected from their communities. Where relationships with family and friends existed, they were typically fraught with conflict. Moreover, experiences of isolation and loneliness were common. Individuals involved in this research discussed the desire to contribute to and become active in society. Through supported housing, each of the individuals focused on activities that provided increased integration in the community through relationships, activities, employment, or training. Lord and Hutchison (1993) similarly found that learning new social roles and initiating/participating in the community accelerated the process of empowerment. The finding of decreased social isolation stands in contrast to some earlier studies of people who have accessed supported housing (Champney & Dzurec, 1992; Depp et al., 1986; Pulice et al., 1995). Perhaps the individuals in those earlier studies had adequate housing, but inadequate support.

Although success levels varied, the supported housing programs assisted each individual to make advances in her/his goals to become more integrated and improve relationships. Based on these individuals' experiences of damaged self-worth due to a lack of belonging in society, the positive feelings and improved assertiveness that developed as they became more active validates the belief that integration is part of empowerment that promotes the development of identity (Kloos, 2001; Lord & Hutchison, 1993; Nelson et al., 2001; Smith, 2000; Weaver Randall, 2001).

The final important component of the empowerment/community integration paradigm is access to valued resources. Like previous research (Depp et al., 1986; Dixon et al., 1993; Goldfinger et al., 1999; Hurlburt et al., 1996; Newman et al., 1994; Tsemberis & Eisenberg, 2001), we found that each of individuals was able to obtain more stable and desirable housing. Moreover, the five individuals experienced their new housing as homes, not just as places to live. While the individuals still struggled with limited income, each made some progress in terms of finding employment, volunteer work, or other meaningful activity in the community. This finding has not been reported in previous research on supported housing.

Overall, there were significant shifts over time in the personal stories of the five individuals. The lives of all of these people prior to their involvement in supported housing were quite

chaotic and troubled. Experiences of powerlessness, dependence, significant mental health problems and psychiatric hospitalization, social isolation, interpersonal conflict, and poor housing were common in the lives of each person. Each person had little sense of identity aside from the role of "psych patient," and none of the individuals had life goals or saw a positive future for themselves. With the resources of housing and support, however, each individual was able to begin to reconstruct their identity, life story, and dreams for the future (Crossley, 2000). Through stable housing and support, individuals recovered their mental health, regained a sense of power and control, developed new skills, became more active participants in life, improved their relationships, and worked towards employment and meaningful activity in the community. These stories of personal transformation go beyond previous studies that have reported some positive outcomes associated with supported housing. We now consider how the context of supported housing contributed to these impacts/changes in the life stories of the individuals.

### How Supported Housing Contributes to Change

We found that both personal motivation and qualities of the supported housing programs were important for the processes of empowerment and recovery. Previous qualitative research has found that "taking responsibility for own recovery" (Young & Ensing, 1999, p. 224) and "time to get going" (Baxter & Diehl, 1998, p. 352) were words used by consumers to describe their own motivation for change. Both Lucksted (1998) and Smith (2000) found that "turning points," either positive or negative events, provide a "shake up" that is the impetus for change. We found that in some cases the acquisition of supported housing stimulated the processes of empowerment and recovery. However, in other cases, support workers needed to spend more time with the individuals to help them become more motivated. Both the consumer/survivors and support workers recognized the need for individuals to want to change. The community workers supported individuals to become ready for change, but the process could not be forced and it was necessary to give individuals the strength to choose and direct their process that would empower them. Had the time not been allowed for individuals to become ready, the process would not have been one of individual empowerment, but forced activity. This stage of developing "readiness for change" is an important component of the empowerment process, but there is currently limited insight into how such readiness develops. Further research is needed on this part of the empowerment process.

The impacts described in the previous section resulted from support that was flexible, self-directed and empowering. This philosophy of "doing with" not "doing for" has been stressed by Carling (1993). Similarly, the support was individualized and ongoing to continue the development in an empowering philosophy once the individual was ready for change. At all times, the support providers kept the principles of empowerment at the forefront by recognizing strengths, teaching skills, providing encouragement, exploring opportunities, and letting the individual chose the process (Hogan & Carling, 1992; Ridgway & Zipple, 1990a, 1990b).

Each individual had goals aimed at becoming more integrated in the community and the component of the program that contributed to the achievement of these goals was diversity. Each individual embarked on a unique process of change, which included developing one's own social network and experiencing different activities and opportunities. Individuals chose their supports and activities not from a list of limited options but from a complete scan of the community and their skills and interests.

As individuals who enter supported housing programs are often lacking resources, tangible support is needed to meet basic needs. Advocacy, support for self-advocacy, and material or monetary resources were used to assist individuals to access valued resources. Once again, we



found that it is not just providing assistance in gaining valued resources, but encouraging individuals to acquire the types of resources that they wish. The empowerment philosophy that underlies supported housing has been successfully used to enable consumer/ survivors to access other valued resources, such as employment (Bond, Drake, Mueser, & Becker, 1997).

### Conclusions

This study provided an in-depth examination of the stories empowerment and recovery of five psychiatric consumer/survivors in the context of supported housing. One limitation of this study is the small sample size. We emphasized depth over breadth in this study to develop an initial understanding of changes in the life stories of consumer/survivors and how supported housing may play a role in facilitating those changes. Another limitation is that this type of research cannot make "cause-effect" conclusions about the extent to which supported housing accounted for the impacts/changes that were reported. Future research on this topic can build on this study in several different ways. First, narrative studies using qualitative data could use larger sample sizes to examine the extent to which factors such as gender and ethnicity influence the narratives of psychiatric consumer/survivors who participate in supported housing. Second, as was mentioned earlier, the issue of "readiness for change" needs more careful examination. How do individuals begin to break the downward spiral of powerlessness and dependence that often characterizes their lives? And how can supported housing staff help the people that they support to prepare for change? Third, the types of changes reported by participants in this study could inform the development of outcome measures that could be employed in more traditional evaluation studies of the impacts of supported housing. In particular, the need for measures of personal empowerment, independence, life skills, and community integration are suggested by the findings of this study.

The results of this study reinforce the trend towards more empowering, consumer-controlled services and supports (Carling, 1995; Nelson et al., 2001). The participants in this study spoke of the importance of individualized, flexible, and consumer-controlled supports, diverse sources of support, and assistance with accessing basic resources for their empowerment and recovery. The shift from "doing for" to "doing with" is one that needs to be supported through staff training and organizational changes (Lord, Ochocka, Czarny, & MacGillivray, 1998). Finally, there is a need for social policy to move beyond the narrow focus on mental health services towards a broader focus on housing, employment, and community support, which is what the individuals in this research felt was necessary for them to pursue empowerment and recovery.

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# Cognitive-behavioral treatment of a patient with vertigo and unusual sensitivity to smells: A case report

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## Abstract

Meniere's disease is characterized by hearing loss, tinnitus, vertigo, and aural pressure. We describe the cognitive-behavioral treatment of a patient who carried a diagnosis of Meniere's disease, with additional symptoms of somatoform disorders. In 16 sessions over six months, cognitive-behavioral interventions reduced his symptoms and improved his quality of life. Implications for the role of cognitive-behavioral interventions in rehabilitation and primary care settings for somatizing patients with vestibular disorders are discussed. We advocate an increased interdisciplinary focus toward helping patients with vestibular disorders.

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## Introduction

Meniere's disease is a disease affecting the vestibular (balance) and auditory parts of the inner ear. It is characterized by hearing loss, vertigo (i.e., dizziness and/or imbalance), tinnitus (i.e., sensation of ringing in the ears), and feelings of fullness or pressure in the ear. The patients often have demonstrable abnormalities on clinical tests of vestibular and audiological function. Prevalence rates reported in various studies are, for Japan: 4, US: 15, Sweden: 46, and for the UK: 15, 100, and 160 per 1000<sup>1</sup>.

In general, vestibular disorders have high rates of psychiatric comorbidity, particularly anxiety<sup>2-3</sup>. One study showed 20% of consecutive patients evaluated in a dizziness clinic had panic disorder<sup>4</sup>. Conversely, psychiatric patients with certain anxiety disorders, particularly agoraphobia, have an elevated rate of balance dysfunction<sup>5-8</sup>. These vestibular-psychiatric interactions can occur in several ways<sup>5</sup>. The dizziness may be a symptom of a psychiatric

disorder ("psychiatric dizziness", e.g. the dizziness during a panic attack). More complex interactions include central nervous system linkage, somatopsychic effects, or psychosomatic effects in which "stress" activates the previously compensated vestibular lesions. There is also the probability that some patients may be especially vulnerable to developing psychiatric symptoms (e.g., those who have somatizing tendencies, are anxiety prone, or have personality disorders or traits)<sup>9</sup>. Finally, the psychiatric–vestibular relationship can be complicated by factors in the patient's health-care and social environment. For example, the patient may react with anger and frustration to the clinician's dismissive behaviors that typically follow lack of treatment success. In the family environment, lack of understanding of the patient's symptoms shown by significant others can lead to feelings of loneliness and depression.

We present the case of a patient with dizziness and other symptoms suggestive of Meniere's disease and somatoform disorder whose symptoms did not respond to the efforts of multiple physicians. The patient's symptoms included an unusual sensitivity to certain smells. After psychological treatment for six months with a cognitive-behavioral approach, the patient's condition improved. We discuss the role of the importance of a cognitive-behavioral treatment approach for patients with Meniere's disease or other vestibular disorders complicated by somatization.

### Case Study

The patient is a 55-year old single man with an associate-degree education who currently was living with his parents. Prior to his hearing disability and related difficulties (both financial and medical), he was independent and lived in his own apartment. He had worked for over 20 years in a sales/marketing position at a large medical supply firm, from which he was fired one year after the onset of symptoms. His peak salary in this position was \$100,000 per year. The official reason for dismissal from this position was alleged "fiscal irresponsibility," but he believed it to be due to his disability, as his supervisor had expressed concerns about his hearing loss. Following that job, he worked for a recruiting firm. At this new position, he noticed that his symptoms would increase when he was exposed to perfume odors used by women in his office. Previously he never had any reactions to perfume. Because of these symptoms, he left that job after six months.

At the time of his initial evaluation, he had been unemployed for six years. His past psychiatric history includes an emergency room visit for panic attacks 15 years ago. He had no history of psychiatric hospitalizations. He never had problems with alcohol or drug abuse. Besides his vestibular disorder, his medical history is significant for Type II diabetes mellitus and asthma.

