Social networks, support and early psychosis: mutual support within service-user communities

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Gayer-Anderson & Morgan (2013), in their review of research on social networks and support in early psychosis, offer some important findings. Social networks are restricted in first-episode psychosis and this restriction often precedes the onset of psychosis. Family contacts, however, do not become restricted. These findings, they conclude, are probably a consequence of the illness, but there is a reciprocal relationship between the restriction of social networks and poor outcome. Support for this last observation comes from the conclusion of the International Study of Schizophrenia (Hopper *et al.* 2007) – a large, long-term study of outcome for over 1000 people with schizophrenia in rich and poor countries – that the enhanced outcome in poor countries is strongly related to greater family involvement and social inclusion. Given these findings, we should ask ourselves, what can we do to make this situation better? and, what are we doing to make it worse? Let us begin with the latter.

Some obstacles to social network building in psychosis are a consequence of cultural beliefs or governmental policy. In the US, for example, there is a cultural emphasis on independent living – an expectation that young people will move out of their parents' home around age 18 – which leads to greater isolation for the person with mental illness. Mental health service providers tend to share this prejudice and feel that, for a young person suffering from psychosis, 'independence' is an important factor in recovery, even though the patient may have limited capacity for success when living independently. Another US-specific problem is restrictive rent-support

regulations. The US Department of Housing and Urban Development offers rent subsidies to the disabled, but they come with the requirement that the subsidy can only be applied to single-occupancy living situations. Disabled people cannot use their subsidy to live with friends or even have a friend stay overnight. For people with limited social networks, the result can be severe loneliness.

A common disruption of social networks in Western countries is the issue of mainstreaming – the assumption that people with mental illness will achieve better social integration if they are dispersed throughout the broad community. This belief leads professionals to routinely place clients in dispersed housing and job settings. A central tenet of the Individual Placement and Support (IPS) model of supported employment, for example, is that clients should only be placed in 'competitive employment' (Bond *et al.* 1997). A community-based jobsite with built-in support or congregate employment for people with disabilities – such as a social firm – is frowned upon by IPS advocates because, they argue, the person may become too comfortable and may not want to move on to a less supported position. The client's report that he or she values on-site support and contact with others with shared experiences carries little weight. The effect of this emphasis on mainstreaming, for some patients, can be social isolation and disempowerment. People gain their sense of identity and power from their social group – their co-workers, friends, neighbours and family. Living and working in proximity with people who do not share one's disability status or life experience make social interaction difficult.

People with mental illness are not only stigmatized by others in the broader community, they also carry a burden of internalized stigma. They often harbour the same stereotype of the 'crazy' person as everyone else in the culture and, if they accept their diagnosis, they are at risk of seeing themselves, in consequence, as worthless and incapable (Leff & Warner, 2006). One of the few ways they may gain respite from this negative self-image is through the empowerment that

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accompanies having a productive role within one's own community. They may be more likely to achieve such a productive role through the identity community of others with whom they share the experience of mental illness than through their interactions with people in the broader community. This takes us to our other question, what can we do to help?

An 'identity community' consists of people with shared interests, beliefs, experiences and needs which influence the identity of group members and the cohesiveness of the group. People with serious mental illness constitute an identity community and we may understand better how important this can be for their being in the world if we first examine the example of an ethnic enclave – a shared-location identity community.

At the end of the Vietnam War, 130 000 Indochinese refugees came to the US and were placed with sponsor families scattered throughout the country. In a secondary migration based on choice, a large percentage subsequently moved to a small number of communities in California. By 1990, almost half of the total Vietnamese population in the US lived in these communities which had developed an infrastructure of businesses and social organizations. Some years after the secondary migration, some Vietnamese immigrants and their children remained in the ethnically concentrated communities, some moved to communities where there were few Vietnamese, and some moved to nearby, but more diverse, communities that allowed them to have activities in both the Vietnamese and the broad community (Portes & Rumbaut, 2006).

Identity communities give immigrants opportunities to build businesses and business aptitude, gain leadership skills and experiences, and create civil society activities and institutions. The broad community provides few similar opportunities because of prejudice, cultural and language barriers and unequal access. Immigrants can deal with this situation by choosing one of three options at different points in their lives. After opting for membership in an identity community, individuals can choose to remain in that community, assimilate into the broad community or move back-and-forth between the two. Research reveals that other social minorities tend to utilize these same three approaches in their relationships to the majority (Berry, 2005). Currently, in mental health services, however, only one of these ways of leading a community life is regarded as successful – assimilation. If the same three options were available to people with mental illness, it could lead to more of them leading successful lives in the community.

