

“Is That All There Is?” Searching for Citizenship in the Midst of Services

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It is very difficult to “stand in the future” as King Arthur did. In 1950, who could have predicted economic globalization, the demise of the Soviet Union, or the fact that institutions for citizens with disabilities would be closing in all parts of the world by the end of the century. As we enter a new millennium, I think it is valuable to reflect back, but recognize that any implications we come up with for the future can only be “best guesses.”

Deinstitutionalization may indeed be regarded as the pivotal development in mental health in the 20th Century. Policies and practices that have created community-based services challenged 150 years of institutionalization. Prior to that period, scholars have noted that people with serious mental health problems were confined to jail, poor houses, and alms houses and were often put on display as part of “freak shows” (Foucault, 1965; Schull, 1977). Noting some progress in mental health in the 20th Century, Davidson (1999) has argued that deinstitutionalization has failed to let people into full citizenship. Rather, most individuals with severe mental illness continue to live out their lives within the institutional and the “contrived” world of community-based programs.

Some years ago I was involved in a series of qualitative studies that involved listening to the stories and experiences of consumer/survivors. Robert, an articulate young man who had been through a very difficult time, was sharing his life narrative with me. Having been “deinstitutionalized,” he was considered a success because he was able to stay out of the hospital and was living in a group home. Robert attended a segregated day program, took extensive medication, and had no friends or relationships outside of one family member and other residents of the group home. He had no connections with community groups or associations. Referring to his life

Citizenship

amidst services, Robert wondered aloud, “Is that all there is?” This statement sums up for me the significance and disappointment of the deinstitutionalization movement.

I believe the legacy of the 20th Century will be more sustaining than deinstitutionalization. There are three other significant developments that reflect an emerging empowerment-community integration paradigm in community mental health, and give hope that people may experience more than a “life of services” (Nelson, Lord, & Ochocka, 2000). These developments are the recognition of power in mental health, the importance of self-help and consumer/survivor initiatives, and the re-discovery of community. Several implications and impacts emerge from these three areas for the new century.

Beginning in the 1980’s, a growing consumer/survivor literature described people’s experience with the mental health system as difficult, alienating, and a major contributor to oppression (Burstow & Weitz, 1988; Capponi, 1992; Chamberlin, 1990). The introduction of “power” into mental health discourse makes current and future mental health reform different than earlier reform efforts. We have learned that power exists on many levels. At the individual level, we have learned that recovery is partly about regaining personal power. Recent research shows that “having personal control” is a key determinant of health (Lord & Hutchison, 1997). In my experience in helping mental health organizations to change, power imbalances are so dominant that it is often hard for people to imagine organizational alternatives. One study showed that many mental health staff were defensive when they heard consumer criticisms of their organization, but at the same time felt they could not speak about their own lack of power (Wadsworth & Epstein, 1998). I now believe that the issues of power relations (including gender, class, and race) must infuse our thinking and acting in community mental health.

Consciously “shifting power” has now become a critical system and organizational issue in mental health. In reviewing several mental health reform initiatives, McCubbin and Cohen (1999) point out that progressive reform has never been able to succeed only on the good intentions of

Citizenship

paternalistic governments and caregivers. They further emphasize that “the objectives of reform will best be met in the long run by placing control of the shaping of the reform in the hands of those whose interests are most consistent with the reform objectives” (McCubbin & Cohen, 1999, p.11). While I agree that participation of consumer/survivors in reform is essential, this “shifting power” must be accompanied by a shift in valued resources. To date in Canada, there has yet to be a significant reallocation of funding from the institutional sector to community alternatives based on the values of the empowerment-community integration paradigm (Nelson, Lord, & Ochocka, 2000). “Shifting power” and the re-allocation of valued resources, such as housing, jobs and support services, in many ways are prerequisites to the development of full citizenship.

In the last third of the 20th Century, self-help witnessed phenomenal growth in the western world. The development of autonomous consumer/survivor self-help organizations has been an important reflection of the empowerment-community integration paradigm. These organizations emphasize mutual aid, peer support, consumer/survivor businesses, and advocacy. They are becoming significant "sites of resistance" for consumer/survivors (Nelson, Lord, & Ochocka, 2000). In my experience, working closely with two consumer/survivor organizations over several years, I have found that the self-help group creates a context for people's gifts and strengths to be honoured. In an effective group, there is sustained mentoring, mutual learning, heartfelt communication, and equal relationships. Peer support relationships enable people to talk freely and test out ideas about their recovery and about their “self in community” (Lord, 1997). The self-help process also has the potential to nurture hope and self-respect.

Autonomous consumer/survivor organizations do not exist as an island. In many communities, they have formed alliances with other players around particular community or province-wide issues, such as economic development and work. These groups also serve as a springboard and vehicle for consumer/survivors to have a voice in mental health decision-making. Furthermore, recent research has shown that consumer/survivor

Citizenship

self-help initiatives are an important “mediating structure” on the path to community and citizenship (Nelson, Lord, & Ochocka, 2000).

