Recovering Citizenship

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ABSTRACT

Recovery as a process through which people reclaim their lives even while continuing to experience symptoms of mental illness has at times been misunderstood or misinterpreted, including being used as an excuse for cutting needed services and supports in the guise of allowing people to pursue their own personal “recovery journeys.” In delivering a message of hope to individuals and fostering initiatives to counter the debilitating impact of clinical pessimism, recovery literature has also, at times, paid less attention to the material, social, cultural, political and economic contexts in which people pursue recovery. The importance of these contexts are implied in a 1961 American Report on Mental Illness and Health that argued that people with mental illnesses should be able to live their lives “in the normal manner” in their home communities. We argue for a disability model that provides people with necessary supports and services to make individual recovery possible for persons with prolonged mental illnesses. Another model that has emerged over the past decade to counterbalance this overweening emphasis on the lone individual pursuing his or her recovery journey is citizenship. We discuss this concept and our research on it since the late 1990s. We then argue for “recovering citizenship” as a concept and metaphor to capture the individual recovery process within the context and goal of a life in the community that the citizenship framework supports.

“In the end, fame is nothing but a constellation of all the misunderstandings that have gathered about a new name”
- Rainer Maria Rilke (1)

From a historical perspective, it would seem that what Rilke came to understand about the nature of fame may, unfortunately, also be said about many of the major mental health policy directions taken since the birth of the discipline in the late 18th century. In this introduction, we mention only two examples of such persistent misunderstandings before turning to the current context, which offers numerous examples of its own. After attempting to clarify these more recent misunderstandings, we then argue for moving the field of psychiatry toward a new vision of citizenship that incorporates but also concretizes many of the admirable values and principles of the past that have yet to make their way fully and effectively into our practice. We end by offering some examples from our own program development efforts of what such a vision begins to look like in practice.

At a time when persons with mental illnesses were locked in chains and filth and either abandoned or abused, Pinel envisioned psychiatry to be a humane science that rendered social therapies with “thoughtful tenderness” to “unfortunate” people who were suffering from “a vivid sensitivity and from psychological qualities that we value highly” (2). He inaugurated the era of “moral treatment” from which Dorothea Dix herself then benefitted some 30 years later; as a result, she dedicated herself tirelessly in her later years to ensuring that people of all social classes would have access to the same kind of safe and family-like setting she had experienced during her own episodes of acute distress. What resulted, however, was over 100 years of institutionalization and largely custodial care from which we as a field are still recovering. What began as “moral treatment” somehow, somewhere along the road became something very different.

With the aging and overcrowding of state mental hospitals breaking the fiscal backs of budget-conscious governors in the 1950s, the U.S. (and many other countries) then turned their attention toward the promise of “deinstitutionalization.” In the words of Eisenhower’s Joint Commission on Mental Illness and Health, with the depopulation of state hospitals it then became “the objective of modern treatment of persons with major mental illness to enable the patient to maintain himself in the community in the normal manner” (3). At the time of
this noble pronouncement, however, there were only “nine halfway houses, fewer than two dozen partial hospitals, and eight rehabilitation centers” in the entire country (4, 5). Given that Congress failed to allocate any significant, new funds for community-based services to replace those provided (or not) in the hospital, it is not surprising in retrospect that many of those discharged from the state hospital system were trans-institutionalized in nursing homes or board and care homes, and that many others have ended up homeless and/or in jails and prisons (5). As a result, the objective of enabling people to live in the community “in the normal manner” became re-interpreted in practice as “maintaining” people outside of hospitals (6).

Such was the conclusion of the most recent federal commission to review the status of mental health care in the U.S. The report of this commission was entitled Achieving the Promise: Transforming Mental Health Care in America (6), and the promise to which it referred in its title was that of the “life in the community” first promised in 1961. The new policy direction laid out in this report is that of transforming mental health care to a “recovery” orientation as yet another attempt to fulfill that promise, and it is with the misunderstandings presently amassing around this term to which we now turn. We do so in the hopes of not repeating the mistakes of the past, and argue for promoting the new concept of “citizenship” (7) as one way of safeguarding and enriching a vision of recovery that, at this point, appears vulnerable to suffering a fate similar to that of moral treatment and deinstitutionalization.

