EXPANDING KNOWLEDGE OF PEER-BASED MENTAL HEALTH ORGANISATIONS: THE EXPERIENCE OF CLUBHOUSE

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ABSTRACT

The special Clubhouse issues of this *Journal* (*7*(1) and this current issue, 2013) feature articles that review the development of a potent social intervention to mitigate the impact of the exclusion and discrimination experienced by many people who suffer from severe and persistent mental ill health. In this short recapitulation, I comment on the key ingredients of the model—the fundamental underpinnings, the organisational elements and the need for further research.

THE SOCIAL AND PERSONAL IMPACT OF SEVERE MENTAL ILLNESS

People suffering from severe and persistent mental ill health typically have small social networks and much less access to opportunities available to healthy members of society. This is in part due to the nature of mental illness as most of the more severe disorders begin on the threshold of adulthood, resulting in enduring educational and occupational handicaps. Sufferers find themselves left behind by their peers, impaired, de-motivated and socially excluded to the extent that the social consequences are often more disabling than the illness itself. Of course,

much of the problem of social exclusion lies not with the mentally ill person but with wider society—how we structure mental health care, the rules and regulations that facilitate access to education and employment, and how we go about delivering assistance. Most mentally ill people have much lower disposable incomes than others in society and even those on welfare benefits often do not receive the full amount to which they are entitled (Becker, Thornicroft, Leese, & McCrone, 1997). In many industrialised societies, rates of employment are much lower than among their healthy counterparts in the general population (Marwaha, Johnson, Bebbington, Stafford, Angermeyer, Brugha, et al., 2007). Participation in leisure activities is also compromised due to the lack of opportunity, limited disposable income, and discrimination. Social exclusion is even manifest in obstacles to elementary civic participation (for example, in the UK a person with a declared mental illness is not allowed to serve on a jury).

The material aspect of social exclusion is widely acknowledged and most mental health services attempt to provide interventions to address the worst of these. However, the manner in which this assistance is delivered can also do harm. Mental health professionals can have very pessimistic beliefs about the capacity for people with severe mental illness to make rational decisions or to function as equal citizens. For example, despite the evidence that many people with severe mental illness would like to return to employment (e.g., Judge, Estroff, Perkins, & Penn, 2008) many clinicians discourage their clients on the erroneous belief that the stress involved will induce a relapse. In fact, being employed or participating in an employment programme is associated with fewer psychiatric hospitalisations and improved quality of life, improved self-esteem, and reduced health care costs (Drake, Becker, Biesanz, & Wyzik, 1996; Bell, Lysacker, & Milstein, 1996; Bond, Resnick, Drake, Xie, McHugo, & Bebout, 2001; Casper & Fishbein, 2002; Warner, Huxley, & Berg, 1999). Similarly, despite widespread acceptance of the principle of service users being involved in the delivery and organisation of services, it is not unusual to find resistance at a practitioner level to its implementation (Tait & Lester, 2005). Pessimism of mental health care staff can easily rub off on their clients; and people who adopt this pessimistic outlook are more likely to be disabled and dependent on services. In one study, people who felt most stigmatized by their illness also had the lowest self-esteem and had the lowest belief that they had personal control over their lives (Warner, Taylor, Powers, & Hyman, 1989).

Social exclusion has another face that is less often talked about. This has been described as a violation of social solidarity (Barry, 2002)—an absence of opportunities to develop the sense of fellow feeling that arises from shared experiences, encompassing matters such as cooperation, joint enterprise, mutuality and support. Humans have an intrinsic need to belong, to be identified with and to feel a part of a social group, to have their efforts appreciated and valued. In short, to have "meaning" to others. But people with severe mental health problems find such validation hard to come by. They have much

smaller social networks with fewer numbers of friends than those in the general population (Goldberg, Rollins, & Leham, 2003; Macdonald, Hayes, & Baglioni, 2000; Stein, Rappaport, & Seidman, 1995) and the numbers dwindle further as unemployment, financial problems and stigmatization take their toll. Studies of friendship in schizophrenia have found that while networks are smaller, the perceived value of friendship is in no way diminished albeit tempered by experiences of rejection, misunderstanding and the lack of shared experience so that those who find companionship often do so with others who have also experienced mental ill health (e.g., Harley, Boardman, & Craig, 2012).