At the initial interview, his medications were fexofenadine (Allegra®, 60 mg, b.i.d.); Methotrexate (2.5 mg, q.d.); diazepam (Valium®, 2.5 mg, b.i.d.); meclizine hydrochloride (Antivert®, 25 mg, t.i.d.); famotidine (Mylanta®, 20 mg, b.i.d.); Prednisone, (30 mg, q.d.); and Glyburide, (2.5 mg, q.d.). These medications suggest that he was receiving treatment for his vestibular disorder (apparently thought to have an autoimmune basis), anxiety, diabetes, dyspepsia, and asthma.

He described symptoms of dizziness, tinnitus, and hearing loss for the past 7.5 years. The dizziness came in attacks that occurred several times per week. During these attacks, he would feel lightheaded and imbalanced, and during many of them he would actually fall. He wore hearing aids on both ears and described progressive hearing loss over the past few years. In addition, he complained of numbness in his arms and legs, severe pain inside his head, and intolerance of certain smells — not only to the smell of perfume already described, but also to cigarette smoke and warm bread. His diabetes was under control; he did not have diabetic

neuropathy. His psychiatric symptoms (which he minimized) included depression and anxiety symptoms, including panic attacks.

He was referred for psychological treatment because several physicians had not been able to find a treatment for him. Over the past year, he had a CT, MRI, EEG, and neuropsychological testing; a review of these indicated no specific pathology. A month before seeing the first author, his otolaryngologist had prescribed diazepam, a drug that has both anxiolytic and vestibular suppressant effects. His otolaryngologist had also referred him to an allergist, internist, rheumatologist, podiatrist, and psychiatrist.

For the first few sessions while receiving his cognitive-behavioral treatment, he was seeing all of the above health-care professionals except the psychiatrist who had referred him on. During most of the cognitive-behavioral treatment sessions he was not receiving any concurrent treatment other than diazepam at the dose specified above.

## Cognitive-Behavioral Treatment

### *Initial Session*

The patient came for treatment after sequential referrals from one mental health care provider to another. These mental health care providers assessed him and did not provide any psychotherapy treatment. The psychiatrist to whom he had been referred by the otolaryngologist referred him on to a psychologist who specialized in insight-oriented psychoanalytic psychotherapy, and who referred him on to the first author, a psychologist-in-training with two years of experience from working in other medical settings using cognitive-behavioral interventions.

The patient described how he was almost constantly preoccupied with seeking a cure for his symptoms. None of his earlier health-care providers had a solution. Although he did not believe that his condition could be affected by psychological factors, he stated that he was willing to try "anything" that would allow him to feel better.

The initial interview established a DSM-IV diagnosis of panic disorder with agoraphobia and of adjustment disorder with depressed mood. Due to his complex case presentation, the psychological testing consultation service was consulted for psychological evaluation.

### *Psychological Testing*

The test report indicated that the test battery included the Millon Clinical Multiaxial Inventory-Second Edition (MCMI-II), Minnesota Multiphasic Personality Inventory-Second Edition (MMPI-2), and a Meniere's Disease-Vertigo Questionnaire<sup>10</sup>. The test results were interpreted as signifying that the patient chose to interpret his symptoms as medical rather than psychological. On the Hågnebo et al. vertigo questionnaire, he consistently and strongly endorsed items comprising factors of somatic and situational origin whereas he did not endorse any psychological correlates with the vertigo attacks. Unlike his psychiatric evaluation, his multiple test scores indicated minimal if any depression or anxiety, but he may have answered test questions defensively.

### *Early Sessions*

The first few treatment sessions focused on providing the patient a rationale for the cognitive-behavioral treatment approach. He was assigned to self-monitor his symptoms and instructed to record antecedents, behaviors, and consequences on a simple monitoring sheet. His recordings would be subject to discussion during the subsequent treatment sessions. Although he superficially complied with these cognitive-behavioral interventions, he remained preoccupied with his various medical appointments, expressing a conviction that one of these might result in a definite diagnosis and specific cure.

### *Intermediate Sessions*

After the first few sessions, the patient had completed the concomitant medical specialist evaluations, the results of which again had been disappointing. Furthermore, his psychological test results were shown to him. At this time, the patient became more cooperative with the cognitive-behavioral approach.

His self-monitoring suggested that a majority of his symptoms were associated with stress or situational factors. For example, the patient described vertigo symptoms while reading computer software at an office supplies store (i.e., visual vertigo<sup>11</sup>). Curiously, a significant proportion of his symptom-triggering stimulus profile was of the olfactory modality. His response to these stimuli could be respiratory in nature. For example, he developed extreme difficulty breathing while visiting his brother because one person at his brother's house was smoking cigarettes. Additional provocative olfactory stimuli included waiting for his medical appointment, smelling perfume from others, and smelling freshly baked bagels at a bagel shop while eating breakfast with a friend.

His treatment included cognitive restructuring and behavioral techniques. The cognitive restructuring component of his treatment included questions and dialogue about possible ramifications about his feared events, all aimed at helping him re-evaluate his phobic belief structure. The behavioral interventions included diaphragmatic breathing and self-paced graduated in vivo exposure to eliciting stimuli related to his problematic olfactory sensitivity. Olfactory sensations were focused upon, as he mentioned that previously he used to socialize with friends at a bagel store while now he was unable to do so. As he was unemployed and not performing any regular activities, the idea was double pronged; he could obtain social support from his friends and also benefit by reducing his anxiety to olfactory stimuli. After this exercise with graded time exposure to the anxiety producing smell of warm bagels, he often frequented the bagel store and had breakfast with his friends. Also, he was instructed to practice diaphragmatic breathing in his natural environment whenever he felt a vertigo attack and to wait out the symptoms for their duration. The diaphragmatic technique was taught with his eyes open, as clinical practice suggests that relaxing with the eyes closed during an episode of vertigo can increase its severity. As his confidence was boosted by the graded exposure to the bagel store, he was repeatedly encouraged to little-by-little try to participate in various activities that he was afraid of, because they had previously been associated with vertigo attacks.

He reported that his vertigo attacks occurred less often and were often reduced in intensity with relaxation/diaphragmatic breathing. He also reported gradual decrements of tinnitus, numbness, pain, allergic symptoms, gastrointestinal distress, depression, and anxiety. The patient began to show an increased awareness of the interplay of psychological factors and his symptoms. He began to react less catastrophically to the symptoms of vertigo. The patient indicated that he no longer feared these symptoms and developed a more accepting attitude towards future vertigo attacks. He became able to discriminate between dizziness related to his vestibular disorder and that related to anxiety. These anxiety-associated dizziness attacks became quite infrequent. Likewise, his non-anxiety attacks decreased in frequency.

### *Concluding Sessions*

The patient came to accept that his Meniere's disease was chronic but would not have to be disabling. He was able to modify and eliminate many of the psychological aspects of his symptoms, such as catastrophizing cognitions, and his fears of olfactory stimuli. He no longer had asthmatic reactions to olfactory stimuli of bagels. He continued to experience slight discomfort to perfume and cigarette smoke, but did not have as severe a breathing difficulty.



He also no longer focused exclusively on his symptoms and even began to consider various career options. He considered re-training in computer programming and was looking forward to a life less troubled by his symptoms of the past few years. Over the last three months of treatment, he only had two attacks (one anxiety and one vestibular), whereas before treatment, he had multiple attacks each week.

Follow-up evaluations at one and three months after treatment indicated that he maintained the improvement in his psychiatric and somatic symptoms. His vertigo attacks were less frequent, and after falling spells, he was able simply to pick himself up from the floor and continue with his activities.

**Table 1**  
Overview of treatment effects

Symptom	Pre-treatment	Post-treatment
Dizziness attacks	Five attacks per week	Once a month
Meaning attribution	Did not recognize "anxiety" as a contributor	Able to identify anxiety-related dizziness
Cognitions concerning dizziness	Catastrophizing	Accepting
Coping	Symptom focused	Task focused (career)

## Discussion

### *Limitations Inherent In Case Reports*

As is true for all individual case reports, we cannot rule out that the improvement noted in the patient may have been due to factors other than the cognitive-behavioral treatment. One possible confounding factor was the concomitant treatment with diazepam. However, the dose of diazepam was not changed during his cognitive behavioral treatment, and the patient did not experience reduction in symptoms until two months after beginning diazepam. Therefore, most of the improvements described below are more likely to be related to the cognitive-behavioral treatment than the benzodiazepine treatment. Also, there is the possibility of observer bias from the therapist and patient as symptoms can be expressed subjectively and were not monitored or confirmed with objective physiological monitoring.

### *Psychiatric Disorder, Vestibular Dysfunction, and Cognitive-Behavioral Interventions*

The treatment of the unusual, "somatizing" symptoms of this patient with suspected Meniere's disease was challenging. Many of the ancillary symptoms of the patient discussed here, have not been described as psychiatric consequences of vestibular dysfunction (e.g., of numbness in his arms and legs, severe pain inside his head, and the "allergic reactions" to the smell of

perfume and warm bread) and may be suggestive of an additional diagnosis of undifferentiated somatoform disorder.

Part of the key to success with this patient may have been a careful individuation of treatment focus to those symptoms that were of the greatest concern for the patient. Rather than the dismissive behaviors that the patient described experiencing with most of his health-care providers, the therapist showed interest in the patient's symptoms and accepted them at face value. Of interest is that self-monitoring suggested that some aspects of his symptoms were situational or stress-related. This impression would be consistent with a study of Meniere's disease patients that showed a concurrent association of stress with their symptoms; however, the direction of causality in that study is unclear, since these symptoms were not associated with stress on preceding days<sup>12</sup>.

Thus, the cognitive-behavioral interventions of self-monitoring, diaphragmatic breathing, and cognitive-restructuring helped this patient from some of the distressing aspects of his symptoms. Although at post-treatment he still would experience intermittent falling on the floor, he now continued with his activities to the best of his ability. The patient's regard for this treatment approach shifted from being hesitant to that of a faithful adherent; over the duration of 16 treatment sessions, the patient only re-scheduled two sessions. He learned to identify and accept anxiety-related dizziness as contributing to his symptoms. After treatment, he chose to no longer primarily focus on his symptoms but to focus on possible career options.

#### *Interdisciplinary Treatment Approach*

Psychologists in rehabilitation settings may find themselves collaborating with physical therapists that treat chronic vestibular disorders such as Meniere's disease and their psychiatric consequences. Vestibular rehabilitation involves exercises that maximize central nervous system compensation for the vestibular pathology and is administered by physical therapists. Beidel and Horak<sup>13</sup> discuss the similarities between vestibular rehabilitation as practiced by physical therapists and cognitive-behavioral therapy as practiced by psychologists. Both perform multidimensional assessments on their patients, including at the degree of functional impairment and coping strategies. Their treatment interventions both include exposure to dizziness or anxiety evoking stimuli and techniques of arousal reduction such as relaxation. However, they differ in that physical therapists aim for central nervous system compensation while psychologists aim for elimination of panic attacks and other psychological distress.