RECOVERY AND RECOVERY-ORIENTED CARE

Almost since its inception (8), the concept of being “in recovery” with a serious mental illness (9) – also described as recovery as a process (10), “personal recovery” (11), or a “consumer” model of recovery (12) – has been the object of considerable confusion and concern. First, it has been conflated with recovery from a serious mental illness, also described as recovery as an outcome, “clinical recovery” (11), or a “scientific” model of recovery (12). While the nature of the relationship between these two forms of recovery has yet to be decided (13, 14), we suggest that as concepts they are conceptually distinct, referring to two different phenomena.

Recovery from a serious mental illness may seem to be a straightforward concept, as it has similar meaning to recovery from other (primarily acute) health conditions, but it has been controversial nonetheless. It refers to a person getting to a point where he or she no longer has any signs, symptoms or sequelae of mental illness. What has been controversial is that this appears to be a phenomenon that occurs much more frequently than has been thought historically (15). Numerous longitudinal studies conducted over the last half-century have consistently found that between 47 and 67% of persons diagnosed with schizophrenia will experience significant improvements in their condition over time, many recovering fully (16-18). This consistent body of research is just now beginning to change a century-old assumption that once you have a serious mental illness you would have it for the remainder of your life. Were this the only meaning of recovery in relation to serious mental illness, it alone would pose many challenges for changing practice, as the system of care that we have inherited from our predecessors was based on “reducing symptoms and accepting long-term disability” (6). If disability is not necessarily associated with serious mental illness, then what causes it and how can it be prevented? The current focus on early intervention represents one attempt to explore and promote this possibility.

This is not, however, the only meaning of recovery. There also is recovery as a process. One way to define this second meaning of recovery would be to suggest that the person in recovery is on the way to, but has yet to achieve, recovery as an outcome. Doing so, though, raises many unanswerable questions, such as can a person still be considered to be in recovery while experiencing a relapse or setback, or is there every a time when a person would not be considered to be in recovery. If that question cannot be answered, then, as Roe and colleagues have suggested, the term becomes meaningless (14).

We suggest that a more useful way to distinguish between the two meanings may be to point out that the second meaning of recovery, i.e., recovery as a process, only makes sense in the absence of the first meaning of recovery, i.e., recovery as an outcome. You do not need to be in recovery if you have already recovered. Being in recovery only becomes a relevant idea for those persons who have persistent, unremitting conditions. For these persons, being in recovery refers to living one’s life as best and fully as one can in the face of a mental illness that won’t go away (i.e., is not cured by current interventions). It is for this reason that we have insisted that the concept of being in recovery is most relevant to, and most urgently needed by, precisely those persons who are the most affected by mental illness, those persons whose practitioners continue to insist are “too sick” to benefit from recovery-oriented practice (19).
It is perhaps in the differences between these two ways of understanding being in recovery that many of the current misunderstandings surrounding recovery can be located. One of the most pernicious misunderstandings, or distortions, of this sense of recovery has arisen as a politically expedient cover for cutting funding for mental health services (20). If so many people recover, so this line of reasoning goes, then we can spend less for services and supports. And if they do not recover, under this scenario, it is because they are not working “hard enough” on their own recovery (21). Such an instance of “blaming the victim” appears to have been supported, unintentionally, by statements about recovery being “the person's responsibility” or a “unique, personal journey.” Rather than empowering persons with serious mental illnesses to reclaim their lives – as was the intent behind such statements – they have been taken, or at least used, by neoliberal policy makers to justify cut backs on care, arguing that to the degree to which recovery is a personal responsibility it becomes less of a societal one (20).