It can be said that the most important adverse consequence of severe mental illness and the way it is commonly managed is the damage done to self-esteem and to the belief in one's capacity to attain the fundamental goals of living: meaningful reciprocal relationships, occupation, and social acceptance. Consequently, it is the success in helping people achieve these goals that psychosocial programmes need to be judged.

CLUBHOUSE FUNDAMENTALS

a. The collective identity: Closely related to the notion of social solidarity is the concept of social capital—the "features of social life, networks, norms and trust that enable participants to act together more effectively to pursue shared objectives" (Putnam, 1996, p. 34). Both focus on the importance of participation in social networks that can facilitate or frustrate access to different kinds of resources (Morgan, Burns, Fitzpatrick, Pinfold, & Priebe, 2007). Social networks can encompass both "bridging" and "bonding" ties between people. Bridging ties describe the wider links between diverse groups, networks of friends and acquaintances, business partners, and so forth. Bonding ties are those that strengthen the cohesion within a social group, typified by high levels of mutual trust, loyalty, and shared responsibility. Mandiberg and Edwards (2013) posit that the development of a strong collective identity should protect against some of the impact of stigma and discrimination in the way that strong ethnic identity reduces the mental health impact of ethnic-based discrimination. They suggest that the clubhouse model may foster such a collective identity, as members have to build mutually supportive collaborative relationships to get through the tasks of the work ordered day and this mutual effort enhances the sense of belonging to and being an important player in the organisation. This sense of collective identity is further enhanced by the principle that the clubhouse belongs to the members, who work at every level of the organisation and who have a lifetime membership that guarantees unconditional welcome. In short, clubhouse is a powerful vehicle for the development of a collective identity and this collective identity may contribute to positive mental health outcomes at an individual level.

b. Reciprocity and the importance of being wanted: When John Beard described the Fountain house model, he emphasised the importance of the personal relationship and linked this with a message of democratization and mutuality. People at Fountain House were members of a club, not clients of a treatment programme and as members their presence was not just expected but *wanted*. Beard points out that the model addresses a '(. . . profoundly human desire to be needed, to be felt as an important member of a meaningful group, and at the same time conveys to each member the sense that each is concerned with all (Beard, Propst, & Malamud, 1982, p. 48)).

As Beard suggests, having good quality reciprocal relationships with peers may be central to recovery. Clubhouse, as described in many of the articles in these special Clubhouse issues, attempts to address this through the "work-ordered day" in which members and staff work alongside each other undertaking the tasks that are essential for the running of the clubhouse, and in so doing provide a supportive network of peers, encourage skill-development, and reciprocity in relationships nurturing self-esteem and self-confidence. In one exploration of the associations between attendance at clubhouse, social network support and subjective recovery, Francesca Pernice-Duca and Esther Onaga interviewed 221 members from 15 clubhouses with follow-up interviews for 179 (80%) 14 months later. Measures at baseline and follow-up included assessments of social network support and of "personal recovery." Although the results broadly supported the hypothesis that social network support and reciprocity was associated with recovery at follow-up, the associations were not all straightforward. For example, the size of social networks decreased over time with fewer clubhouse staff named at follow up while levels of subjective recovery was similar at both time points. Social network support, particularly involving reciprocity in relationships was associated with greater recovery at both time points. However the extent to which clubhouse membership accounts for this association is unclear as no significant associations were found with any measure of clubhouse attendance.

In a further analysis of data collected from the same network of clubhouses, Conrad-Garrisi and Pernice-Duca (2013) focused on the role of "mattering" in recovery. Measures of the sense of mattering, personal recovery, perceived social support, and stigma were collected from 143 participants across 10 of the clubhouses. As hypothesised, the sense of mattering (the opportunity to both give and receive support) and perceived social support were predictive of personal recovery and played an important role in minimizing perceived stigma. The study was cross sectional and there was no comparison group so it is not possible to know the extent to which it was clubhouse membership that conferred these advantages.