Integration of the two approaches can benefit patients with anxiety disorders complicated by vestibular dysfunction. One study of patients with both agoraphobia and vestibular dysfunction had participants complete a four-week self-directed behavioral-exposure program followed by a 8-12 week program of vestibular rehabilitation. Although the behavioral treatment improvement occurred in some parameters, there were no significant changes in anxiety or phobic avoidance. After the vestibular rehabilitation program, there were further improvements in clinical global impressions of severity, anxiety, and phobic avoidance<sup>14</sup>.

Besides rehabilitation settings, primary care settings can quite often benefit from the psychological approach toward treating those with vestibular disorders. There is increased collaboration of mental health professionals with physicians in primary care settings<sup>15-16</sup>. This case study was instrumental in helping to increase the collaborative relationship between psychology professionals and internists and otolaryngologists at this particular hospital. Although quite well read and practicing in their field for many years these medical professionals had not thought of the possibilities that psychological interventions could offer

to patients experiencing vertigo and other somatizing symptoms related to Meniere's disease. Following this successful outcome, the psychology staff received numerous referrals from the primary care physicians and also increased questions about the possibilities regarding if psychological treatment approaches could benefit their patients.

### *The Specific Role of the Psychologist*

The psychologist may have a role beyond that of the physical therapist especially in those cases where physical rehabilitation proves problematic or ineffective. In addition, psychologists can offer specialized assessment for psychiatric disorders and psychological difficulties.

Each of the main symptom categories of Meniere's disease, (i.e, tinnitus and vertigo) can lead to psychological difficulties. Especially, chronic tinnitus can cause disrupted sleep and there may be an inability to concentrate. Psychological difficulties associated with chronic tinnitus include anxiety, depression, feelings of hopelessness, irritability, and even suicide<sup>17-18</sup>. Furthermore, as already discussed, vertigo or dizziness symptoms can result in adjustment issues depending on the severity and frequency of the attacks. Psychological difficulties associated with vertigo include panic attacks, fear leading to activity restriction, and if an individual's gait becomes unstable, embarrassment and ridicule leading to social avoidance.

More generally, there is a need to develop interdisciplinary programs for vestibular patients, similar to what has been done with chronic pain patients. However, such a program would need to be adapted, taking into account the physiology of the vestibular system as it relates to symptom formation and the possible situational triggers. Furthermore, in the future, more attention should be focused on the psychological screening of patients with vestibular disorders so that appropriate cognitive-behavioral interventions can improve their recovery and quality of life.

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# What Does Social Justice Mean and Require in the Rehabilitation of Ex-Convicts Addicts in the Era of Privatization

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## Abstract

The paper presents a model of treatment of ex-prisoners with addiction problems aimed at facilitating re-entry in the society. A comparison is made between two therapeutic approaches: Bribing the criminal and Converting criminals into non-criminals in the Half-way house model. The present global trend of privatization is also addressed.

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## Introduction

In this paper we are going to present a model of rehabilitation which enables the ex-prisoner to return and integrate to society, as compared with models which tend to perpetuate the individual's dependence. This model has been shown to succeed in 96% of cases since it was started in 1988, success defined as permanence and integration of the individual who finished the program to society, without returning to prison. We are also going to consider the possible repercussions of privatization in the future of those individuals who until now were a burden for society, relied and depended on it. They will now be forced by the new reality of the Israeli society to enter into an open-market economy with the inherent concurrence. **Punishment**, as well as two basic **treatment and rehabilitation** approaches will be discussed: a) **Bribing the criminal**, and b) **Converting criminals into non-criminals in the Half-way house model**.

The paper will compare both approaches from the point of view of what *social justice* requires with respect to: a) the individual and b) society. From the point of view of the **individual** we will discuss the issues of 1) autonomy and freedom; and 2) paternalism, and how these items are considered in the bribing the criminal and in the Half-Way-House model, and how the individual's right to autonomy and freedom is best considered. From the point of view of **society** we will discuss: 1) what is better for society, meaning: less threatening for the normative majority, more rapidly achievable, cheaper and with a longer-lasting effect; 2) what is socially accepted, and 3) what is more cost-effective.

After discussing in the paper all the above mentioned, we claim that the Half-way house approach is the most socially just and most effective, in meeting the needs of rehabilitation in the new era of privatization.

Addictions and the inherent criminality, have become one of the seven plagues of the 20<sup>th</sup> century, and, as things go, they will also be one of the seven plagues of the 21<sup>st</sup> century. All kind of different habits, like using chemicals, overeating, gambling, having a prolific sexual activity, etc., have been defined as addictions. But there is an obvious difference between at least two groups of addictions: those which are detrimental **only** for the individual, like overeating, or being addicted to dangerous situations (mountain climbing, etc.), and those addictions which are detrimental **for others and for society** as well, like addiction to drugs and/or to alcohol.

When a person uses drugs and cannot afford the cost of the drugs, then he has to resort to illegal activities, such as theft or dealing in drugs, in order to obtain the money to pay for his addiction, the problem is a social one. The individual is causing a damage to others with his addiction, and there is a societal interest in the case. The cost of such individuals for society is extremely high. One estimate for Israel is that an average heroin addict has to cause propriety damage of about 1.000 U/S dollars a day to support his habit and himself.

This ridiculously high price does not include: loss of wages; police, court and prison costs; health care for the results of drug consumption; health and/or psychological care for people who may result hurt during a delictive act performed by the addict; treatment of persons who may have been infected with HIV or other infectious diseases as a consequence of intercourse with the addict, or by sharing his needles, etc.; support for his family while the addict is in prison; psychological and social treatment for his wife and children; keeping the children in institutions when the mother cannot cope alone, or when the children begin to exhibit behavioral problems as a result of their defective rearing.

It is obvious that we are not facing only an individual problem or a possible damage to the physical and mental health of the addict and his family. We are facing a serious problem for society.

For millennia societies have been faced with the problem of criminality, and in the last century, also with the one of addictions. In the course of time, two contradictory approaches have been developed: 1) Punishment and 2) Treatment, each of them with different variations. We are going to analyze different aspects of this dilemma. In this paper we will focus and emphasize the treatment approach in general, and the non-coercive treatment in particular, which we consider the best solution to the problems. We are also to refer briefly to some aspects of punishment, which in our opinion is less successful than treatment.

### **1) Punishment:**

Punishment is usually culturally dependent. Three basic approaches have been delineated for punishment (Walker, 1991):

a) - Punishment as revenge or to obtain compensation fits the old Anglo-Saxon social system, and also the old Biblical tradition of an eye for an eye, but it is not adequate for modern, big societies;

b) - Punishment as deterrence, or to defend society, is more adequate for big, cosmopolitan societies, in which crime is often committed not against individuals but against impersonal consortiums and companies. In this approach, individuals who are the victims of crime and who want to obtain compensation have to have obtained insurance previously in order to be protected. Nevertheless, the approach provides relative protection for individuals, entities, and the State.

Three) - Coercive treatment and rehabilitation, as has been used in some places, is based on the supposition that crime is a byproduct of a defective education, and that correctly-educated individuals should think and act as everybody else, otherwise, they have to be re-programmed.

Harsh punishments, either in approach a) or in approach b), have proven non-effective. Countries where punishments are very harsh have the same incidence of criminality (depending on socio-economic factors) as countries with less severe punishments. The failure of the primitive Social Justice concept of equal punishment for equal crime has filled the prisons of the world, but did not solve the problem of criminality.

The purpose of the law and of correctional entities may ultimately be defined as: to prevent crime and reincidence. This prevention may be defined as the ultimate goal of society in this respect (Parent, 1990). Society is not interested in crime, thus, preventing criminality serves society well. But society, even in rich countries, is also not interested in spending unnecessary amounts of money in order to prevent criminality. Thus, preventing criminality in a cost-effective way is better for society than preventing criminality in an inefficient, expensive way.

## 2) Non-coercive treatment:

Among the many treatment and rehabilitation modalities available today, which cause serious ethical dilemmas among therapists (Reamer, 1982), we want to refer to two in particular: a) Bribing the Criminal, and b) The Half-Way-House Model:

### a- Bribing the criminal:

We have preferred to call so a correctional attitude characterized by trying to keep criminals out of criminal activities by bribing them in a relatively organized fashion.

The policy of bribing the criminals by allotting them a series of social benefits, like social welfare, privileges for housing and the acquisition of small shops, etc. can only keep criminals at bay for short periods of time. In most cases, after a more or less serious attempt at using the services provided, the criminal finds out that his economic level was better while he was a criminal, and consequently tends to relapse into delinquent activities.

This system keeps the criminal inactive for short periods only, and it is very costly for society and for the individual. It reinforces the criminal's narcissistic perception of reality and of the rights of the individual. It also creates in the clients the habit of obtaining secondary gains, *because society is to be blamed, society owes me: (it's because of them)*. As a consequence, the criminal who wants to obtain a determinate benefit will break the law with ease if he considers that by doing so he is going to obtain at the end the benefit he was asking for, and which he considers "his legitimate right."

This system does not take into consideration *individual dignity* in the sense that it does not respect his autonomy as a rational moral agent. According to (Kant, 1965-1797). Clients of this system become parasitic, and depend upon the continuous reception of benefits in order to subsist. This system does not lead the individual to *autonomy* and to *freedom* because the individual becomes dependent on the continuous provision of funds (for example, from Social Security) by a system which at the same time forbids him to develop independent means of survival (people receiving Social Security are specifically prohibited to work beyond a limited amount, which cannot exceed the monthly sum provided by Social Security).

### b) - Converting the criminal into a non-criminal by the Half-Way-House model:

The model presents an opposition of authority in contrast to freedom, and when first looked at seems to be paternalistic, but after analyzing the rationale of the model, it is a necessary and justified paternalism.

The theories and concepts of: a) Winnicott (1965) (transitional object) are applied in the Half-Way House, which provide the opportunity for a corrective experience (F. Alexander, 1956), of an earlier incomplete developmental process.

and b) Seligman (Seligman et. al, 1979) (learned helplessness and its treatment by "forced response") provide an excellent framework for achieving the reversibility of cognitive, emotional and behavioral deficits under the protection of the transitional object (the Half-Way House), where clients have to work to provide for their basic needs, **thus passing from dependence to independence, in a fashion which could be superficially interpreted as paternalistic**, but which really leads the individual to autonomy and freedom that he never reached before. They undergo a treatment pointed at improving their socialization, re-structuring their lives and becoming functional, non-addicted and non-criminal members of society.