Governments and formal agencies often fail to understand the importance of consumer/survivor initiatives that give voice to new stories and new awareness. Ruth Behar, in her book The Vulnerable Observer: Anthropology That Breaks Your Heart, argues that “there are new stories... rushing to be told in languages we’ve never used before, stories that tell truths we once hid, truths we didn’t dare acknowledge, truths that shamed us” (Behar, 1996, p.33). Many of the stories we hear from consumer/survivors are filled with emotional pain and woundedness, but they are people’s reality. The stories also reflect people’s struggle for identity, meaning, and community participation. When we really listen, we learn volumes about how communities and services could respond differently to people who are vulnerable.

The re-discovery of community in the late 20th Century reflects both the limitations of the modernist era and the desire of the human spirit for social activity and sense of community. It is well known that citizens with significant mental health problems often have few friends and relationships and very limited community involvement. Unfortunately, modern suburban communities and the professionalization of services have both kept people with mental health challenges separate from the fabric of community life, whether it be neighbourhoods, personal networks, or associations of common interest (McKnight, 1995; Putman, 1993). Our understanding of community has been complicated by the fact that “community” in the traditional mental health paradigm has meant “community based services,” which simply reflects the location of the services, not the capacity of organizations to foster genuine community participation.

On the other hand, I have found that genuine community is everywhere in our own towns and cities, we are simply not used to looking for it! One basis for community is people coming together in associations of common interest, ranging from art galleries to fitness clubs. As part of the Welcome Home Initiative in Kitchener-Waterloo, for example, we have

Citizenship

found that people with significant mental health problems can participate in these settings of common interest. When hospitality is central to these communities, people are welcomed and included. In the last twenty years of the 20th Century, a growing number of groups (such as the Healthy Communities movement) have become concerned with building the capacity of communities. In addition, the commitment to community and inclusion has become a central tenant of all disability movements throughout the world (Carling, 1995; Condeluci, 1991; Schwartz, 1997). There is great promise here for the 21st Century, as citizens hunger for more sense of community in their lives.

I have suggested that the three significant legacies from the 20th Century (power, self-help, and community) have the possibility of framing a new paradigm of community mental health in the new century. This empowerment-community integration paradigm has many implications for the principles we use, the policies we implement, and the practice we support. It is clear that values will be a central guide to the emerging vision; values that are grounded in dialogue with people, and values that reflect strengths, relationships, capacity, and community. It would be hopeful to think that the deficit-oriented approaches that dominated the 20th Century will vanish, and that social justice will emerge as a key value in the new paradigm.

Let us conclude by re-visiting Robert's story. If his story of being "surrounded by community services" represents the best of the 20th Century, can we dare to hope that "citizenship and meaningful relationships" will be at the centre of his story in the new century? Can we build welcoming communities that respect citizenship and inclusion? With work, commitment, and collaboration, can we build on the legacies of the 20th Century to create such a world in the future?

References

- Behar, R. (1996). The vulnerable observer: Anthropology that breaks your heart. Boston: Beacon Press.
- Burstow, B., & Weitz, D. (Eds.) (1988). Shrink resistant: The struggle against psychiatry in Canada. Vancouver, B.C.: New Star Books.
- Capponi, P. (1992). Upstairs in the crazy house: The life of a psychiatric survivor. Toronto: Viking.
- Carling, P. J. (1995). Return to community: Building support systems for people with psychiatric disabilities. New York: The Guilford Press.
- Chamberlin, J. (1990). The ex-psychiatric patients' movement: Where we've been and where we're going. The Journal of Mind and Behavior, 11, 323-336.
- Condeluci, A. (1991). Interdependence: The route to community. Winter Park, Florida: PMD Publishers Group, Inc.
- Davidson, L. (1999). Psychiatric disability and the restoration of citizenship. Presentation to Conference on Assertive Community Treatment Teams, London, Ontario, October, 27.
- Foucault, M. (1965). Madness and civilization: A history of insanity in the age of reason. Toronto: The New American Library of Canada.
- Lord, J. (1997). Empowerment process and community: Reflections and paradoxes. Presentation to empowerment practice in social work conference, University of Toronto, Toronto, September 25-26.

Citizenship

- Lord, J., & Hutchison, P. (1997). Living with a disability in Canada: Toward Autonomy and Integration. In National Forum on Health, Determinants of health: Settings and issues. St. Foy, Quebec: Editions MultiMondes.
- McCubbin, M. & Cohen, D. (1999). A systemic and value-based approach to strategic reform of the mental health system, Health Care Analysis, 7:1, 1-21.
- McKnight, J. (1995). The careless society: Community and its counterfeits. New York: Basic Books.
- Nelson, G., Lord, J. & Ochocka, J. (2000). Shifting the paradigm in community mental health: Toward empowerment and community. Toronto: University of Toronto Press
- Putman, R. (1993, Spring). The prosperous community: Social capital and public life. The American Prospect, 35-42.
- Schwartz, D. (1997). Who cares? Rediscovering community. Boulder, Colorado: Westview Press.
- Scull, A. (1977). Museums of madness: The social organization of insanity in nineteenth-century England. New York: Penguin Books.
- Wadsworth, Y. & Epstein, M. (1998). Building in dialogue between consumers and staff in acute mental health services. Systemic Practice and action research, 11:4, 353-379.

**This article appeared in
Canadian Journal of Community Mental Health, 19:2, 2000.**