Finally, in a qualitative study of the nature of peer relationships formed and maintained through the work ordered day, Kimiko Tanaka (2013) interviewed 45 members and 11 staff in-depth about the work ordered day, how participants viewed the nature of relationships in the clubhouse, and how the member changed

across time both personally and in terms of a sense of belonging. Summarising a very rich data set, the work ordered day did indeed mediate peer support and the latter reflected the sort of support seen in the outside world. Clubhouse was seen as a safe place to be, that engendered hope and a shared identity, the results clearly echoing notions of reciprocity and mattering seen in the other investigations.

Through the research it appears there are empirical bases to the notion that clubhouse does indeed provide a vehicle for bringing people together and that issues of "belonging," "mattering." and a shared identity may be important drivers of recovery. However, the studies are largely reporting cross-sectional associations so causality cannot be asserted with conviction and it remains unclear who benefits most from membership. Further studies including comparisons with non-clubhouse populations and using longitudinal designs are needed to take these findings further.

c. Organisational elements: Other key elements of the model are that staff should have no special professional therapeutic status (i.e., not be selected on the basis of nursing, psychological, or occupational therapy skills) and should work "alongside" members who play the central role in all decision making.

This approach coming as it did in the 1950s clearly owes something to other group based therapeutic approaches popular at the time including the therapeutic community approach to psychiatric rehabilitation. Tom Main writing in 1946 described the approach as an attempt to use a hospital "not as an organization run by doctors . . . but as a community with the immediate aim of full participation of all its members in its daily life" (p. 67) emphasising the change in the status of patients with staff working alongside residents. Of course, the goal of this way of working was intentionally therapeutic; senior staff, however closely they worked alongside the patients, were nevertheless clearly in charge with explicit obligations to the larger organisation. Clubhouse goes somewhat further and as noted by Borkman (2013) is closer in form to a service user self-help organisation, sharing in common with such organisations the importance of respect and dignity in egalitarian peer relationships, a non-medical emphasis (i.e., no diagnosis or pathology), and an emphasis on empowerment, advocacy and a Recovery philosophy. But it also differs from most self-help organisations in having a Board comprising "sympathetic" professionals or businessmen that are involved in negotiating funding and have links with the wider community but play little or no direct role in the daily life of the clubhouse. This "hybrid" structure has been a core feature from the outset and it comes as a surprise to many unfamiliar with the model that it has long had its psychiatric champions, starting with Hiram Johnson and the formation of the "We Are Not Alone" (WANA) group in 1948, and on through the efforts of Lawrence Kubie and Arthur Pearce whose interest in milieu therapy and the therapeutic benefit of work so influenced Beard (Anderson, 1998).

In addition to the work ordered day, clubhouses were among the first organisations to recognise the importance of employment away from the settings providing treatment and therapy. Initially the clubhouse offered "transitional

employment programmes" in which members could engage in a number of part time, relatively short tenure jobs with local businesses. Job coaches (i.e., staff) learned the jobs, trained members and provided ongoing support. The jobs were held by clubhouse who contracted responsibility for filling the post— effectively by guaranteeing that staff would cover should members be not available. As time passed, the model came under criticism as falling short of the ideal that people should be employed in "permanent" positions held in their own right. Clubhouses now offer this form of supported employment in which the focus is on helping members attain competitive employment through rapid job search and time unlimited individual job support. In a very important study, clubhouse attained as good open (i.e., competitive) employment outcomes as did the model standard for supported employment operating from within an assertive community treatment team (Macais, Rodican, Hargreaves, Jones, Barreira, & Wang, 2006; Schonebaum, Boyd, & Dudek, 2006).