A number of approaches recognize and build upon the value of mutual support within the service-user community. Such programmes include the therapeutic

community, the psychosocial clubhouse and social firms. Less well known are the clustered-housing model, business incubators and using an economic analytic approach to identify ways in which the service-user group can benefit from its own consumption power. Let us review these approaches to evaluate the feasibility of building support for people with mental illness through their own identity community.

The therapeutic community model was introduced in the post-world war II period as a treatment approach for demoralized ex-soldiers and then modified for use in the wards of public psychiatric hospitals to prepare inmates for transition to the community. Along with other changes, the therapeutic community introduced a radical shift in the staff-inmate power relationship. Patients and staff sat together to discuss ward management, the introduction of novel, normalizing practices and relationship issues (Jones, 1968).

The therapeutic community was important in Northern Europe in making transition to community care feasible, but faded as lengths of stay became much briefer. Interestingly, however, a similar approach was independently introduced in the late 1940s in New York City at Fountain House – a community-based psychosocial clubhouse model that has diffused widely around the world in well over 300 certified clubhouses in 30 countries (ICCD, 2012). The clubhouse provides a casual environment in which members and staff treat one another with respect and value is placed upon mutual support within the community and productive activity in maintaining the clubhouse environment.

Social firms are businesses created with a dual mission – to employ people with disabilities or social disadvantage and to provide a needed product or service. The earliest social firms for people with mental illness in Europe were created in Trieste in 1973 during the deinstitutionalization of San Giovanni Hospital. The first business employed ex-hospital patients and non-disabled workers in a street-cleaning company. Since then, the number of social enterprises has increased progressively to become a major economic force in the city. The range includes a family-style hotel, a café, an apartment restoration business, a moving company and all the public building and street cleaning contracts. By 2004, these social firms generated revenue of over €10 million a year and employed 300 people with disabilities as regular employees and another 200 as trainees (Warner & Mandiberg, 2006). The model has diffused broadly across Europe. Before 1997, there were just six social firms in the UK; currently there are over 150.

The principles of European social firms include: over one-third of employees are disabled or disadvantaged, each worker earns a fair market wage, disabled

workers are provided needed accommodations and the businesses are economically self-sustaining. There are multiple advantages to this vocational model. For the individual they include a variety of full-wage job options, an integrated workplace and empowerment opportunities through managerial involvement. The business benefits from the social mission of the firm which enhances worker participation and the mental health rehabilitation service benefits from an employment programme that operates with little or no subsidy. The sense of community and social support offered by these business entities is illustrated by the manager of a Trieste social firm who described her workplace as 'una piccola famiglia allargata' – a small extended family (Warner & Mandiberg, 2006).

The clustered apartment project in Santa Clara County, California, developed housing programmes for people with serious mental illness (SMI) in the 1990s in which no resident lived more than 5 mins walk from another. A central community space was established and community organizers, instead of mental health staff, were hired to foster a mutually supportive community. The clustered communities developed mutual supports including acting as their own community organizers and developing crisis response services (Mandiberg & Telles, 1990). Colorado Recovery, in Boulder, has developed a similar community living programme staffed only by community organizers.

Just as ethnic communities develop their own business, social and civil society infrastructure, identity communities of people with SMI can do so as well. The earliest examples were service-user-run drop-in centres, but more recent examples hint at what is possible. Service-user communities in Madison, Wisconsin, and New York City have established business incubators to assist people with entrepreneurial ideas set up micro- and small businesses. These incubators offer basic business training, consultation and office supports such as space, office equipment and book-keeping assistance. An obstacle that many service-users encounter in developing a business is access to capital. A service-user organization in New York is establishing a credit union, a type of community bank, using deposits from service-users, family members and supporters.

Warner & Polak (1995) conducted an economic analysis of the assets of 50 people with SMI in Boulder, Colorado, with the goal of developing businesses that would exploit the purchasing power of the service-user community, creating jobs for community members and recirculating money in the community to produce an economic-multiplier effect. The analysis demonstrated that service-users command substantial markets through their consumption of psychiatric services, housing, food and medication,

revealing possibilities in each of these areas for targeted businesses that could employ service users and expand their community assets – food and housing cooperatives, for example, and jobs for service-users within the psychiatric services. The authors also developed a user-employing pharmacy that serves the user community. The pharmacy, which has been in operation for over a decade, and has been franchised, provides a better level of service to customers, employs four people with SMI as part-time pharmacy technicians and makes a substantial profit which is available to support other identity community-based ventures (Mandiberg & Warner, 2012).

In summary, an analogy with the ethnic enclave form of community reveals a way to preserve the social networks that can be so valuable to people with SMI. Integration in the dominant community, or mainstreaming, is not always the answer. People with SMI should be allowed to choose their own pathway which may include mutual support within the service-user community. We have outlined several approaches to successfully harnessing service-user mutual support to enhance social networks and support and potentially improve outcome from the disabling effects of illness.

Declaration of Interest

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