This treatment model *is better for society* because the system permits individual dignity (Kant, 1965-1797). Clients become productive and independent members that undergo a resocialization process, restructuring their lives and becoming functional and self-esteemed, non-addicted and non-criminal members of society.

It also provides a better opportunity for an equalitarian distribution of resources and better standards of living, consequently it is socially and morally more acceptable. Paradoxically, those were originally also the goals of the welfare state, as mentioned by E. Hertzog (1996): Distribution of public assets and resources on an equalitarian basis.ertzog (Her

This long-term process of a year in residence and a second year in intensive follow-up requires more time and effort but its effects last much longer, and it is less expensive for society and individuals, consequently, **it is more cost-effective.**

The Half-Way House model is a very adequate instrument to achieve the goal of preventing criminality and reincidence at very low cost for both society and individuals in the new era of privatization Israel is undergoing where everybody, including ex-convicts addicts, will have to compete for resources.

These two approaches represent two schools of thought: the first school claims that if we give the clients sufficient material means to meet their basic needs they will not have to resort to drugs and delinquency as an escape from their fear to cope with life. Expectation from the individual by this school are very low.

The second school represented in the Half-Way House believes in teaching the clients how to be free and claims that if we give the patients the necessary tools and opportunities they never had before of learning how to solve problems and confront life, just as everybody else, they will not need to resort to delinquency and drugs in order to avoid the vicissitudes of life. They will not only be able to satisfy their basic needs, but beyond that they will be able to compete on an equal basis with others, and achieve their full potential, in the sense mentioned by Plant (1987).

From the social point of view, the model is based on the idea that most criminals never had a second chance, which the rehabilitation process can offer, and that, given the adequate conditions, they can profit from it. This possibility of a second chance offered on the long term in the Half-Way House, is much closer to the ideal of Social Justice.

The controversy between these two last approaches is not new, it is mostly a particular case of a wider controversy between two schools of thought regarding a much wider topic: **Freedom.** (according to Stuart Mill (1909), and according to Rousseau (1967) ).

For Mill, the individual is sovereign of himself. For Rousseau the individual, for his own good, has to submit his individual will to a superior collective will. According to Rousseau, paternal treatment should be admitted because it is in the benefit of society.

Berlin, in 1969, offers a helpful distinction between Negative Freedom, which we would link with Mill, and Positive Freedom, which we would link with Rousseau.

The question of the limits of individual freedom has been raised since antiquity. Curiously enough, not only democrats *strictu sensu*, but even totalitarian regimes have claimed the words Liberty and Freedom as their own (George Orwell, 1984); Democratic Republic of Germany (East Germany), Torrijos democratic dictatorship in Panama, etc..

The problem of the confrontation of individual freedom as opposed to collective rights has always been debated. Paternalists have used the concept of the rights of society as opposed to the rights of the individual in order to impose their ideas to revolutionaries.

The first approach, Bribing the criminal, is more closely related with Mill, and the second approach, the “Half-Way House, is mostly related to Rousseau.

Mill rejected most but two forms of Paternalism. The ones he accepts are: 1) that if a child could take rational decisions he would agree with our decisions about his own welfare); and 2) that no adult may sell himself into slavery, since doing so is inconsistent with any future autonomy). According to this, the ex-convict addict who is



treated in the Half-Way House in a justified paternalistic fashion, should even be accepted by Mill's view because the patients as a result of an incomplete development, are fixated in the childish stage of dependency, and still have to learn how to make rational decisions by going through a maturational process in a facilitating environment (the Half-Way House).

The tendency toward privatization, which characterizes present-day economies and also Israel, and the scarcity of funding caused by an ever-increasing population who needs access to resources which grow less rapidly than the population, configure an appropriate field for the application of the principles and techniques of the Half-Way House rehabilitation model.

## Conclusions

When answering the question: What does social justice mean and require from the individual and from society in the rehabilitation of ex-convicts addicts in the era of privatization, it is obvious that we are not facing only an individual problem but a menace for society. Addictions and the crime inherent to it are not detrimental only for the individual, but for others as well. When a person uses drugs, he resorts to illegal activities and his problem becomes a social one. Preventing criminality in a cost-effective way may be defined as the ultimate goal of society in this respect, and the Half-Way House is an adequate instrument for this purpose, while enabling the ex-convict addict, after completion of treatment and reaching finally a fair "start point", equal opportunities for free competition in the era of privatization.

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# Evaluating the Effectiveness of Supported Apartment in Facilitating Community Integration and Mutual Help among Residents with a Chronic Mental Illness in Hong Kong: Some Preliminary Findings

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## Abstract

**Objectives:** The effectiveness of supported apartment in enhancing community integration, mutual help and social support network among persons with a chronic mental illness was examined in this study. **Methods:** Three well-established instruments measuring the above-mentioned variables were administered to 14 residents in their first, sixth and twelve months of residence in supported apartment. **Results:** Positive changes in community integration, mutual help and social support network were found at twelve months. Only one resident had experienced relapse during this period of evaluation. **Conclusions:** The results provide some initial support for the effectiveness of supported apartment in facilitating community integration, mutual help and social support network among residents.

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## Introduction

Residential services for persons with psychiatric problems aim to assist the persons to live independently and to re-integrate into the community (Hong Kong Government, 1999). In Hong Kong, halfway houses and long-stay care homes are two major types of community-based residential programs to serve the above goal (Hong Kong Government, 1999). Long stay care homes intend to provide accommodations and basic skills training for chronic patients with psychiatric problems who require nursing care but do not need active medical treatment (Hong Kong Government, 1999). However, it has been suggested that only a few residents were able to move along the ‘residential continuum’, and many remained in long-stay care home (Carling & Curtis, 1997). Indeed, according to the statistics of a local agency running long stay care homes for persons with psychiatric problems, there were around 9.5% of residents living in these facilities who could be successfully discharged (New Life Psychiatric Rehabilitation Association, 1997, 1998, 1999). It has also been criticized that such a large institution with 200 residents creates segregation rather than integration, and dependency rather than independence (Yip, 1997).

Halfway houses provide transitional residential care for persons with psychiatric problems who are able to return home or live independently and to re-adjust to normal life (Hong Kong Government, 1999). Through small group living, various types of skills training and professional support, residents are expected to be able to maintain mental stability and develop skills and confidence for community living (Hong Kong Government, 1999). Studies conducted overseas (e.g. Rog & Rausch, 1975) and in Hong Kong (Lai, 1986) reveal that halfway houses could reduce recidivism and enhance residents’ independence. However, halfway houses in Hong Kong have been criticized as another form of ‘community institution’ (Yip, 1997). With a capacity of 40 residents, halfway houses provide limited personal privacy (Nelson, Hall & Bowers; 1998) and depersonalized care practices (Kruzich, 1985) and possibly produce institutionalized residents (Yip, 1997). Indeed, local studies have found that psychiatric patients discharged from halfway houses were living in deprived situations and many were still in need of regular care and psychosocial support (e.g. Mak, Gow & Mak, 1993).

Drawing on the experiences of other countries, the Mental Health Association of Hong Kong has introduced supported apartment as an alternative residential facility for persons with psychiatric problems. This type of residential service is less structured, and encourages residents to draw on their own personal resources to help one another. As a home-like environment, this apartment has fewer residents, and employs mainly non-professional staff (i.e. 1 welfare worker and 2 caretakers, in the case of Hong Kong) to be responsible for house keeping, clerical duties and assistance to residents. In Hong Kong, supported apartment is run according to the following principles:

### 1. Privacy and home-like environment

Privacy refers to ‘the ability to control access to one’s personal space and what happens to and in one’s private space and time (Wilson, 1991). Privacy includes the availability of personal space as well as the right to use one’s space. In the development of this supported apartment in Hong Kong, particular attention has been put towards ensuring that residents have freedom in the way they use their apartment space. They are free to keep a certain amount of personal belongings, and to decorate their own space. Moreover, they keep the keys to their rooms.

Our supported apartment service has two adjacent units. Each unit is decorated as an ordinary home with a sitting area, a kitchen and a laundry. The unit has single and three-person rooms and can accommodate a total of 10 residents. Besides common areas, each resident has about 70 square feet of personal space. With such a relatively small number of residents and a rather large area, it provides a sense of comfort and quietude for the residents. Since there are few rules that govern the

daily routines of residents, residents can structure their own daily activities and enjoy normalized household practices such as cooking and laundry.

## 2. Minimal rules and maximum choices for residents

Residential services should create opportunities for making choices and decisions. Staff respect the decisions of residents in their choices of daily living schedules and activities unless these choices create inconvenience and/or are harmful to others. Supported apartment in Hong Kong aims to create an environment so that residents can be fully involved in choosing their living preferences: what they want to do and how they go about doing these. Minimal rules and regulations are set to ensure that individual choices do not interfere with the lives of others. Otherwise, residents can enjoy as much freedom and choices as they desire.

## 3. Residents' initiated approach to programming

Unlike staff of a halfway house, staff of the supported apartment in Hong Kong do not attempt to actively engage residents in the planning and implementation of their rehabilitation plans. Nor do they purposefully organize activities for the residents. However, if and when residents raise personal interests that involve himself or herself or other residents, staff will assist them to fulfill their needs and interests. For example, a resident who wanted to learn to cook Chinese foods was assisted by a staff to learn to do so. Another example is that: a resident who wanted to watch a movie with other residents was assisted to approach other residents and to organize the event. While this approach helps residents to develop their own interests and fulfill their own needs, it also develops residents' abilities to take initiative to deal with their own concerns.

## 4. Development of mutual help among residents

The availability and adequacy of social support are found to be a key condition for successful community integration (Froland et. al., 2000; Nelson et. al., 1998). Therefore, supported apartment in Hong Kong attempts to foster a sense of mutual support among residents. Through the monthly residents' meeting and informal gathering organized by the residents themselves, residents were encouraged to develop friendship among each other. It is believed that such a kind of support is more appropriate for residents, as friendship developed may be enduring and stable. The role of staff is to link and facilitate the development of this mutual help among residents.

This study aimed to examine the effectiveness of supported apartment in facilitating community integration and social support of residents. As such, it is necessary to delineate how we conceptualized the concepts of community integration and social support.