CHALLENGES AND THE NEED FOR FURTHER RESEARCH

1. Adapting to changing demography: Many clubhouses were first established in the early phase of the development of community psychiatry. They provided an essential safety net for people being discharged as hospital asylums were run down and closed; they were largely populated by people who had suffered from severe mental illness for many years. Surveys of the membership of individual clubhouses as well as larger audits carried out with the assistance of directors of clubhouses nationally and internationally, show that members are mostly male, around 40-50 years of age and the majority suffer from schizophrenia or other psychosis and have done so for many years (e.g., Warner et al., 1999; Macias, Jackson, Schroeder, & Wang, 1999; Macias, Barreira, Alden, & Boyd, 2001). But most severe mental illness first presents to services at a much younger age and although there have been improvements in the treatment of first episode psychosis with improved short-term outcomes (Craig, Garety, Power, Rahaman, Colbert, Fornells-Abrojo, et al., 2004; Petersen, Jeppesen, Thorup, Abel, Ohlenschlaeger, Christensen, et al., 2005) the short-term gains from early intervention are not maintained when people move on to less specialised services (Gafoor, Nitsch, McCrone, Craig, Garety, Power, et al., 2010; Bertelsen, Jeppesen, Petersen, Thorup, Ohlenschlaeger, & le Quach, et al., 2008) and as many as 1 in 10 still continue to suffer debilitating disorders. Yet these young people are markedly underrepresented in most clubhouses. In part, this represents youth's tendency to "seal over" and deny the consequences of ill health (Birchwood, Todd, & Jackson, 1998) but a large part is down to the clubhouse environment and what they have to offer to younger members. Some clubhouses recognise the problem and are taking steps to make the setting more youth friendly

but it remains a significant challenge that needs resolution particularly at a time when the focus is on early intervention and service dollars are tight.

2. Adherence to the model standards: Ideally clubhouses should meet 36 standards set down by the International Center for Clubhouse Development (ICCD). These are partly an attempt to provide uniformity in replications of the model but are also designed to be broad ethical principles. One of the most important of these is the non-professional non-hierarchical staff-member relationship. Not surprisingly, the extent to which any clubhouse can deliver against these higher level objectives will vary from one setting to another and wax and wane in time. What is quite unclear is whether there are truly fundamental elements without which benefits cannot accrue.

The tension between cultural adaptation and fidelity to ICCD standards is nicely illustrated in a study from Taiwan. In this study, Frank Wang and Yu-Hui Lu (2013) describe the evolution of two local approaches both owing allegiance to Clubhouse ideals but with very different implementation in practice. While one follows clubhouse standards and has indeed been ICCD approved, the Hsin-Ye takes an altogether different approach. The organisation is based around families coming together to provide mutual support, the healthy family members in effect replacing the staff function in more orthodox clubhouse settings. Just as clubhouse encourages peer support and member participation, Hsin-Ye encourages collaboration and support within networks made up of around 30 families coming together to set up a small businesses, in effect, echoing the work ordered day that underpins the traditional clubhouse model.

The need for flexibility in clubhouse implementation is further highlighted in the article from Matsui and Meeuwisse (2013) comparing the working of a clubhouse in Sweden and in Japan. Both clubhouses were among the first in their respective countries and are actively engaged in international clubhouse activities. Neither has official approval from the ICCD but for very different reasons which highlight the challenge of delivering to fidelity criteria developed in one country but applied to another. The Swedish clubhouse shares many of the characteristics of the U.S. model. It is an independent organisation with its own Board. Members have a clear voice throughout the organisation, and none of the staff have professional backgrounds in mental health. Staff and members work side-by-side, jointly responsible for all the activities of the work ordered day. It is not ICCD approved because of an inability to implement transitional employment within the wider regulations concerning employment rights of disabled people in Sweden. In contrast, the Japanese clubhouse reflects a health system where deinstitutionalisation still has a long way to go and where families play a central role in community care. The clubhouse is part of a larger welfare corporation, staff comprise professional mental health workers as mandated under Japanese welfare regulations and the activities and tasks of the work-ordered day are set down in written manuals which members are expected to follow. There is an active outreach to members' families. In the face of

such obvious differences in organisation and culture, it is striking that both clubhouses expressed strong commitment to core values—both believed firmly in the value of peer support and both claimed to be empowering members toward greater self-confidence and autonomy.