Such a misinterpretation might be less harmful were it only made about persons who have recovered from serious mental illnesses; persons, that is, who no longer require intensive psychiatric care. But to make this argument about persons in recovery, persons who are doing their best to live their lives in the face of a serious mental illness, belies a serious misunderstanding of the nature of “personal recovery.” As we noted above, being in recovery is not best understood as being on the way to or approaching recovery as an outcome; to use a marketing term, it is not recovery “lite.” Rather, being in recovery was introduced initially, and we suggest is best understood, on the basis of a disability model. Consistent with the inclusion of mental illness as a disability under the Americans with Disabilities Act, Pat Deegan (22) drew inspiration from, and parallels between recovery and, the Independent Living Movement among persons with physical disabilities. She envisioned “recovery” as a way for persons with serious mental illnesses to take back control of their own lives even while they remained disabled.

No rationale or justification for cutting funds for mental health services or supports can be derived from such a disability model. A disability model draws attention to person-environment interactions as the locus where disability is situated, calling for practitioners and society at large to craft environmental modifications, such as curbs in sidewalks, that enable persons with particular needs to have full access to community life. As a result, one of the advantages of adopting a disability model is that it argues for removing the arbitrary funding restrictions currently placed on community-based supports in mental health, such as job coaches. It makes no more sense to take a job coach away from a person with a serious mental illness after a few months than it does to take a wheelchair away from a person with a mobility impairment or a service dog from a person with a visual impairment. Persons with what have been described as “psychiatric disabilities,” persons who are “in recovery” with a serious mental illness, may still have profound needs for services and supports in order to live the best lives they can – just like people with other forms of disability to whom our societies have pledged the resources, opportunities and supports needed to make it possible for them to have as independent lives as possible.

Perhaps recovery advocates have been mistaken to emphasize that recovery is a unique and personal journey for which the person bears a majority of the responsibility. But these statements were made within the context of understanding being in recovery to be a long-term process of learning how to live one's day-to-day life with an on-going condition that one neither asked for nor earned as punishment for an undisclosed sin. People in the position of having no choice but to do so (i.e., to live with a disability) warrant our compassion and support – social, emotional, instrumental and material – rather than our blame, shame or neglect (23).

Many of the concerns expressed about (23), and abuses of (21), the term recovery are best addressed by referring back to this understanding of being in recovery. For example, one of the most common concerns expressed about recovery by practitioners and policy makers is that of risk (23). The concern is that encouraging persons with serious mental illnesses to articulate their aspirations, set their own goals, and make their own decisions will increase the degree to which they will make bad choices and put either themselves or others at risk of harm. On what is this concern based? Would such a concern be expressed about persons with any other type of disability? And what makes practitioners or policy makers think that they know better how to live with a disability they have never experienced than people who are living with that disability every day? In the end, persons with mental illnesses living outside of institutional settings will make their own decisions anyway; what harm could be caused by acknowledging this fact openly and working collaboratively with them to assist them in making the best decisions that they can? People in recovery are no more aggressive, pose no more risk, than people with, or without, other forms of disability (24). Having a mental illness does not make a person “bad.”
The flip side of confusing mental illness with risk has been confusing recovery with being mature or becoming a “better” person (25). While some people in recovery do talk about having become a more compassionate and/or open person by virtue of their suffering and overcoming adversity, we should not (mis)take this admirable byproduct of the process to be its aim. Describing someone as being in recovery should be taken to mean that this person is striving to live his or her life as fully as possible in the face of a serious mental illness, it should not be (mis)taken to be expressing a value judgment about this person's moral worth or degree of social-emotional maturity. There is just as much diversity in terms of moral worth and social-emotional maturity among persons in recovery as there is among persons who have never experienced a serious mental illness, including mental health practitioners. Given the history of the field, no one should equate psychiatry with moral philosophy. Similarly, we should neither expect nor demand that persons with serious mental illnesses become “better” people in order to be viewed as being in recovery. They have their hands full, first dealing with the curve ball thrown to them by life and then in figuring out how to live their lives in the face of an illness that will not go away. Should they become more compassionate and open people as a result of doing so, all the better for them. We have no right, however, to mandate that as an expectation or stipulate that as an aspect of recovery per se.