## Conceptual Understanding of Community Integration and Social Support

### The concept of community integration

Community integration is a multi-dimensional concept that has not been well-defined (Carling, 1992; Kennedy, 1989). A review of the literature suggests that community integration may be defined according to the following dimensions:

#### 1. Reduced rate of recidivism

A reduction in the rate of readmission to mental hospitals has been proposed as one-way of defining community integration (Rosenblatt & Mayer, 1974). Living in the community is, indeed, a pre-condition for community integration. This is particularly meaningful for people with a chronic mental illness because individuals with a chronic mental illness will have a greater chance of relapse should they be improperly managed in the community. Therefore, it is not surprising to find that

community-based psychiatric services use recidivism as an important indicator of successful community integration (Kruzich, 1985, New Life Psychiatric Rehabilitation Association, 1998).

a) Social integration

Forrester-Jones and Grant (1997) suggests that social integration includes three dimensions:

a) Locational integration refers to the physical integration of individuals within community setting (Malin, 1987). People with disabilities should not be placed in remote and segregated areas in the community, and should be present in accessible and visible areas in the community.

b) Environmental integration is defined as ‘the physical context in which individuals live, and the wider community in which people interact’ (Forrester-Jones & Grant, 1997). Individuals with disabilities should not be placed in large and institutional-like settings, but live in ordinary facilities with maximum opportunities to interact with people outside of the facilities (Davey, 1994, Hogan & Carling, 1992).

c) Participatory integration denotes ‘the frequency of clients’ participation or involvement in the ongoing activities of their community (Dilks & Shattock, 1996). These activities include: accessing to basic, personal and community resources; participating in family life, friendship relationship and community groups; and using community recreational facilities. These kinds of activities were regarded as normative social behaviors. An individual may be perceived as socially integrated if he or she participates in these activities on a regular basis (Shadish & Bootzin, 1984).

In this study, community integration was defined in terms of the rate of recidivism and the level of social integration found among residents living in the supported apartments. It was hypothesized that residents who had lived in the supported apartment after a period of twelve months would have lower rate of recidivism and be more socially integrated.

The concept of social support

Despite the diversities in the definitions of social support, researchers have generally agreed that social support consists of the following two dimensions (Barrera, 1986; Newcomb & Chon, 1989; Sarason, Pierce & Sarason, 1990)

1. Social network

Social network is a specific set of linkages among a defined set of persons (Mitchell, 1969), and that individuals within this network have regular face to face interactions and a degree of commitment to one another (Broom & Selznick, 1973). Essential characteristics of a network include such things as size (i.e. the number of people who make up the network); density (i.e. the ratio of actual links in the network) and multiplexity (i.e. the prevalence of certain types of ties). It is generally believed that the larger the network size and the broader the linkages, the greater the availability of social support.

2. Support function

Social support may be defined in terms of support functions exchanged by network members in a social relationship. House (1981) identifies four main functions of social support that include emotional support, appraisal support, informational support and instrumental support. Other researchers have suggested other functions of social support such as action-facilitating support and nurturant support (Cutrona & Suhr, 1990); material aids; and guidance (Barrera, 1981). Studies have found that these functions of social support can enhance the physical health and psychological well-

being of an individual (Forrester-Jones & Grant, 1997). In the field of psychiatric rehabilitation, social support is also found to be a significant factor in enhancing community integration of persons with a chronic mental illness (Forland et. al, 2000; Caron et al, 1998).

In this study, social support was defined in terms of social network and support functions. It was hypothesized that residents who had lived in the supported apartment for a period of twelve months would have a larger social network with a greater exchange of support among residents.

#### Relationships between Community Integration and Social Support for Persons with Mental Illness in Residential Settings

Studies have revealed that social support was found to be closely related to residents' overall functioning, subjective well-being (Lehmann, 1982) and community integration in residential care settings (Nelson et. al., 1992; Caron et al, 1998). Particularly, Nelson, et al (1992) noted that residents in group homes and supported apartments had more supportive social network transactions with friends and professionals and greater frequency of support exchanged among people in the community. Lehmann (1982) also found that social support, which enhanced residents' well-being and social contacts within and outside of a residential setting, were associated with greater satisfaction and better functioning of residents. To conclude, these studies show that a living environment with sufficient social support is beneficial to facilitating residents' rehabilitation and social integration.

### Objectives

This study had the following objective:

1. To evaluate the effectiveness of supported apartment in facilitating community integration, social support network and mutual support among residents with mental illness

### Method

#### Research design

A time series research design was adopted, and residents were individually interviewed according to a structured questionnaire in the first month of having resided in the apartment, at the sixth and twelfth months. The questionnaire contained questions on demographic characteristics of residents and three well-established instruments:

1. External Integration Scale aimed to examine the level of community integration of residents, (Segal & Aviram, 1978). A five-point scale, with '5' denoting 'Most Frequently' and 'Very Easily' and '1' being 'Never' and 'Very difficult' was used. The Cronbach's alpha scores for the full scale and their domains achieved in this study were 0.90; 0.61; (frequency of daily outdoor activities); 0.92 (level of independence in accessing public facilities); 0.83 (level of independence in handling issues of personal care); 0.75 (degree of easiness in maintaining contact with family members); 0.43 (degree of easiness in maintaining friendship); 0.83 (frequency in performing voluntary work) and 0.50 (frequency of leisure activities).

2. Lubben Social Network Scale attempted to tap the frequency of contact initiated by the resident towards his/her family members and friends (Ma, 1990), and it had two subscales: social support network-family members and social support network-friends. Residents were given six choices regarding how often they had contacts with family members and friends and how many times they had such contacts. The Cronbach's alpha scores for the full scale and their subscales were 0.73; 0.63 (social support network-family members) and; 0.92 (social support network-friends).

3. Mutual Support Network Scale was used to measure the perceived instrumental support and social companionship obtained by residents from other residents of supported apartment (Fung, 1999). Residents were asked the extent to which they found certain elements of instrument and social companionship support as sufficient or not. It was a five-point scale with '5' denoting 'Very Insufficient' and '1' being 'Very Sufficient'. The Cronbach's alpha score achieved in this study was 0.88.

### Samples

All residents living in the supported apartment who met the following criteria were included as subjects of this study.

- 1) Residents must have continuously resided in the apartment for twelve months prior to post-test,
- 2) Residents had to be between 18 and 60 and had a diagnosis of a serious mental illness such as schizophrenia.

### Data collection procedures

All incoming residents were informed of the purposes of the study prior to admission to the supported apartment. Three ratings were taken: within the first month, at the end of the sixth month and at the end of the twelve months of residence at the supported apartment. All residents were personally interviewed according to the structured questionnaire designed by the researchers. A student research assistant was recruited and trained to conduct these structured interviews.

## Results

Table 1 shows the profile of the residents. There were more male residents than female residents living in Clara House. Many were single, with an average age of about 45 years old, and suffer from chronic schizophrenia. Most of them had multiple admissions to the hospitals in the past. The majority of residents worked in sheltered workshops. Since some had income below the level set by the government, they received income supplement through social security.

Table 1: Demographic characteristics of residents of supported housing (N=14)

<u>Characteristic</u>	<u>Frequency (%)</u>
Sex	
Male	8 (57.10%)
Female	6 (42.90%)
Age	
29-40	5 (35.70%)
41-50	6 (42.80%)
51-60	3 (21.30%)
Mean (S.D.)	44.93 (7.46)
Marital status	
Single	11 (78.60%)
Divorced	3 (21.40%)
Type of illness	
Schizophrenia	13 (92.90%)
Other	1 (7.10%)
Duration of illness	
Under 5 years	1 (7.10%)
6-10 years	1 (7.10%)
11-15 years	3 (21.30%)



Over 20 years	9 (64.50%)
Number of hospitalizations	
Once	3 (21.40%)
Twice	4 (28.60%)
Three times	4 (28.60%)
Four or more times	3 (21.40%)
Income source (more than one type)	
Open employment	2 (14.30%)
Sheltered employment	11 (78.60%)
Supported employment	1 (7.10%)
Social security assistance	6 (42.90%)

Table 2 indicates that residents had made some improvement in community integration, social support network and mutual support over a one-year period. At twelfth month, a slight improvement in the overall score in community integration was noted. Specifically, residents achieved a higher level of independence in accessing public facilities, attending to personal care, and feeling easy in maintaining contact with family members and friends. In terms of network size, it is noted that residents had expanded their overall social network size, as well as in family and friendship networks. The sense of mutual support among residents had also increased from time 1 to time 3. Lastly, only one resident experienced a relapse at time 2. On the whole, although changes were modest and did not achieve a statistically significant level, residents' community integration, social support network and mutual support had improved over a one-year period.

Table 2 Residents' change in scores in community integration, social support network and mutual support (N=14)

<u>Items</u>	<u>First months</u>	<u>Six months</u>	<u>Twelve months</u>
Overall community integration (CI)	2.70	2.80	2.76
CI- frequency of daily activities	2.94	3.06	2.85
CI- level of independence in accessing public facilities	3.07	3.32	3.28
CI- level of independence in handling issues of personal care	3.25	3.55	3.46
CI- level of ease in maintaining contact with family members	2.63	2.75	2.69
CI- level of ease in maintaining friendship	2.62	2.62	2.82
CI- frequency of performing voluntary work	2.29	2.14	2.14
CI- frequency of leisure activities	2.13	2.13	2.13
Overall social support network	2.50	2.74	2.75
SSN-family	2.52	2.71	2.60
SSN-friends	2.45	2.76	2.90
Overall mutual support	2.97	2.95	2.81
Relapse	0	1	0

## Discussion

Before embarking on a discussion of the findings, it is important for readers to realize the limitations of the present study. First, this study adopted a non-randomized time-series design and did not have a control group. In the initial stage of the process, the researchers did attempt to identify and recruit

persons with a chronic mental illness who chose to live independently as subjects for the control group. However, the response rate was so low that the researchers had to forgo such an idea. In the absence of a control group, it was impossible to make an affirmative conclusion of the improvement found in residents in this study. Another limitation is that, this study was not a double-blinded design and both the researchers and the residents were aware of the purposes of the evaluation. Consequently, biased results might have occurred. Therefore, ideas discussed below should be considered as tentative, and require further examination.

This study reveals that there was only one resident who had relapsed and had to be hospitalized. The rest remained mentally stable. It has been argued that a reduction in the rate of rehospitalization is an indication of successful community integration (Rosenblatt & Mayer, 1974). Indeed, mental stability is a precondition for community living, and therefore, is also a necessary condition for successful community integration. Residents' stable mental conditions may be related to the fact that supported apartment provided residents with a sense of comfort, ease and enjoyment in having personal space. Therefore, these positive elements in the living environment served as protective factors that maintained the mental states of residents (Nelson, Hall & Bowers, 1998).