In a further study, this time comparing Japan to Italy and the United Kingdom, Rosario Laratta (2013) distinguished "sympathetic" and "professional" staff. The former, more common in the United Kingdom and Italy, aligned themselves with members, seeing their role as facilitating empowerment and self-help. Sympathetic staff tended to view their governments as ignoring their responsibility to the deprived and saw time spent on upward accountability (audits, submission of expenditure, and activity reports, etc.) as a hindrance to the more important member-focused activity. Professional staff, on the other hand, saw their role as leaders and instructors with a responsibility to the wellbeing of the wider community, and while also conscious of their dependency on government funding, were more likely to acknowledge the importance of upward accountability—to value showing that the money they received was well spent.

Such variability in process and outcome can also be found within what might be expected to be a much more uniform system. A study of 31 clubhouses in the state of Michigan, explored the extent of member involvement in decision making (e.g., who makes decisions about hiring staff or changing the budget), as well as in support and problem solving assistance and deciding the number of specialised services offered. These were correlated with characteristics of the setting of the clubhouse, member characteristics, programme resources and aspects of the internal organisation of the clubhouse. Most clubhouses offered a wide range of specialised services but evidence of empowerment in terms of shared decision making (setting rules, hiring staff, and budgeting) was rather lower than might be expected given the clubhouse rhetoric. Member involvement was lower where there was a high proportion of more disabled members and where there was a high ratio of members to staff. The latter is particularly interesting given the clubhouse philosophy that encourages lower numbers of staff in order to encourage member participation—in practice the reverse seems to be true (Mowbray, Lewandowski, Holter, & Bybee, 2006).

Despite these variations, Clubhouses that work well gives visitors a strong impression of a cohesive community. Members are often enthusiastic about the clubhouse, proud of their collective identity and that they belong to something that has an international identity.

3. Throughput vs dependency and the cult of the individual: The therapeutic community movement, once very popular, has been in something of a decline in recent decades and one senses a similar disquiet about clubhouse. There are many reasons for this decline but it reflects in part, a drift toward more "personalised" medicine where the focus is on the unique biological and psychological characteristics of the individual. Health professionals and the organisations that pay their wages are more excited by the promise of technologically

sophisticated approaches that offer quick fixes than they are by open ended social programmes. With the move away from the institution to community care, there has also been a shift in emphasis away from providing continuing care in favour of more "through-put" models that demand clearly defined and time-limited treatment programmes that people move through, and not a facility that encourages life-long membership with all the connotations of dependency and institutionalisation.

The rise in popularity of Recovery also plays into this in a curious way. Recovery in the sense of the subjective experience of empowerment and a sense of the self apart from illness is now a key feature of mental health policy in many countries around the world and is, of course, at the heart of clubhouse. But how exactly this is translated into service delivery is less clear and largely a matter of interpretation. So, for example, the policy is often interpreted as a version of normalisation with the target of "mainstreaming"—ensuring that people suffering from mental health problems are separated from fellow sufferers and re-integrated into the mainstream community. As a result the policy has been called on to justify earlier discharge from mental health care and has encouraged considerable scepticism about clubhouse as its offer of life-long membership is seen as "encouraging dependency." This issue of dependency is a particularly tricky one, almost always defined by someone other than the so-called dependent person and almost always viewed as a bad thing despite the fact that we are all to a greater or lesser extent dependent on key people and institutions in our lives.

CONCLUSIONS

Clubhouse emerged in the United States at a time of rapid deinstitutional-isation and provided a light in the darkness of the disarray and fragmentation of community care. It was way ahead of its time in advocating side-by-side working, the flattening of hierarchy between users and staff and particularly the shift from the role of "patient" to that of "member." Its success around the world also probably reflects its role in helping to manage deinstitutionalisation and it seems likely that it is in societies that are beginning the deinstitutionalisation journey that new clubhouses will emerge and flourish.

But for existing clubhouses, where there is competition for the use of community care resources there is also a need to consider the future development of the model and in particular to address the interface with other components of community mental health care. The articles in these special issues of the *Journal* show clubhouse as a mature organisation with international reach. Like all long-standing institutions it runs the risk of stagnation and must evolve to keep up with local pressures, while at the same time not losing the foundation of Recovery principles, peer support, and peer working that has helped it to reach across continents.

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