As we can see in the examples above, many of the misunderstandings that have amassed around the concept of recovery have focused narrowly on the individual person and his or her attributes. Has he recovered, is she likely to hurt someone, has he become a better person, and, perhaps most importantly, is she taking responsibility for taking up her own unique journey? Less attention has been paid to the material, social, cultural, political and economic environment in which recovery can be impeded or nurtured, or the nature of the interpersonal relationships needed to support persons in their recovery, whether with mental health practitioners or with family and friends. Over the last decade or so, another concept has begun to develop around the globe to counterbalance this over-emphasis on the individual nature of recovery and to begin to articulate the nature of the responsibility that the community bears, not only in promoting recovery per se but in affording persons with serious mental illness full “citizenship” as a foundation for recovery (rather than as its eventual reward; 26). It is to that concept that we now turn.

**CITIZENSHIP AND CITIZENSHIP-ORIENTED CARE**

We have defined citizenship as the person’s strong connection to the 5 Rs of the rights, responsibilities, roles, resources and relationships that a democratic society makes available to its members through public and social institutions, the “associational life” of voluntary organizations such as churches and neighborhood organizations, and social networks and everyday social interactions (7, 27). Further, a sense of belonging in one’s community and society both supports and is supported by a strong connection to the 5 Rs. This sense of belonging must be validated by others’ recognition of one’s valued membership in society (28, 29).

Two main paths to citizenship are available for excluded persons and groups. One involves individual efforts and supports to gain access to full citizenship; the other involves society’s responsibility to open up access to citizenship, including but not limited to legal citizenship for previously excluded or marginalized groups (30). As governments and societies erect barriers to this path to citizenship, social activism of excluded persons and their supporters, and resulting social conflict, is often required to clear the way.

Citizenship has gained traction in the mental health field over the past decade but still is a relatively new and less widely known concept than recovery. In addition, ours is a particular approach to citizenship that emerged from mental health practice in the later 1990s. Thus it will be useful to review some key marker points for our efforts to begin to realize this vision of citizenship in practice. We briefly discuss five: (1) initial development of citizenship theory in mental health outreach (homeless outreach); (2) a citizenship-based community coalition; (3) an individual citizenship intervention; (4) development of an instrument to measure citizenship at the individual level; and (5) in-progress efforts to develop and test citizenship-oriented care at a large community mental health center.

1. **Homeless outreach and citizenship.** The notion of citizenship as a way of thinking about full membership in society for people with mental illnesses was, in retrospect, a logical outgrowth of a sociological understanding of homeless outreach and of the limitations, as well as the strengths, of that work. Homeless outreach, based in part on the Assertive Community Treatment (ACT) model, was a response to a new phase of homelessness in the U.S. starting in the late 1970s and early 1980s, characterized broadly by a massive increase in single persons, largely male, living on the streets who were poorer and more likely to have serious mental illnesses than was the case...
in the “Skid Row” era of homelessness that preceded it (31). In homeless outreach, clinicians, case managers, and others leave their offices to find, make contact, and build trust with people who, in many cases, have dropped out of treatment and shun mental health care. Building on people’s strengths and addressing their stated needs first whenever possible, outreach teams help their clients gain access to income through entitlement programs or employment, primary and dental care, and other services and supports with the goal, eventually, of persuading them to accept treatment and helping them find housing (7, 32).

Our ethnographic research on outreach work (7) led us to conceptualize the encounters of people who were homeless and outreach workers as transactions and negotiations at the physical, socioeconomic and psychological borders of society and as involving the instrumental domain of practical services and supports and the expressive domain of relationships and identity. The last – identity – was potentially troublesome for outreach clients, as they contemplated an exit from the highly stigmatized category of homelessness to what might be substandard housing and social lives defined and arranged around their status as patients receiving public mental health care (7). We found, during the early stages of housing clients, in fact, that some people felt so isolated, out of place, and disconnected in their apartments that they began to consider a return to living on the streets. There, they had friends and the status of being able to survive homelessness. What seemed to be missing was support for having friends and a positive status, along with many other aspects of full citizenship in mainstream society, once housed and engaged in care (30).