This study has also found that residents became more socially integrated into the community. They had achieved a higher level of independence in accessing public facilities, handling issues of personal care, and feeling easy in maintaining contact with family members and friends. A number of reasons might have accounted for the positive results in social integration. First, the positive changes in social integration may be related to the style of operation of the supported apartment. King and Raynes (1968) have proposed two operational styles of residential service. Institution-oriented style of operation denotes that residents living under this type of operation are often treated alike for ease of management. As a result, rigid daily routine, block treatment and formalized skills training are often imposed on the residents irrespective of individual needs. On the other hand, resident-oriented style of operation emphasizes individuality, and that services will try to accommodate to residents' individual needs (Wilson, 1991). Under this type of operation, residents learn to take initiatives and make decisions to address their own needs. They tend to be more independent and maintain a greater sense of control over their lives. Supported apartment in Hong Kong operates according to a resident-oriented style of management, and the positive changes in social integration might have been a reflection of this style of operation. There were minimal rules and regulations that govern the operations of the apartment and residents were free to engage in daily and social activities outside of the residence. Consequently, there was a higher level of social integration achieved by the residents.

Another reason for a positive change in social integration is that, social companionship established in the apartment had encouraged residents to jointly participate in social and daily activities in the local community. It is not uncommon to find that residents went shopping together and accompanied one another to tea drinking, sports and other social activities. While it might be difficult to venture out on one's own, it would be much easier to do so with others. Indeed, the positive effects of social companionship go far beyond the realm of social integration, it can promote health and well-being among the persons involved. Indeed, studies have found that social companionship was an important determinant of mood and well-being (Rook, 1987), and enhanced self-esteem through compassionate interactions (Hays, 1988).

This study reveals that residents expanded their size of social networks and perceived themselves as having sufficient instrumental and social companionship support from others at the twelfth month. The increase in friendship network size might have been due to the fact that residents had built up friendships among other residents. The questionnaire did not ask the source of friendship and therefore could not distinguish friendships established inside of the residence and in the community.

Nonetheless, the increase in social support network can enhance the social integration of residents because residents receiving instrumental and social companionship support are likely to be motivated to participate in social and daily activities in the community. Moreover, a supportive and harmonious living environment is conducive to mental stability of the residents. Studies conducted by Breier and Strauss (1984) have actually found that the existence of supportive social network can protect residents from the impact of life stresses, reduce morbidity and provide the support that are important for community living.

The modest increase in family network size was a positive and encouraging sign because it has always been an objective of psychiatric rehabilitation to help persons with a chronic mental illness to be socially connected to their family members as much as possible. Indeed, studies have found that family support was associated with improvement in well-being for persons with mental health problems (Sun, 1994). Besides, it has always been a Chinese virtue to foster a sense of family spirit of mutual sharing and support among family members. The tapering of the score at twelfth month can be explained in terms of the fact that, in the initial stage, family members might have been more involved in helping the residents to settle in the apartment. Once, the residents had adapted to the new environment, it was not uncommon for family members in Hong Kong to become less involved. This is a common phenomenon that happens to many residential services and often challenges the workers to find ways of helping residents and family members to be as connected as possible.

It is found that residents perceived themselves as having more and more mutual support from other residents at time

3. While it is understood that living together might have provided a platform for mutual support and help, it is more likely the atmosphere of the setting and the opportunities for interactions that had accounted for the perceived sufficiency of mutual support generated among residents. As supported apartment in Hong Kong aims at providing a home-like environment where residents can enjoy as much privacy and freedom to choose their own preferences, it has become a safe and comfortable place for residents to linger, wander and return (Copper, 1989). A safe and home-like environment might have encouraged the development of trust and mutual support among residents.

The opportunity for interactions among residents is essential to building residents' mutual help and support. The staff of supported apartment encourage residents to raise ideas about social and recreational group activities and to implement these activities with the help of the workers. However, workers have also initiated some activities for residents from time to time, such as Lunar New Year celebration and Mid Autumn Festival. Through these activities, residents can build up friendships and mutual help among each other. Besides, 'old' residents are encouraged to help newcomers to settle in the apartment. They escort residents to community walk and help them with shopping and etc. With these opportunities available for interactions, it is understandable why residents had an increased sense of mutual help and social support at the end of their first year of residence in supported apartment.

### Conclusion

This study provides some initial evidence about the effectiveness of supported apartment in facilitating community integration and mutual help among residents with a chronic mental illness in Hong Kong. Findings suggest that at twelfth months, residents were more social integrated, and achieved a higher level of independence in accessing public facilities, attending to personal care and feeling easy in maintaining contact with families and friends. Moreover, they experienced an expanded family and friendship networks at the end of the

twelve months. However, these results will certainly be enhanced by the inclusion of a control group in future studies.

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# Is Supported Employment Cost Effective? A review

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## Abstract

There is a growing interest in supported employment within mental health services, reinforced by the importance placed on occupation by service users, and by the development of specialist inter-disciplinary teams with a remit to treat individuals holistically. One model of supported employment, Individual Placement and Support (IPS), has ample evidence for its effectiveness, and this is reviewed briefly here. However, information about the costs of IPS and their relation to outcomes is patchy and equivocal. This paper reviews some basic approaches to evaluating cost effectiveness, looks at what inferences can be drawn from previous studies, including those that span all disability groups, and describes the findings of costs studies focused on interventions for people with mental health problems. In relation to the latter, it summarises what is known, what is uncertain and areas for future research. It makes recommendations about how costs should be taken into account in the development of new employment interventions, and in the evaluation of existing schemes.

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## Aim

The aim of this paper is to describe and summarise evidence for the cost effectiveness of supported employment, highlighting the way forward for the development and evaluation of supported employment.

## Background

Supported employment is a model of occupational intervention that has attracted considerable interest, and the literature on its effectiveness for people with severe mental health problems is strong. The emphasis placed on occupation in the UK National Service Framework (Department of Health, 1999) and the widespread development of specialist teams practicing assertive outreach, early intervention and crisis resolution highlight the need for greater knowledge about effective employment interventions. Several reviews of this literature have been published. The greatest volume of literature is about the Individual Placement and Support (IPS) form of SE, whose characteristics Bond et al. (1997) list as:

1. Competitive employment



2. Rapid job search
3. Integrated with mental health care
4. Responds to user preferences
5. Continuous and comprehensive assessment
6. Time-unlimited support

Bond, Becker et al. (2001) “do not view Individual Placement and Support as a distinct supported employment model. Instead it is intended as a standardization of supported employment principles ... so that supported employment can be clearly described, scientifically studied and implemented in new communities.” The same group of researchers has produced a fidelity scale that assists in this standardization and measurement (Bond, Evans et al., 2000; Bond, Vogler et al., 2001).

Another model of SE operating in the UK is known as User Employment (sometimes referred to as Pathfinder after the trust where it began). This is employer-initiated, through a policy of positive recruitment of people with personal experience of mental health problems. Support is offered in the workplace following the IPS approach (Perkins et al., 1997; Perkins, 2001).

Little doubt remains about the effectiveness of IPS. Here, we summarise the evidence very briefly. Bond et al. (1997) compared IPS to other forms of support aimed at employment, including vocational rehabilitation, the standard state-federal supported employment programme, day treatment and sheltered workshops. Overall, the authors conclude that IPS proved more effective with respect to employment outcomes than the other models, but it did not seem to affect non-vocational outcomes (e.g. symptoms, self-esteem). These findings have stood the test of subsequent reviews (Drake et al., 1999; Bond, 2001; Mueser, Bond et al., 2001) as well as from the Cochrane review of vocational rehabilitation by Crowther et al. (2001).

The findings demonstrating the effectiveness of supported employment in terms of work outcomes also gain support from four studies published since the Cochrane review that are described below (Mueser, Salver et al., 2001; Lehman et al., 2001; Bond et al., 2001; Dixon et al., 2002).

The first, the Hartford, Connecticut, RCT compared IPS to a psychiatric rehabilitation centre (PRC) and standard care (Mueser et al., 2001). This found, at two year follow-up that the IPS group were significantly more likely to obtain any paid work (75%) than those in standard care (54%) or those in the PRC (34%) (Chi squared, 52.71 22.53 respectively, df 2,  $p < .001$ ).

A second RCT published by Lehman et al. (2001) is important because it was carried out with a population that is relatively disadvantaged. The sample of service users had high levels of psychosis (75%), ethnic minority status (75%), and current substance abuse (40%). It also differed from most previous IPS trials because it did not recruit the sample through induction groups, which may tend to generate self-selected samples of people who are positively motivated to work.

Nevertheless, it was found that the sample on IPS were more likely than those using standard psychosocial rehabilitation to attain employment (47/113 v 12/106,  $p < .0001$ ); and more likely to be in open work ( $p < .001$ ). In either group, for those people who achieved employment, hours worked and wages did not differ significantly. Overall rates of employment were relatively low even for IPS (42%) and very low for the comparison group (11%) which possibly reflects low levels of motivation in the participants.

Bond et al. (2001) perform secondary analysis on data from the RCT of IPS conducted in Washington, DC (Drake, McHugo et al., 1999). This study is innovative in its attention to effect size, which is an important topic in studies of interventions where clinical significance and statistical significance may not always coincide. The authors explore the non-vocational outcomes – self-esteem, quality of life and psychiatric symptoms, of four groups of service users: those who did a substantial amount of competitive work, those who did sheltered work, those who did a minimal amount of competitive work and those who did none. Over 18 months, people in competitive employment had greater satisfaction with vocational services, finances and leisure activities when compared to the rest of the sample taken together. They also showed a greater improvement in self-esteem and psychiatric symptoms, none of which showed any improvement in people who did sheltered work or a minimal amount of open work. However, the ‘control’ group may have deteriorated through demoralisation or discouragement arising from failed employment, making the cause of the difference ambiguous. Two further inferences may be made from the analysis. The findings indicate that it is continued employment, rather than temporary exposure to employment, that has positive effects. Bond et al. also demonstrate that, contrary to the assumption of many clinicians and carers, working does not appear to lead to deterioration in psychiatric symptoms.

In a cost-effectiveness comparison over 18 , Dixon et al. (2002) compare IPS, which focused on competitive employment, with enhanced vocational rehabilitation (EVR), which offered paid training in sheltered settings as well as competitive employment, yields frustratingly equivocal results (Dixon et al., 2002). To overcome the technical difficulties of costs analysis (Gray et al., 1997), this study adopted the perspective of a single payer and used bootstrapping to generate estimates of incremental cost-effectiveness ratios (ICER; increase in effectiveness divided by increase in costs). In the context of this particular study, because the EVR group were also being paid, it was not possible to draw any firm conclusions in relation to the differential impact of IPS on total earnings from competitive and non-competitive sources. Yet employment outcomes were superior, and the authors conclude that it is statistically highly likely that IPS both costs more and produces more competitive employment (p 1123). This result highlights the importance of comprehensive evaluation of employment programmes. When an intervention is both more costly and more effective, a proper appraisal requires details about its social acceptability, and any indirect benefits and costs.

While IPS has considerable evidence in its favour when employment is the outcome of interest, there is only limited evidence of its effects on symptoms, self-esteem and other non-vocational outcomes. Questions remain, concerning the impact of working on mental health status and service use. We also need to compare the direct service costs of IPS to those of other mental health interventions, both those aimed at employment and those aimed at other aspects of recovery, to understand more fully the cost effectiveness of the model. Few studies of IPS report its immediate costs, and data on longer-term costs (as well as benefits) is even more limited.

Lacking evidence relating specifically to people with mental health problems, findings concerning supported employment for people with learning disabilities are included here. In the main body of this paper, available costs data are brought together in one place, drawing on reviews of costs studies, evidence from large-scale surveys in the United States, and, finally, costs studies of specific models of supported employment. First, three different approaches to costs analysis are set out, and some of their implications for the generation and interpretation of cost effectiveness information are discussed.

## Perspectives on costs

The costs of occupational interventions can be assessed from the perspective of the individual service users, taxpayers or society at large. The simplified components of each of these perspectives

are shown in Table 1. This is not a definitive list, but serves to highlight some differences between three approaches. In practice, there is scope for varying these elements according to what information is available as well as what is theoretically desirable. Studies also differ in the length of time over which they measure these elements (longitudinal versus cross-sectional) and in the ways of attaching costs to each of the elements listed.

Table 1: Perspectives for Costs Studies

Individual perspective	Taxpayer perspective	Societal perspective
Net earnings minus welfare benefits foregone Change in health or well-being	Tax revenue plus welfare benefits saved and savings on alternative programme inputs (e.g. day care) minus employment support to service users	Savings to the state from alternative programmes; increased productivity (earnings + tax minus baseline productivity plus employment support); and changes in health or well-being

The interplay between state-funded welfare benefits and individual earnings is clearly a determining factor in estimating the cost-effectiveness of occupational interventions at the level of the individual. By implication, the limit on earnings under certain benefit regimes also affects the taxpayer perspective. Because of the part played by tax and welfare incentives, empirical studies from one system can only be applied with great caution to another welfare context. It should be noted that most studies reviewed here were undertaken in the United States.

A cost-benefit ratio can be derived by dividing net benefits (gross benefits minus gross costs) by gross benefits plus gross costs, yielding a ratio between  $-1$  and  $+1$ . It is more commonly derived by dividing gross monetary benefits by gross monetary costs. Using this method, cost-benefit ratios of less than one mean that costs exceed benefits, at least in monetary terms. A cost-benefit ratio of less than one needs to be judged in the light of any alternatives. As Thornton (1992) notes, such ratios are meant to inform policy makers who have other social agendas to balance against net costs. For instance, the cost-benefit ratio of a given employment intervention might reasonably be compared to that of day care for the same individual. A return of 80% on investment in employment might for instance be compared to negligible financial return on investment in day care.

Very few studies incorporate a full cost-effectiveness analysis including social costs and benefits, because this entails quantifying in monetary terms intangibles such as user satisfaction and quality of life. Since such potential benefits are seldom measured in costs studies, the evidence may underestimate the actual benefits, and hence the cost-effectiveness, of occupational interventions (Cimera, 2000).

### Reviews of costs studies

A critical review by Cimera (2000) identified 21 costs studies of supported employment, nine published since 1991, all relating primarily to people with learning disability. He found that, at the individual level, the cost-benefit ratio is almost always positive, regardless of level of disability.

At the taxpayer level, by contrast, the evidence is equivocal. This may change over time, as the costs of the programmes go down and the earnings (and hence taxes paid) by the users go up. By approximately the fourth year, Cimera estimates that taxpayers obtain a net benefit. By comparison, Noble et al. (1991) hold that projections of increasing productivity and decreasing support use are unreliable. They advocate a more conservative approach by taking measurements only during the period in which costs are incurred. The assumption is that the costs of a mature programme that has attained long-term stability with a mix of new and old clients are in fact reliable.

It is important to note, however, that the cost effectiveness of the services reviewed by Cimera appears to be correlated with the level of disability of the clients with learning difficulties (McCaughrin, 1993; Lewis, 1993). 'Individuals with higher IQs appear to benefit more monetarily from being enrolled in supported employment programmes than individuals with lower IQs' (Cimera, 2000, p. 57). This casts doubt on how far results from studies dominated by this client group can be extrapolated to people with mental health problems.

It might be assumed that people with mental health problems on average would have higher levels of cognitive functioning. A further consideration is that people with fluctuating illness may periodically incur support costs and experience variations in productivity in a way that does not affect most people with learning disability. These considerations make it practically impossible to draw inferences from cost effectiveness data dominated by people with other disabilities, unless the sample is so large that separate analyses by disability group may be reliable. Below, some key surveys are reviewed.

### Large-scale surveys

Several studies of the costs of employment programmes for specific US states have been published since 1991. Although the study of McCaughrin et al. in Illinois (1993) concerns people with intellectual impairment, it conforms to the pattern identified by Cimera (above): the client's cost-benefit ratio was positive, the taxpayer's was negative in year 1 but (marginally) positive in year 5. The benefits to individuals with mild, as compared to moderate or severe, impairment were 4 times greater. Supported employment was consistently less costly than sheltered work. However, in the learning disability field, SE clients tended to experience greater loneliness on the job. "Efforts to decrease loneliness in competitive employment is an important consideration that needs to be addressed in future research on quality of life for individuals with mental retardation" (p47). There is not much evidence to indicate that this is also true for people with mental health problems.

Similarly, Lewis et al. (1993) explored the costs of 41 programmes in Minnesota for people with learning disability and concluded that 'the clearest case for monetary efficiency from a social perspective was found when individual SE programs were compared to all other training and employment options' (p 83). As noted elsewhere, disability and cost were positively correlated.

Within the sample of 1,250 individuals studied by Noble et al. in New York state (1991), 246 clients were classed as 'mentally ill, psychotic'. The programme costs of people with this label were lower, on a par with people with visual impairment and traumatic brain injury - by contrast with the higher programme costs of people with cerebral palsy, deafness, epilepsy, autism, and learning disabilities. The variance explained by disability group was 19%. For people with psychosis, societal benefits were similar to the average for all clients (\$4,468, as compared to \$4,500). The taxpayer benefits for this group were also similar (\$3,568 as compared to \$3,895). Evidence of benefits in psychosocial functioning is unreliable due to small sample size (9). The costs of SE provision conservatively estimated were \$6,360 per client (averaged across all disability groups), giving a cost-benefit ratio to society of 0.7 for people with mental health problems. It should be noted that 45% of the subjects of this study were not earning, and their successful placement in paid work could dramatically affect the costs of the programme.

In a state-wide study of the wage effects of supported employment in Michigan, Thompson (1992) used regression analysis to control for factors that might influence wage outcomes for people in SE, compared to people in sheltered work (SW). Only 53 people in the whole sample had mental health problems as a primary diagnosis, most had learning disabilities. Males were over-represented in both SE and SW samples, and younger people predominated in SE. The IQ of people entering SE tended to be higher. Controlling for prior wage levels, gender, race, number of disabilities, IQ and living arrangements, the analysis indicated that SE was associated with higher wages in 10 of the 11 quarters monitored (on average \$1.85 ph in 1986-1990). It was also associated with a higher number of hours worked. One problem with this study is that there is likely to be a good deal of variability in work skills that has not been taken into account. Besides being a largely discredited indicator of intelligence, IQ is an inadequate indicator of functional ability: other factors, notably social skills, are arguably more likely to affect employability and hence earnings.

Rusch et al. (1993) included 45 people with mental health problems in their state-wide sample in Illinois, but this was only a small proportion (6%) of the 729 participants with all disabilities, so it is impossible to say whether the findings are applicable to the small sub-group. The state-wide employment programme included a range of provision, mainly as individual placements (53%) and in 'enclaves' or groups alongside people without disabilities (39%). Rusch et al.'s findings over time are in line with Cimera's general inference: individuals benefited throughout the 4 year period, but the economic return to society only became positive in the fourth year, averaging 0.91 overall. The taxpayer perspective showed an average cost-benefit ratio of 0.77. The trend over time was clearly towards greater returns from societal and taxpayer perspectives, but longer-term projections are hampered by a number of uncertainties.

Thornton (1992) highlights the problem of 'uncertainty' in cost-benefit analysis of interventions that are novel and complex, and illustrates this with reference to supported employment research. The principal sources of uncertainty are the population served, the process of the intervention and the methods used to evaluate it. Reviewing the history of SE costs studies from the 1980s onwards, Thornton explains the favourable findings for SE over sheltered employment settings, as being due mainly to:

- -higher earnings in SE, which generate tax revenue;
- -support costs that are geared to need in SE settings, and usually decline over time, by contrast with the constant and unchanging costs of support in sheltered settings; and
- -savings to the extent that SE represents an alternative to day care or other provision.

Should any of these factors differ, for instance in another service delivery model or under a different system of tax and benefits, the cost effectiveness of supported employment would be called into question. We therefore turn now to examine studies of individual interventions, taking particular account of their earnings, support inputs and comparator groups.

### Studies of specific interventions

Sciarappa et al. (1993) followed 19 people with mental health problems over a year's participation in SE (choose-get-keep model). Ten (53%) had a bipolar disorder, two (11%) had current substance abuse and 16 (84%) were 'taking psychotropic medication' and all had some work experience (averaging 12 months in previous 5 years). They collected actual costs data over one year prior to enrolment (retrospectively) and during the year on the programme. The results showed increased employment and decreased service use,

including a reduction in supported housing. The final benefit-cost ratio came to 0.89. This is judged by the authors to be relatively small, and is attributed to the small size of the programme and limited time frame of the study.

There was no control group, so these findings are merely indicative. Moreover, this was a highly selected group of subjects, characterised by their desire to work in a university, and a disproportionate number of people with bipolar disorder, so they are not representative of a typical community mental health caseload. Nevertheless, the finding that supported housing use declined highlights the importance of costing accommodation as well as discrete health and social care services. In the UK, housing typically represents 80% or more of total community care costs, and it is vital to include this element in comparisons in order to make reliable comparisons between programmes that might have an impact on living arrangements, including hospitalisation, as one means of meeting needs for accommodation (Beecham, 1995).