2. A citizenship-based community coalition. The first citizenship intervention – Citizens – was an attempt to put the community- and society-wide path to citizenship into practice. Citizens was a community coalition – a diverse group of people working together to address health and social problems with socioeconomic and political, rather than personal, roots (33) – composed of people who were or had been homeless, mental health providers, and community members who were not homeless or directly connected to mental health or other service systems. Among its objectives were to educate the public about the needs of people who were homeless and the contributions they could make to their home communities, and to “seed” the citizenship idea in local mental health care and social service systems. This, in turn, meant seeding the idea of the collaborations of the very groups of which the project was composed (30).

Citizens made its mark in its community education objectives by developing a book of interviews with people who were or had been homeless that chronicled their successes and struggles in making an exit from homelessness (34). Citizens also began to establish its presence in local service and care systems by creating the Leadership Project (nicknamed “Representation of the Governed”), which trained people who were or had been homeless to sit on the boards of agencies and action groups of local government and a statewide advocacy organization. The project was largely successful for students-interns and for board members, although it lacked the evaluation resources and time to measure its impact on agency policies and services (35). Citizens made only modest inroads into community organizing that we discuss below.

3. Criminal justice and an individual path to citizenship: The Citizens Project. The opportunity to support individual’s citizenship trajectories more holistically than the relatively narrow Leadership Project came about through work with the jail diversion program of the mental health center with which we are affiliated. The project’s director, Dr. Madelon Baranoski, found that she had bumped up against a ceiling in her work similar to the one we had bumped up against in homeless outreach work, providing multiple services and supports to clients but learning that we could not confer upon them the status of neighbors, community members and citizens (personal communication, 1998). Similarly, jail diversion, as Dr. Baranoski had learned, could rescue people, with their agreement, from the criminal justice system in exchange for their accepting mental health care, but in transferring them from one system to another, more benign one, it did nothing to help them establish “a life in the community,” a core goal of community mental health care from its inception in the 1950s and 1960s (36).

The Citizens Project, designed by clinicians, peer staff, advocates and researchers for people (students) with mental illness and recent criminal charges ranging from petty to felonious, is an integrated four-component intervention. A citizenship course based on the 5 Rs of citizenship is taught by community members, mental health and social service experts, staff and peer mentors, and students. Following the course, students complete socially valued role projects – teaching police cadets, for example, to more successfully and humanistically approach people who are street homeless and have mental illnesses. Valued role projects demonstrate to citizenship students and other community members that people with mental illness
and criminal histories can make positive contributions to society. Peer mentors provide individual recovery and advocacy support to students throughout the 6-month project (37). “What’s up?” is a group exercise that starts each twice a week class or valued role session. The exercise gives people an opportunity to talk about themselves and their lives in an “extra-clinical” setting – the project meets at a community soup kitchen – and manner – the topics of family and social relationships, housing status, personal and social goals, and responsibilities are encouraged and more frequently voiced, with group support and feedback, than mental health symptoms, drug use, and criminal justice issues. “What’s up?” supports individual citizenship work while fostering creation of a supportive community of citizens within the project itself (29).

A randomized controlled trial comparing the citizenship intervention to usual care found that citizenship participants had significantly decreased drug and alcohol use, increased quality of life, and increased satisfaction with work for those employed. Arrests decreased in both groups (38, 39).

4. “Going to the source”: Citizenship measure development. With a definition and key principles and with interventions that addressed both community responsibility for increasing access to full citizenship and supporting individual’s citizenship aspirations, we turned to developing an empirical measure of citizenship. Wanting to reflect individual and collective citizenship in our process as well as our outcome, we hired and trained a co-researcher group of persons with lived experience of mental illness, and “went to the source” by conducting focus groups, followed by concept mapping sessions, with people with mental illnesses and others with or without significant life disruptions (40) of incarceration, military services overseas, serious medical illnesses, and combinations of these including mental illness. Our completed 46-item measure, distilled from almost 800 items, followed by use of concept mapping software with hierarchical cluster analysis, resulted in seven citizenship domains: personal responsibilities, government and infrastructure, caring for self and others, civil rights, legal rights, choices, and world stewardship, or “giving back.” These domains, which generally map on well to the 5 Rs and “belonging,” also, in effect, responded to an occasional critique of citizenship as being so predominantly a legal status that it was of little use in addressing the social inclusion and participation of people with mental illnesses. Our respondents, in fact, viewed citizenship broadly and deeply, including but reaching well beyond legal citizen-

ship (41). The measure has since been validated (42).

5. Citizenship-oriented care. With definition and principles, positive empirical research findings, and an individual measure in hand, a next logical step was to take citizenship to scale by making it available to more people than the 25 to 30 who could go through a citizens project in a year. One way to do this was to develop “citizenship-oriented care” for use in mental health centers and clinics. This step, though logical, seems to contradict a core tenet of our framework – that systems of care are not equipped to support people’s valued community membership and participation and, in fact, undermine this goal by their hegemonic presence in the lives of many people with disabling psychiatric disorders, conferring only a “program citizenship” that not only is a poor substitute for, but seems to render nearly impossible the achievement of, full citizenship. Our tentative solution to this contradiction is borrowed directly from the notion of recovery-oriented care. If clinical care cannot confer personal recovery on its clients but can support and be consistent with recovery principles, then clinical care, likewise, cannot confer citizenship on its clients but can be supportive and consistent with their citizenship efforts and aspirations. In the citizenship case, however, greater access to community resources and help in weaving those supports into persons’ lives is imperative (29), as is an understanding of the impact of discrimination and deprivation on this population.

Citizenship-oriented care at our local community health center and local community is in its early stages. Current projects include replication of the citizens project model in an outpatient program for young adults and in a state psychiatric hospital for forensic patients preparing to return to their home communities; citizenship-oriented care for an assertive community treatment (ACT) team; “financial health” interventions to support and enhance clients’ coping with their finances and moving toward greater financial security (43); linking people to community resources and social networks through their interests and passions rather than generic community connections; and building relationships with neighborhood associations to support their community building efforts and their inclusion and support of persons with mental illness in their midst. These projects build on the “two path” citizenship approaches of individual support and community change. In addition, the collective work of the overarching project has brought to the fore the need to address systemic issues within and outside mental health systems of care including social and health inequities, racism, and other forms of systematic exclusion and barriers to “a life in the
Recovering citizenship also suggests that individual recovery can be achieved through access to the 5 Rs and belonging, based on the logic that you don’t have to wait to recover in order to become a citizen. This logic emphasizes recovery’s link with “do it now” psychiatric rehabilitation approaches such as supported housing (45) and supported employment (46). These practices, reversing decades-old applied theories of gradual improvement in the stability, but not the recovery, of persons with mental illness, argue that you do not have to wait to “get better” in order to have access to basic normative goods such as independent housing and a job. Given the proper supports, a gradual movement from quarter way to halfway to through quarter way housing can be replaced by immediate access to independent housing. Given the proper supports and training, sheltered workshops and trial employment with staff accompaniment can be replaced with immediate entry into competitive employment. While acknowledging that there may be exceptions to this approach – some people may benefit from short-term transitional housing and not everyone may be “ready” for employment – the “do it now” approach represents a sea change, and a welcome one, in psychosocial theory and practice, for which recovery can claim an influence. Recovering what should be available to and possible for people with mental illnesses, then, is part of recovering citizenship.

Finally, recovering citizenship means that while recovery is replenishing its social roots, it also reminds citizenship, with its emphasis on the person’s rightful place in society, of the person’s unique journey to citizenship and life as a citizen. This remind, in turn, leads to another – that citizenship lives on the cusp of tensions between individual and social paths toward it, and must strive to maintain that tension, with neither one forcing out the other. Our colleague Patty Benedict, Director of the ongoing Citizens Project, contends that modest progress in one’s individual recovery prior to enrollment in the project is helpful, if not imperative, for success as a citizenship student (personal communication, 2007). Yet that said and in closing, citizenship calls for socioeconomic and political efforts and a reaching across boundaries of disability and other barriers, including poverty and racism, to help people with mental illness, and others, to recover their right to full and valued participation in society. It is this vision that we argue must provide a foundation and framework for clinical practice to be effective, rather than continuing to view these broader, community-level issues as someone else’s problem (47).

References