In a natural experiment of transition from day provision to supported employment in two sites, Clark et al. (1996) measured costs and vocational outcomes at three time points between 1989-90 and 1993. Following conversion of the first site from day programme to IPS, case management input increased at both sites, and at site 2 (the 'control') outpatient services increased. This may be due to substitution, perhaps driven by clients' needs not met in SE, or it may be affected by providers trying to recapture revenue lost from day care. Taking community costs separately, there was a significant drop following conversion at both sites, suggesting that IPS was taking the place of other community mental health services. However, a general trend towards lower overall costs indicates that programme change was not the only causal factor. There was a negative correlation between work and use of services. The authors conclude that vocational opportunities can be improved significantly without increasing costs. Differences between sites in cost reductions highlight the impact of service context and client characteristics on cost effects. It is important to note that, without closing day care, the total costs would have appeared less favourable. As for negative effects, hospital and crisis intervention remained relatively unchanged, suggesting the conversion had little effect on relapse rates, and, while the 27 regular attendees interviewed recognised several positive outcomes, they reported loss of social opportunities as the main negative effect (Torrey et al., 1995), although this was quickly remedied through the introduction of social groups.

Clark et al. (1998) analyse the New Hampshire study of IPS versus group skills training (GST; a combination of pre-vocational training and supported employment after job placement) from the three perspectives summarised above (Table 5). While they did not include 'hotel accommodation costs, staff costs associated with supported accommodation were included.

At the individual level, while IPS clients earned more, GST clients had more income from benefits, so that the net economic benefits did not differ significantly. The two programmes produce different levels of benefit, depending on the perspective from which they are analysed. IPS had higher benefits from the societal and taxpayer perspectives and lower benefits from the individual perspective, but the differences in net benefits were not significantly different between any of the three perspectives. This study, like many costs analyses, can be criticised because the sample size was too small to detect meaningful differences, given the huge variation usually found in costs.

Over an 18-month follow-up, people using the programme also used more state resources. On average, there was a significant increase in benefit income, causing costs to the state/government, but not a significant increase in income earned. Analysis of earnings for 137 clients showed that being on benefits reduced earnings significantly ( $p < .01$ ), as did being on GST. Having a work history increased earnings ( $p < .05$ ). This analysis controlled for diagnosis, education, site of treatment and baseline severity of mental health problems. It therefore indicates fairly persuasively that being on benefits tends to limit earnings. Much more data would be required to understand the dynamics of this relationship. In addition, such findings would be highly specific to the welfare entitlements and disincentives in operation in a given context (Turton, 2001).

The important message to learn from these findings is to proceed with caution, since increasing earnings to clients can also increase costs to the state.

There is evidence from New Hampshire that users of SE with mental health problems appear to make fewer demands on community health care provision while in a SE programme, but this may be related to how local provision is organised (supply-side factors). This finding is not supported by the study of Dixon et al. (2002), who found higher costs for IPS, together with better competitive employment outcomes. The difference between IPS and enhanced vocational rehabilitation in that study depends on the value placed on competitive, as compared to sheltered, employment.

Latimer (2001) undertook a detailed review of three RCTs and five non-randomised studies, and concurs with Clark's inference from the New Hampshire studies of IPS that the effect of supported employment on costs depends largely on the service context. The introduction of supported employment into a service where no substitution can be made is likely to increase service costs. Given that direct savings seem unlikely to compensate for the investment in supported employment, Latimer states that such investments may be justified in terms of increasing social inclusion ('community integration').

In a large-scale two-site study of two approaches to employment support in England, Johnson et al. (2001) surveyed all clients of a provider agency (Shaw Trust) who were on the government-sponsored Supported Placement Scheme (SPS) and the newer Personal Advisor Scheme (PAS) for disabled people. Both can be seen as forms of Supported Employment. Briefly, SPS was not time-limited and paid a wage subsidy to employers, while PAS was time limited and paid the job broker for training and placement. Both were run under contract to the Department for Work and Pensions by stand-alone providers, voluntary and statutory. We are not aware of any SPS or PAS schemes that operated as an integrated part of community mental health services.

Only a small proportion of respondents to this survey had a mental health problem (7% of PAS clients and 1% of SPS clients) so no analyses were conducted on this sub-group. Overall, cost benefit ratios of PAS were favourable to taxpayer (2.74) and societal (1.12) perspectives, but due to lost benefits and taxes paid, unfavourable to clients (0.47). By contrast, SPS was favourable to client (6.97) and society (1.53) but not so for taxpayers (0.45). These findings were robust to sensitivity testing. Qualitative data also presented.

These findings may be criticised because they do not have a control group, and as such do not allow for the possibility that people might have gone to work without PAS and SPS. The effect of this would be to reduce the relative benefits of the schemes. Another important consideration is the short-term scope of the study, longer-term savings are not known. The novelty of PAS introduces a bias compared to SPS, with the possibility that PAS costs (and benefits) never achieved stability. In this study, it appears that no control was taken of the variable lengths of time that people had been in the schemes. Prior to the publication of these findings, policy developments meant that PAS ceased to exist as such but was 'rolled out' as the New Deal for Disabled People Job Broker scheme, while SPS was phased out altogether and partly replaced by a time-limited placement and support programme known as Workstep.

For our purpose, the fact that these findings are averaged over different disability groups is a severe limitation. It does however highlight the low use made of such programmes by people with mental health problems, and reinforce earlier findings. When Beyer et al. (1996) explored the cost-effectiveness of SPS compared to sheltered workshops, they found that only 6% of their representative sample of SPS and sheltered workshops had mental health problems.

## Summary of the evidence

### ***What is known***

Since 1991, considerable evidence has been generated concerning the costs and benefits of supported employment as compared to vocational training or sheltered employment. However, this evidence is highly generalised, being drawn largely from state-wide evaluations of global programmes in the US. In both the US and the UK, it applies predominantly to the largest consumers of SE; people with learning disability.

The general findings noted by Cimera, that individuals benefit to a greater degree than the state or society, at least in the short term, is largely supported by the evidence from studies of IPS for people with mental health problems (Clark et al., 1998; Bond et al. 1995). In addition, both of these studies found that people in SE earned significantly more than people who underwent pre-vocational training (earnings evidence summarised by Crowther et al., 2001, Table 2).

At the global (state or national) programme level, Supported Employment tends to be more favourably evaluated than sheltered work or training, and this is because of its superior employment outcomes, which generate greater tax revenue.

### ***What is uncertain***

The costs of SE provision are difficult to describe, because of the variation in models, but they appear in most cases to be less than sheltered workshops or day care. However, this is partly due to assumptions about the tapering off of support over time, which may not apply equally to people with mental health problems.

The longer-term impact of SE is still not known. For example, a small increase in hospital use might only be detected in very large samples, and could affect costs disproportionately. Nor do we know if SE has costs implications for housing or education. Perhaps most importantly, there are a priori reasons to expect that their support-use profile will differ considerably from people whose disabilities do not fluctuate.

There are clearly structural factors imposed by welfare benefit systems that constrain earnings and thereby influence benefits from an individual perspective. There may also be structural factors in how mental health systems operate that also affect use of other services by people employment, and hence the variation in costs. For example, a reduction in use of community mental health provision that only operated during working hours might not be due to a decrease in need of that provision, and might be storing up trouble in the longer term.

### ***Future directions for research***

The range of benefits measured in most of the costs research reviewed is largely limited to employment outcomes: job tenure and earnings. A few studies take hospitalisation into account. More work needs to be done to quantify 'intangible benefits, which might include satisfaction, quality of life, social inclusion, physical health and independence in activities of daily living. To this end, Kirsh advocates a shift in focus from individual pathology to the dynamic inter-relationships among the work, the people and the environment in understanding the process and outcomes of work integration for mental health consumers (2000, p 29). In so doing, the value placed by society on social inclusion would need to be estimated. Given that there is no firm evidence that IPS is more cost-effective than some less inclusive approaches, a social consensus that places greater value on competitive employment than on sheltered work would tip the balance in favour of IPS.

It is likely that the unit cost of supported employment can be reduced by methods such as large caseloads, or retiring people from a programme after a certain period if they have not succeeded in obtaining work (Clark, personal communication). Similarly, the impact on the 'tapering off of support of diagnostic group, severity of impairment, mode of intervention and funding system has yet to be investigated.



There is a strong consensus on the best methodological approaches to the complex task of costing employment interventions. The recommendations of Clark and Bond (1996) are still valid. They list seven key actions for costs research in vocational rehabilitation: measure costs and benefits comprehensively; define the perspective for viewing costs and benefits; use appropriate comparison groups; control for the effects of other mental health treatments on outcomes; examine long-term costs; assess mature programmes as well as new ones; and explore the influence of client characteristics, welfare incentives and other variables (p 233).

Longitudinal data collection should be undertaken for newly-established programmes, and large-scale, cross-sectional data collection for established, robust, programmes. It is vital to include all services used in the costs comparisons, not merely the costs associated with employment programmes or mental health services, to monitor the possibility of cost-shifting. These costs should include accommodation as well as health, education and social care services. Recent advances in health economics indicate that the application of cost-effectiveness acceptability curves (Fenwick et al., 2001) may augment the information that can be derived from imperfect data.

The potential of pooling real-world data pertaining to people with mental health problems from larger datasets spanning a wider range of disabilities for the purpose of secondary analysis should be investigated. This might be a relatively inexpensive way of exploring further the predictors of SE costs and outcomes. Econometric modelling of such data could investigate, among other things, the level of investment in supported employment programmes that is likely to optimise benefits for individuals, taxpayers and society at large.

We have found no published evidence that such cost-benefit comparisons have been made explicitly between supported employment and alternative, non-employment interventions. The costs and benefits of supported employment have yet to be compared to alternative interventions to judge its relative efficacy, taking individual and societal perspectives into account. In mental health care, these alternatives could include (for instance) individual psychotherapy, group work, day care, art therapy, physiotherapy or no specific intervention.

## Conclusion

Supported employment systems are each a product of a particular constellation of labour market conditions, tax structures, social security, education and social welfare provision. It is risky to make assumptions about the cost effectiveness of a given programme on the basis of findings from similar programmes undertaken in different contexts. In most cases, the costs to the taxpayer of supported employment exceed the economic benefits, at least in the short term. Bearing in mind the possibility that the alternatives might provide benefits which employment cannot, supported employment is likely to compare favourably for several reasons. It is socially inclusive, which can be taken as a societal benefit that derives from employment interventions but not from most alternatives. Moreover, employment generates some financial 'return on investment', and this has been shown to be a benefit from the individual's perspective in most cases. This income also offsets the costs to the taxpayer. Since most other mental health interventions listed here are unlikely to make the service user economically better off, much less the taxpayer, the evidence for supported employment over alternative interventions is strong, but still not conclusive. The uncertainty arises from the variability in costs of implementing such support. It is likely that the ultimate criterion of cost effectiveness will be the value that decision-makers place on the greater social inclusion promoted by some models of supported employment.

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